

California Pioneers of Santa Clara County
Essay Contest
Adult/Adult Education
2012

LIGHTING A SPARK

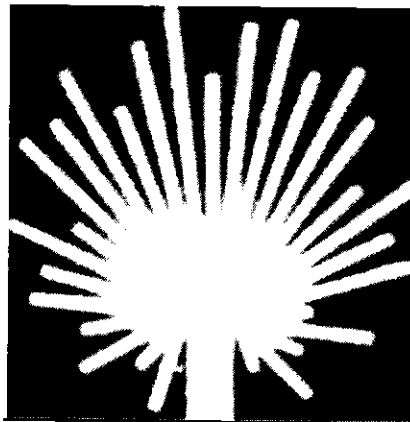
Santa Clara Valley Autism Pioneers in the 1980s and 1990s

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Introduction

This essay is about autism pioneers in Santa Clara Valley. When people think of autism today, they tend to think of mild learning difficulties. But autism at midcentury meant a lifelong disorder of behavior, speech and learning; 60 to 80 percent had developmental delay. Parenting styles were wrongly blamed. Today, we know that autism stems from a brain injury due to traumatic birth, genetic factors, or exposure to toxins in the environment.

My main focus is on one of the first pioneer programs, dubbed Spark Foundation, founded in 1984. Articles and interviews from the past and contemporary articles and interviews have been compiled to show how Spark parents struggled to and succeeded with opening community group homes for youth with autism. (From 1985 through 1994 in my Community Outreach role for Spark, I initiated most of the interviews and wrote many of the articles.) If not for these parents' efforts, many endearing young people would have ended up either behind the locked doors of a state hospital or at home with untrained families overwhelmed by their care.

In March of 2012, a devoted Sunnyvale mother whose son was in between programs and living at home became overwhelmed by the intensive care required. One day, she snapped and took her own life and that of her son. Her despair and tragic actions are not unfathomable to us parents of the autistic. Each of us understands how it could happen. Exhaustion and frustration with traumatic conditions similar to those on a battlefield have led to thoughts like driving off a bridge with one's child. Sadly, those without day and residential services remain vulnerable to despair. The good news is that Santa Clara Valley has more services for the autistic than most parts of the world. But it was not always so.

This essay is dedicated to the local parents who never gave up on their dreams of special education and community group homes for their autistic children. Because of them, autistic children and adults can continue to live in the community with staff trained to help them reach their unique potential.

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Views on Autism—1949 to the 1980s

"When first discovered in 1949, Autism's cause was a mystery and parents were blamed. That had been completely disproven. Research indicated that it was a neurological, biochemical disorder – its cause is still a mystery." – Lynn Rogers in 1993.

"Autism. It's the name of a mysterious and misunderstood disorder that affects children, usually in the first three years of life and one that wreaks havoc with normal day-to-day functions. It's a frustrating and exhausting disability that often is diagnosed as mental retardation. Up until a few years ago, most people with autism were simply placed in state institutions that had neither the manpower nor the knowledge to adequately care for their autistic patients. "¹

"Autism is a disorder marked by serious disturbances in social relationships, communication and development. The syndrome, which often includes mental retardation, begins in infancy or childhood and almost always lasts throughout life. In its most severe form, autism results in total withdrawal, frequent temper tantrums and acts of self-destruction, such as cutting one's arms or banging one's head against the wall. Ritual behavior, such as tearing up paper or endlessly repeating words, is common. "²

"Autism is a developmental disability. It's a neurological dysfunction that interferes with their ability to communicate, to learn efficiently, and to relate well to other people. They can be mildly to severely retarded but some have splinter skills. For instance, my son can play piano by ear, but otherwise he is like a three year-old."³

¹ "A home away from home," *Los Gatos Weekly*, 26 August 1987, p. 1.

² "They hear a different drum," *San Jose Mercury News*, 2 March 1988, extra 2, p. 1.

³ "A home away from home," *Los Gatos Weekly*, 26 August 1987, p. 12.

"When autism, a severe lifelong disability affecting speech, mental development, and perception of sensations and people, was first identified by Leo Kanner in 1949's post-Freudian era, parents were wrongly blamed — 'refrigerator mothers.' It has now been firmly proven that parenting style has nothing to do with the origin of autism.

Current medical science has established autism as a neurological disorder that appears in the first three years of life. It is more common than blindness and is found in four times more males than females in families of all racial, ethnic and social backgrounds throughout the world. At least eighty percent of autistic persons are developmentally delayed, though many have distinct 'savant' skills in areas like music, mathematics, spatial concepts, and, I have discovered, heightened psychic awareness." – Lynn Rogers in 1994.

"There has been practically no recourse for a person who is autistic except in a state hospital. An autistic person cannot live forever with his family because it's highly stressful. The family is not geared to take care of this person for life."⁴

Three Mothers Make a Difference

The following material demonstrates the difference parent pioneers can make.

Three mothers, one Jewish, one Catholic, one Protestant, all with autistic sons, would meet in a living room and spark a program that would come to serve disabled young people of all races and cultures.

Sheila Dermer

Sheila Dermer of Los Gatos has an autistic son, Joshua; she chose to raise him at home, despite the difficulty.

⁴ "City loans to aid elderly, handicapped," *San Jose Mercury News*, 15 April 1987, p. 2.

"Autistic children are very hard to care for, because they have strange behaviors. A lot of the time they are frightened of their environment and they require constant parental attention." Dermer explains. "After he reached adolescence, I just couldn't care for my son anymore." Unfortunately, the alternative to having Josh at home was state hospital placement and Sheila balked at that. "I wanted a respite, but there was no way we'd institutionalize him."⁵

Indeed, so much time and energy was required. Even at twenty-three, Joshua still needed to be bathed, shaved and helped with toileting.

Like some other baffling autistic youth, he had unusual talents. He received media attention as an autistic savant with his abilities in music bordering on the genius. And yet the lifetime responsibility for this son added to the burdens most women face. It was difficult for Sheila to parent her other, gifted sons when each child's needs were so different.

Sheila chose to translate her background in education into avenues of service to the disabled and disadvantaged. Thus began a fifteen year volunteer odyssey along two paths. First, Sheila volunteered to work with emotionally disturbed residents of Ming Quong, abused adolescent *girls* at the County Children's Shelter, and disabled swimmers at Timpany Center. Second, she promoted such organizations to the community, soliciting equipment for Idylwild Children's Center; mobilizing investors and fundraisers for Peninsula Children's Center and C. Thomas Foundation, and, as board vice-president for Housing For Independent People, setting up homes for the disabled. For Sheila, the best was yet to come.

⁵ "A home away from home," *Los Gatos Weekly*, 26 August 1987, p. 1.

Mary Flanagan

Not long after her son Mark's birth, Mary Flanagan learned he was autistic. His ability to learn, to communicate and to make sense of the world was impaired for life. He experienced explosive upsets and repetitive use of speech – "Mark's OK, Mark's OK, Mark's OK." He had an awkward gait and strange rituals, like tasting things, drinking water compulsively, and endless rocking motions and sudden shrieks. He would never get married nor go to college. Mary realized that parenting an autistic child was a nearly insurmountable task. No matter what, the family must survive.

Mary turned to community agencies for support and relief. Discovering there were no programs in place to provide this relief because autistic children "fell through the cracks," Mary set about to fill these cracks and overcome the obstacle of her son's constant care. "Like other children, my son, sweet, eager, happy-faced Mark, inquisitive eyes, hyperactive movements, autistic, locked into his own world, developmentally delayed for life, had a right to a future in the community—and the state hospital was no future at all."

Mary turned her experience as an educator, both secondary teacher and women's study groups, toward volunteer efforts to help developmentally disabled children and their families: Community Association for the Retarded (CAR), the Betty Wright Therapeutic Swim Center and C. Thomas Foundation. She served as a program committee member of the San Andreas Regional Center (SARC) planning needed programs. She was an organizer, co-founder and visiting parent for Parents Helping Parents (PHP), a support network for the parents of newborn handicapped infants who ask during the first dark hours "What can I do now?" Mary organized PHP in its formative years, setting the foundation for its future success.

Mary was a mentor and a role model for other mothers who faced a lifetime of frightening responsibilities for a handicapped child. On call 24 hours a day, she opened her home to counsel the new parents of handicapped infants. Mothers learned from Mary's example to call on newly developed strengths and that the family could remain intact — that joy would be found through a special child. And Mary still had more to offer.

Marilyn Norling

In 1969, Marilyn Norling's son Chris was just 18 months old when, during a family vacation, he slid off a motel room bed onto 40-cent, plastic truck, whose metal axle penetrated 1½ inches into his skull. "It was just like driving a nail into his left temple," said Marilyn, who remembers the day of the accident as the "the worst" of her life.

After Chris underwent brain surgery and some subsequent testing, doctors gave Marilyn and her husband, Don, the devastating news that Chris was retarded. Hearing that, said Marilyn, was "like having somebody punch me in the stomach. I was crushed." In tears, she called her parents in Texas to relay the news. Her father, a preacher, "talked about making triumph out of tragedy." In the years that followed, this is exactly what Marilyn did.⁶



Marilyn and Chris

Marilyn volunteered to serve on local, area wide, and state committees and boards with the purpose of advocating for improved services for developmentally disabled individuals. She had established a home care program at CAR (Community Association for the Retarded) and coordinated grant project for services for handicapped residents of a four county area at Agnews State Hospital.

⁶ "A mother becomes an activist," *The Peninsula Times Tribune*, 6 February 1981, sec. B, p. 1.

Marilyn assisted with fundraising events for groups such as the San Jose Institute of Contemporary Art, C. Thomas Foundation, and for legislators Senator Dan McCorquodale and Assembly Member John Vasconcellos.

The stage was now set for the trio to join forces.

Pioneering Spirit: Formation of the SPARK Foundation

This section documents the grass roots efforts of the three mothers to develop from scratch an innovative, community-based program for young people with autism. It was an idea that was a Spark that took hold like a brushfire, igniting the community's enthusiasm and setting about to do the impossible, what others said couldn't be done.

A scenario such as this,

"Don't do it. You have no idea the work involved."

"What shall I do with my son?"

"Have you ever written a proposal?"

"He can't stay home any longer, and he doesn't belong in a state hospital."

"A new program for autistic people - not behavior modification? How will you get funding?"

"He needs a place!"

points out the ongoing needs of autistic people and the problems their parents have traditionally encountered. It also "lit the spark" from which came Spark Foundation. Response to a need for a place for autistic young people was the genesis of Spark Foundation in May 1984, when three women, Sheila Dermer, Mary Flanagan and Marilyn Norling, stepped out to build that place. The mission of Spark was to provide life-long

community-based residential services and related training for individuals with autism and similar disabilities, with the focus of its program on individualized training in the skills of daily life activities.⁷

**SPARK
FOUNDATION**

Building new lives within the community for young people with autism.

The Purpose

Did you know that autism strikes more children than blindness? A severe incapacitating disability, autism interferes with learning, communication, the development of appropriate behavior, and the ability to make sense of the world.

The fragility of children with autism makes them extremely vulnerable in ordinary settings of everyday life. Isolated and alone in the world they cannot understand, these young people formerly spent most of their lives locked in state hospitals, only experiencing their alienation.

Founded in 1984 by parents determined to provide a more hopeful future for young people with autism, **Spark** became the first residential skills training program for them within the community.

The Program

Spark has established and maintains several homes in Santa Clara County. At each residence, professionally trained staff implement the program which highlights:

- Pleasant, safe, home environment within the community
- Positive skills training approach
- Individually designed skills training plan for each resident
- One-to-two staffing ratio
- Training in self-help and household management skills
- Opportunities to develop social and communication skills
- Coordination of skills training plan with educational day program
- Continuity of family relationships
- Supervised exploration of the surrounding community

A natural outgrowth of the program is the development of a positive reciprocal relationship that benefits residents and community alike.

The Future

Prompted by an increasing number of requests for new homes, **Spark's** vision of the future is to establish a continuum of community services for young people with autism of all ages and levels of functioning. With careful planning we will continue to create quality, cost-effective programs, being responsive to the unique needs of those who want, as well as the emerging needs of our current residents.

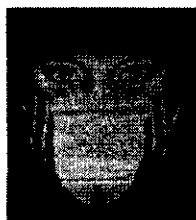
Working together, parents and professionals at **Spark** are committed to helping these young people meet the life-long challenges they face by offering a lifetime of opportunities for learning and growth. With skills training, the vision of the future for individuals with autism is more productive and independent lives.

Spark Foundation Pamphlet with Purpose, Program and Future Detailed

After deciding they wanted to create a home for their children and others like them, the three women talked to people at the state Department of Developmental Services and at the San Andreas Regional Center. "We submitted a proposal describing the type of program we wanted to have and we were told we had to be licensed by community care services. So, we searched the area for a house, got it licensed and vendorized, and I then raised the funds to get the program started." Dermer says making the monumental undertaking sound easy.

⁷ "An Anniversary Message from the President," *Spark Letter*, April 1987, p. 1.

"All our funding came from grants—\$25,000 from the Henry Cowell Foundation, \$30,000 from the David and Lucille Packard foundation, and \$30,000 from the Valley Foundation, all of which went towards furnishings and appliances, choosing and hiring staff, and so on," Dermer explains. "Most of our major funding comes from the San Andreas Regional Center (SARC), as do many of our clients." But, like social security, the money is never enough, so Spark Foundation does its own fundraising, such as staging an Ella Fitzgerald concert at Paul Masson Vineyards (when Lynn Rogers called her, she was happy to



Psychic Fair

appear), a groundbreaking psychic (even Sylvia Brown donated services), a fashion show and a festival at Kotani-En Gardens in Los Gatos.⁸



**Ella Fitzgerald
Concert Program**

In April 1987, the Cupertino City Council agreed to lend the non-profit Spark Foundation \$125,000 as a down payment for a home for six autistic youngsters who would otherwise be in a state hospital. Because only six people ages 12 to 17 will be served at the home for autistic youths, "It's only scratching the surface," said Mary Flanagan, president of the board of the Spark Foundation. "But this is very much more economical than putting an autistic person in a state hospital," she said. She said it costs about \$30,000 a year to care for each person in her program, compared to about \$120,000 a year in a state hospital where "they're not served as well." Flanagan said the council's action shows what direction the city is about to take. "This helps identify the community's conscience.... I see Cupertino looking for its identity."⁹

⁸ "A home away from home," *Los Gatos Weekly*, 26 August 1987, p. 12.

⁹ "City loans to aid elderly, handicapped," *San Jose Mercury News*, 15 April 1987, p. 1.

Excerpts from the SPARK President's First Anniversary Message

As the Spark grew brighter, over thirty other parents joined forces with Dermer, Flanagan and Norling. This group of mothers and fathers would work tirelessly to help expand Spark's residences to three, including a girl's home. (It turned out more fathers and stepfathers, like Spark board member Joseph Haddox, had stuck by their autistic daughters and had protected them often as single dads after the divorces so common under the strain of parenting a special needs child.

Spark's president, Mary Flanagan, shared these thoughts on the momentous day:

As we celebrate the first anniversary of the first Spark Group Home, I reflect briefly back over the struggle to create and establish this new program. Many a long day and late hour went into conceptualization and implementation of the project. Many people, many efforts were behind the making of Spark Foundation and its program. Louise Emerson, Director of Morgan Center, was our first mentor and continues as Program Consultant.

We were helped by the advice and receptiveness of San Andreas Regional Center, and by our inclusion in their plans for the future. The Department of Developmental Services listened and agreed to fund the program.

A house was acquired through grant monies administered by Housing for Independent People. Help came from Santa Clara County. Community organizations and businesses made contributions. Major fundraisers were supported by friends and the public: a festival at Kotani-En Gardens in Los Gatos, an Ella Fitzgerald concert at Paul Masson Vineyards with dinner and auction, a psychic fair, and a fashion show, as well as various sales. The Couplestones of Campbell helped gather furnishings for the house and

worked with parents to paint the entire interior. Parents and dedicated volunteers cleaned the house and yard.

The Spark Group Home, located in Los Gatos, was able to open its doors on April 1, 1986, with a trained staff under the supervision of Director Cheryl Lemke and Assistant Director Andy Duprey. To the many individuals and groups who were a part of our efforts, the Board of Directors of Spark Foundation extends our most heartfelt expression of gratitude.

We are now at the threshold of a new phase, where Spark Foundation has actively begun commitment to its larger vision of developing not only a place, but lifelong residential services with community-based opportunity for autistic people, with consideration for their needs as they may continue or change. To this end, we have taken on a Project Developer who is currently spearheading expansion and start-up activities for an additional four group homes, intending to serve 30 people in the next five years.

Spark Foundation has come a distance. It has now committed to go further, to expand and keep the high quality programming for which it has become known. We ask others as well to be a part of our commitment to those with autism. How can one help? By taking part in any of a number of volunteer activities, or by participating in our auxiliary.

We look to the future and again send many, many thanks to all who helped Spark Foundation create a place for the young autistic people it serves today, and to those who have already given of their time and effort to help us begin the next phase of our services.¹⁰

Notes from SPARK Foundation's Program Director

Program Director, Cheryl Lemke expressed her thoughts:

¹⁰ "An Anniversary Message from the President," *Spark Letter*, April 1987, p. 1.

I look back on the first year of Spark's skills training program, and several images come to mind: newspapers spread on the floor of the house, and a paint spattered crew of energetic volunteers painting the walls of the house on short notice. I see the look on the first crew of staff as we met the day before the program opened, as we realized that no matter how much we planned and prepared, there were still going to be lots of "surprises". I smile when I see the faces of our clients as they moved in on opening day and looked around the house, unsure yet smiling. As they walked in with their bulletin boards, radios, phonographs, toy tractors, and photo albums, little did they realize that they and their housemakers were helping to found a new type of program that would someday benefit many others.

Still, those images of happy parents, worried parents, enthusiastic staff and tired staff, interested teachers and family members all fade into the background. Outstanding in my mind is the image of each and every client, in their daily routine or on special occasions, teaching us why we're there. The clients have been exceedingly patient with us, kept their sense of humor, exerted their independence, and constantly reminded us what Spark is all about. So on the anniversary of our opening, I would like to sincerely thank Chuck, Randy, Chris, Mark, Eric, and Josh for teaching me so well.¹¹

A Look Into SPARK's Future

Emir Berg, Project Developer, shared this on behalf of Spark's Board of Directors:

This is an exciting time for Spark Foundation and I am very pleased to be a part of it.

As many of you may know, my son Colin attends Morgan Center. It was through Louise

¹¹ "Notes From Our Program Director," *Spark Letter*, April 1987, p. 2.

Emerson that I became involved with Spark and its principle members right around the time they were opening their first group home. I was tremendously impressed with these folks and their achievements in a relatively short period of time. It is my honor and privilege to be serving Spark Foundation as its Project Developer for the next two group homes.

In November of 1986, the Spark Board held a planning retreat. Many of you answered questionnaires that, in addition to information obtained from the State Developmental Services Five-Year Plan and the San Andreas Regional Center Two-Year Plan, provide information for Spark planning efforts. The results of that retreat are that the Spark Foundation Five-Year Plan that will direct Spark's efforts through April, 1992, and will direct my efforts as Project Developer for this year.

Eight Plan Goals were developed by the Spark Board and staff. Each of these Goals will be evaluated yearly and updated. Objectives will be written for that year to guide annual Foundation activities. At the end of the five-year period, a new Plan will be written, with new goals. In this way Spark Foundation is laying the groundwork for programs that will respond to needs and continue throughout the lifetimes of the children and adults it serves. In this way, Spark Foundation is ensuring the groundwork for programs that will last beyond the current directors or staff. The Eight Foundation Plan Goals for April 1987-April, 1992 are:

GOAL 1: To develop a continuum of residential services for a range of ages, skills, and behavioral needs focusing on the highest quality of programming at the minimum cost per client.

GOAL 2: To influence other programs toward replicating the skills training model as a preferred training approach.

GOAL 3: To develop and maintain a management structure for effective administration, staff and program development that is not dependent for basic activities and critical functions on voluntary parent involvement.

GOAL 4: To develop formal and informal working relationships with similar and associated organizations.

GOAL 5: To have a working Board of Directors that serves in an advisory and policy-making capacity and ensures the philosophical, programmatic, and fiscal integrity of the organization.

GOAL 6: To create a public image of Spark Foundation as a community asset.

GOAL 7: To develop sound fiscal policies and management practices and maintain a balanced budget.

GOAL 8: To expand the sources of organizational revenue.

As Project Director, I am working under the direction of the Board of Directors and with Spark staff, in line with our Plan Goals, to develop the next two Spark Group Homes, to assist with the development of a management plan and structure, and to assist the Board in developing a variety of funding sources.

The next two Spark Group Homes are expected to be opened this year, the first towards the end of the Summer and the second, towards the end of 1987. The first home will be for adolescents and the second home will be for young adults. Additionally, Spark has plans to open a fourth home in 1988 and will be looking, the end of this year, at further residential development past four homes. Spark is also considering administrative staff, following the development of the third home, and is considering the development of an endowment program to provide a secure financial base for programs.¹²

Words From Those Who Wait

¹² "A Look Into Spark's Future," *Spark Letter*, April 1987, p. 3.

As the mother of a fourteen-year-old autistic teenage girl, I am especially pleased to hear that the Spark Foundation is anticipating the opening of two new homes this year, 1987. Spark Foundation would be an ideal placement for our daughter because she would live in a safe, loving environment with a skills training program to help her reach her greatest potential, and the rest of her family might then have the opportunity for a more normal life (to reach our greatest potential).

Spark differs from other programs I've visited in that our daughter could:

1. remain a part of our family even in placement because of a very reasonable visitation policy
2. learn life skills through a positive approach rather than with all attention focused on "negative behaviors"
3. live in an environment resembling a home, with all the dignity and peace that word connotes.

The heartfelt hopes—and those of families like ours—rest with Spark Foundation's new endeavors. – Lynn Rogers in 1987.¹³

SPARK Has Two New Homes

After a tremendous amount of hard work by parents and community volunteers including the Center For Infinity Growth, UCM church, the three homes were all up and running. It was a big leap from three mothers huddling together, overwhelmed by their son's care to leading an award winning new program demonstrating autistic youth could live successfully in the community and not languish in state hospitals. These

¹³ "Words From Those Who Wait," *Spark Letter*, April 1987, p. 4.

lovely young people helped teach the community that there was more than one way to be normal and shine their unique light.

The fall of 1988 celebrates the second and third Spark group-homes, located in Cupertino and San Jose, and opened within only two years of the first home in Los Gatos.

Spark is now providing an intensive skills-training program within the community for 18 young people, ages 12 to 26 all autistic or otherwise developmentally impaired. In response to demonstrated need, Spark plans to continue development to serve other young people who require community residential services.

In this stage of development, Spark looks to the establishment of ongoing support that will assure its financial future and a quality program for its young people. Spark's most critical need is financial. State funding does not cover the expenses of each home, no matter how carefully administered. The shortfall must constantly be met from other funding sources: fundraising and donations.¹⁴

They Hear a Different Drum

Maria Lopez comes home from school, slaps Peter, Paul and Mary on the record player and flops down on the couch. The first song is "Blowin' in the Wind," and Maria sings along, rocking from side to side. The scene isn't much different from what most 15-year-old girls do on a weekday afternoon. But Maria's gaze is a little more distant, her rocking more regular and persistent. Maria is autistic.

¹⁴ "Spark Has Two New Homes," *Spark Letter*, Fall 1988, p. 1.

Most autistic people have to live in state institutions, cut off from their families.



Vanessa hiding herself.

Maria is luckier. She lives with four other adolescent girls in a pleasant ranch-style home on a Cupertino cul-de-sac. The home, owned by the Spark Foundation, opened Nov. 4. "It's really a godsend for parents," says Lynn Rogers, whose 15-year-old daughter, Vanessa, also lives in the Cupertino home. "I've been carrying this burden alone, and so have the other parents."

The girls in the Cupertino home are generally in the middle range of autistic symptoms, according to house manager Tracy Smith. Full-blown tantrums are rare, although the girls occasionally may hit each other. One resident suffers from a tendency to bang her head, so she wears a protective helmet.

The Spark Foundation, which also runs similar programs in Los Gatos and San Jose, was founded by three mothers unhappy with what the state hospitals had to offer their children.

Sheila Dermer, now the treasurer of the agency, was one of them. She says she finally reached a point with her son, Joshua, where she felt the constant attention he needed was hurting the rest of her family.

"You can't help but feel guilty," she says. "You have to ignore your other children. You're in a no-win situation."

Autism affects boys three to four times as frequently as girls. As a result, the few community-based programs that do exist are generally set up for boys.

But the Spark Foundation, using a low-interest \$125,000 loan from the city of Cupertino, was able to buy a house and set it up just for girls. There is a space for one more autistic girl in the Cupertino program.

Jean Gonsier, the program director at the house, says the staff tends to downplay the traditional reinforcement techniques used with autistics, in which rewards are given when a troublesome behavior is controlled. Instead, the Spark approach tries to turn the bad behavior into a good one. Those who compulsively tear paper, for example, are taught to instead use the paper to make collages or draw.

Like most autistic people, the girls, who attend a special school every weekday, fluctuate between sensing too much and too little.

Maria, for example, pulled the curtains shut in one room to block out the bothersome sunlight. Meanwhile, Kelsey O'Connell, 13, was sitting on a couch, stroking her arm over and over, as if trying to make herself feel something.

"There's a lovely, almost ethereal look in their eyes," Morgan says. "It sometimes makes us feel they're aware of other levels of consciousness." Many autistic people also seem to have a strongly developed sense of intuition, she says. Some even have extraordinary talents, such as Joshua Dermer, who has perfect pitch.

Originally thought to be the result of poor parenting, autism is now considered a neurological illness, although the exact mechanism of the disorder is unknown.

Rogers began noticing something wrong with Vanessa when she was about a year and a half. The baby would trip and fall and then "regress, cry, withdraw."

"It was as if her soul wasn't tucked into her body," Rogers says. "One Easter vacation, I had to leave her in the care of my daughter (then 12 years old) for five minutes. She put her head through the bedroom wall within minutes. There was no feeling of pain."

Minor changes in what's going on around the child, such as moving to another classroom, can set off autistic symptoms.

"You're walking on eggshells," Rogers says. "You never know what will set them off."

Spark is trying to buy another house in Cupertino, possibly with the help of the city, and begin a fourth program there.¹⁵

Three Portraits: The Young Residents and their Homes in 1988

Chris (20) is one of the senior residents at the Los Gatos home, for he has lived there since its opening two years ago. A student at Morgan Center, Chris has developed an interest in trucks. With the Spark staff he will discuss machinery as well as trucks. He is also interested in people, inquiring of their whereabouts. Chris enjoys baseball too, particularly devoted to the Oakland A's.



**Los Gatos Residential Home:
Founded 1986**

Visitors to the Cupertino home will always be pleasantly greeted by Christie (18).



**Cupertino Residential Home:
Founded 1987**

She is expanding her contacts by learning how to type letters. At the home she enjoys working alongside her roommate, Vanessa. She also has fun on picnics with her father, Bob. Her favorite activity twice a week is

¹⁵ "They hear a different drum," *San Jose Mercury News*, 2 March 1988, extra 2, p. 1,3.

hanging out with the peers in Jim's program.

Asya, also 20, is one of the newer residents moving into the San Jose home in July. She lives there with four other young people. One of her favorite activities is swimming, so she enjoys the pool-parties there. She is learning sign language to communicate with her roommate, Jennifer Ainsley.



**San Jose Residential Home:
Founded 1988**

With the other residents. Asya recently went to see **BIG** and **BAMBI**. She also has enjoyed dinners out and the recent visit to a dried-fruit packing plant.¹⁶

Grants, Support and Accolades

Spark has recently received a \$2,500 grant from the IBM Fund for Community Service. The check was presented to Marilyn Norling, former President of Spark's Board of Directors at its February meeting. Martin Goff, a member of Spark Foundation Advisory Board was instrumental in obtaining the grant from IBM where he is employed as a Marketing Support Representative.

The funds will be used toward purchase of a computer and software for Spark. Benefits derived from the purchase of a computer and software for the young people with autism that Spark serves are numerous. They include survival reading skills, training for the lower functioning individual as well as training in simple data basing skills for the higher



**Joe Haddox with his
beloved autistic
stepdaughter, Vanessa.**

¹⁶ "Three Portraits: The Young Residents and Their Homes," *Spark Letter*, Fall 1988, p. 5.

functioning individual so that he/she may become a more productive member of the community. The computer will also be useful in monitoring the progress of clients in all skill training areas. THANK YOU, IBM.¹⁷

We are pleased to announce that Spark Foundation has been selected to join the ranks of agencies funded by United Way during fiscal year 1988-89.

A community-serving organization, United Way is now reaching out to those with autism, a segment of the population which has long been unrecognized and in need of resources for living in the community. Spark is very grateful to United Way; its help will make a difference.¹⁸

SARC Responds to SPARK's Future Plans

".....regarding your intent to develop a five-year plan for the development of additional residential programs. Let me start off by saying how pleased I am to see this type of proactive planning effort occur. It is only in this way that our system can be truly responsive to the needs of our community. Your board is to be commended for its continued commitment to excellence." - Maryfrances Shanahan Walker, M.S, Director, Resource Development and Evaluation, San Andreas Regional Center¹⁹

The main benefit of Spark was to the young people it served. Now they lived with friends, held simple jobs as they matured and were in a structured environment that counterbalanced the neurological chaos in their brains. Testimonials, like the ones to follow, came to the attention of Santa Clara Valley award organizations.

¹⁷ "IBM Awards Spark Grant," *Spark Letter*, April 1987, p. 2.

¹⁸ "United Way Funds Spark," *Spark Letter*, Fall 1988, p. 1.

¹⁹ "SARC Responds to Spark's Future Plans," *Spark Letter*, April 1987, p. 3.

From the Residents: What I Like Most About SPARK House

Working with the staff - Chris

Spaghetti for dinner - Josh

The fun holiday outings - Chuck

Trips to the store - Eric

Helping with the household chores - Randy

Spending time with my friends - Mark²⁰

From the Parents of Residents

It's almost a year since the first Spark Home opened and your program got underway. I feel that the results are commendable. My son, Chuck, has benefited in many ways and he is very happy. Along with the skills training, etc., you have lots of fun activities in the home and the community. My sincere wishes for your continued success because there are many others who need these services. - Chuck's Mom

Last April, when Randy left home to live at Spark, he was 24 years old. Having him live at home for that many years, and his being the last of our 3 children to leave home, brought on many mixed feelings. Now after one year, hopefully, we are all adjusted.

This adjustment has been made easier by the philosophy of the Spark Foundation. Because Spark is a parent organization, we believe that it holds the welfare of the residents as its highest priority. This is a comforting thought and leads us to believe that Randy has a permanent home even when we are gone. Another comforting thought is that Spark parents and Board members are a dynamic group with expertise in law, accounting,

²⁰ "Residents Corner: What I Like Most About SPARK House," *Spark Letter*, April 1987, p. 4.

engineering, real estate, psychology, teaching, fundraising, and grant writing, etc. Not only is this professional expertise of great assistance in the business of the Spark Foundation but to me it's the greatest asset and comfort of all knowing it's there, whenever needed, to advocate and take action to benefit the children under their care. - Randy's Mom and Dad²¹

"I Like Spark"

My autistic daughter Vanessa remained at home for the first 15 years of her life because I felt that she had the same right and perhaps even greater need for the nurturing of a family as did her bright but normal sister.

In 1981 when Vanessa was nine, I was told that she needed 24-hour placement in a program for the autistic. By this time, the overwhelming demands of her care had contributed to her parents' divorce. The few possible existing residential programs for handicapped children were full or inappropriate. One "recommended" program was many hours drive away with no staff trained to deal with autism.

More exhausting, hopeless days of picking up spilled food, handling toileting accidents, despairing when neighborhood children shunned Vanessa, becoming frightened when she banged her head into a wall out of frustration...days turning into years.

In 1985, I heard of a group of three mothers of older autistic sons who had begun efforts against great odds to open a home in the community for young adult youth like their sons. Upon meeting with them, I was immediately energized from a state of hopelessness beyond burnout. We parents could make things happen ourselves if we supported each other, were willing to engage in creative thinking, and converted despair to assertive action. This was exciting. For the first time, I had met peers—parents in like situations who

²¹ "Parental Perspectives," *Spark Letter*, April 1987, p. 4.

hadn't been crushed by the tremendous burden of care for their autistic children, but ones who actually had forged hope for others out of despair.

Within 30 months the second Spark home had opened, this one for adolescent girls. Vanessa entered that comfortable Cupertino 4-bedroom home on November 4, 1987. Her feelings on opening day, as they are today ten months later, were excitement and enthusiasm. She too was sparked to new hope. Now she had a roommate, a home full of peers, and normal socialization opportunities with the girls and boys of Spark's homes. Her days were structured to maximize her potential to function, and contribute to her community.

Thanks to Spark's flexible visitation policy, I am not cut off from my daughter. We are an extended family of child, parents, and Spark staff. Vanessa is able to come home and to invite me into her new home in Cupertino.

Before Vanessa moved into her new home, her repetitive use of language would drive me to the brink. Now there is one sentence of hers which I never tire of hearing, and I hear it often: I like SPARK." – Vanessa's Mom, Lynn Rogers²²

SPARK Foundation: Raison d'être

Dr. Arthur Schawlow, Nobel Prize-winner and co-inventor of the laser, wrote a letter to Spark Foundation in response to news of its inception and plans for development of a unique residential program for autistic young people in Santa Clara County. The following are excerpts from that letter:

²² "I Like Spark' A Parent's Testimonial," *Spark Letter*, Fall 1988, p. 2-3.

"My wife and I are delighted to hear of the establishment of the Spark Foundation, and of its plans. We are painfully aware of the terrible shortage of residential facilities for autistic people. Because of lack of a suitable program and place, such as the one you are planning, our son had to spend ten years in Agnews State Hospital, years that were pretty much wasted for his development. Now, at long last, he is thriving in a residential program and continuing to reveal abilities that no one suspected. Unfortunately, though, his home is 200 miles from here, because a lengthy search revealed no suitable place closer.

We are convinced from our experience that many autistic people have great hidden possibilities that can be developed. They can become useful citizens and live happy lives if they are given the right opportunity." ²³

From SPARK's Project Developer and Parent of Resident

It's not easy being green—or a Project Developer for Spark, for that matter. On the anniversary of the opening of our first home, in Los Gatos, I was your relatively newly appointed Project Developer, responsible for coordinating the implementation of the objectives of our Plan Year, principally, the development of two more homes in 1987-88.

Now as I end my tenure as Developer and begin as a member of the Board, I pause to reflect, to look over the past 18 months: I see that what we have done has been good and that it has not been easy.

The two new Spark homes, in Cupertino and San Jose, have opened because of hard work finding private and public community dollars, including \$60,000 from David and Lucile Packard Foundation, \$65,000 from the Valley Foundation, \$3,750 from the Lockheed Bucks-of-the-month Foundation, \$15,000 from special fund-raising projects, and \$23,000

²³ "SPARK Foundation: Raison d'être," *Spark Letter*, April 1987, p. 1.

in Project Development monies from the County of Santa Clara. These monies were used for start-up expenditures—purchase of furnishings, food and supplies, repair and refurbishing of the houses, and staff salaries, as well as all other expenses for three months.

Because of this effort, and with hours of work preparing the homes, we have expanded the Spark family from the original six residents and their families to 18 residents and their families—a very large "family" indeed. The residences, their siblings, and parents have scrubbed floors, peeled off old wallpaper, pulled weeds, and pruned trees to make the new homes attractive and comfortable.

When my own family was looking for a program for our son Colin, we passed up residences where Behavior Modification was the principal method of training. Even though our need was acute, we held on until we found a place where Colin would be accepted for the human being he is, **as he is**, a program which would use his abilities to teach him skills that would support his continued growth, instead of assessing his deficiencies and determining which of those need to be "fixed" or "extinguished."

At Spark. Colin and the other young people are told, "You are OK," not "You can't unless you...." It is a difference that recognizes the "many ways of being human" as opposed to holding up a psychological model of the "normal" human. It is a difference that directs developing and maintaining a home as opposed to developing a "residential facility." The Spark program presents an individualized plan that stresses increasing skills in activities designed to support the learning of those skills, not a plan that stresses "targeted behaviors" and "program interventions." This translates into the way we furnish and decorate our homes, the way we talk about and describe our children's needs, the way we train staff, the way we use the community as a teaching resource, the way we try to

respond to each of our children, and the way we want parents to continue their involvement, especially in the decision-making around their child's program.

The results of Spark's approach to training are profound. And the success requires on-going parental vigilance. In the past we have called upon parents to write their legislators on behalf of their children, to call or send telegrams to the Department of Developmental Services. With this continued vigilance, hard work, and continued help from the community at large, Spark will continue to grow and prosper.²⁴

Awards

Women of Achievement, 1988: SPARK Founders

On May 4, 1988, the three founding mothers of Spark were honored as nominees for the 10th annual Women of Achievement awards at a reception at the San Jose Museum of Art and at an awards banquet of 800 people at the San Jose Fairmont Hotel.

At the beginning of the banquet, Sheila Dermer, Mary Flanagan, and Marilyn Norling walked into the packed hall just after the governor's telegram of congratulations had been read. The spotlight shone in turn upon each of them as they were honored for their outstanding contribution to our community, the founding of Spark for the autistic. The women's contributions were listed that evening in the program. – written by Lynn Rogers²⁵

Junior League of San Jose Alexis Award, 1993: Mary Flanagan

On April 22, 1993, Mary Flanagan was honored as one of the one hundred volunteers nominated for the 24th annual Volunteer Recognition Luncheon sponsored by the Junior League of San Jose at the Santa Clara Marriott Hotel. All nominees received a

²⁴ "Vigilance Pays Off," *Spark Letter*, Fall 1988, p. 1-2.

²⁵ "Spark Founders: Women of Achievement, 1988," *Spark Letter*, Fall 1988, p. 2-3.

certificate. Twenty-five of them were selected for special recognition for their outstanding contributions and each honored with a silver bowl. And there was one more award, the highest award, the Alexis Award named after Alexis de Tocqueville. He came from France in 1830, and wrote about the American people:

"These Americans are a peculiar people. If in a local community, a citizen becomes aware of a human need which is not being met, he thereupon discusses the situation with his neighbors. Suddenly, a committee comes into existence. The committee thereupon begins to operate on behalf of the need, and new a committee function is established. It is like watching a miracle."

When the moment arrived, the guest presenter, Pablo Morales, Olympic gold medalist in 1984 and 1992, and graduate of Bellarmine College Preparatory in San Jose, California and Stanford University in Palo Alto, California, took the podium. After a proper buildup, he said, "This volunteer... leaves a legacy to benefit thousands of handicapped persons.... The person whose efforts on behalf of the autistic and developmentally disabled – best exemplifies the creativity and courage represented by the Alexis de Tocqueville award is Mary Flanagan!" – Written by Lynn Rogers to commemorate the day for Mary.

The SPARK Foundation's Legacy

Spark developed a significant model and foundation which remains in use with residential programs today. Have they improved over the years? Of course.

On Friday, April 13, 2012, former Spark co-founder, Sheila Dermer, was interviewed. She said her son Josh now lives at PACE (Pacific Autism Center for Education), which absorbed Spark Foundation in 1994. (Programs have been consolidating for some years so they can save costs by operating under the same leaders.) PACE operates six group homes and offers "cradle to grave" services. These services include preschool, early education,

elementary and secondary education as well as adult day programs. In the beginning, Josh was diagnosed as emotionally disturbed. There were no autism programs in Santa Clara Valley. They put him in Ming Quong back then, over 40 years ago. He's 47 years old now.

Programs have come and gone. Because of the Lanterman Act, the County of Santa Clara now has an autism education program. The school districts have their own. People come to the Santa Clara Valley because there are so many programs, including Stanford Hospital. Miss Dermer states that the autistic population is now maturing and there are senior programs, like HOPE on Parkmoor Avenue in San Jose for autistic and developmentally delayed seniors. People aren't dying early in state hospitals; they are enjoying longer life spans in the county.

When Spark sadly closed its home for autistic girls in Cupertino due to state funding problems in 1994, the six residents came to be housed by Mr. Lito O'Campo, an excellent for-profit provider with his own approach to the care of autistic residents.

Mr. O'Campo had worked in residential homes and had opened such a Level 3 facility (for less intensive behavioral needs). In 1994, he was hoping to take similar residents leaving Agnews State Hospital and give them an opportunity to live in the community. When the Spark girls were suddenly without a group home in the middle of the winter of 1994, parents prayed for a solution.

At the eleventh hour, after most everyone had taken their kids back home for a grueling month, Mr. O'Campo was introduced to them by San Andreas Regional Center. Just prior to this, parents had been told that there were just no beds available for Level 4 girls except for one in a (rougher) co-ed home. One young lady could not return home even temporarily as her mother had three other handicapped children, made so when a bomb

was dropped on their home in Vietnam. All the girls' families were grateful that Mr. O'Campo was willing to provide a level 4i group home to them. When the families first saw the lovely decorations, including a glass sculpture, they rolled their eyes in disbelief—fearing their daughter would be the one to damage it. Years later, the home remains as tidy as on that first day. Mr. O'Campo speaks to that subject:

“At the start it was really hard. We had to do a lot of things, like getting the ladies out to parks, getting them to exert energy and helping to calm the behavior. Everybody enjoyed it; we used to walk six to ten rounds around a local school track, the equivalent of two miles. If the ladies did any damage, we fixed it the next day; after one and a half to two years it was much better. Now it is very seldom that someone punches a hole in the wall. We kept it nice so the residents would take pride in their home and holiday decorations.”

Mr. O'Campo has subsequently received two distinguished service awards from the San Andreas Regional Center. His approach is one of gentle redirection, and many difficult autistic behaviors have decreased in his four homes, which are very clean and orderly. “When they become older, we plan to keep the girls together in a continuum of care. They are like sisters, they have been together so long; we want to keep them together.”

Today, Mr. O'Campos' daughter, Angel (raised in the United States and also up to date of the latest developments in nutrition) is taking some responsibilities around the girls' home, bringing energetic organizational skills and a fresh spirit. This Easter she prepared the girls' baskets.

Most of the O'Campo residents attend the Morgan Autism Center in San Jose. (Other adult work programs in the area include Better Horizons and Hope Developmental Center.) But in 1969, when Morgan Center day program was formed by its first director, Louise

Emerson, there were no services for autistic kids. Soon she realized these students were very different from emotionally disturbed kids. Quickly it had become apparent: “they think and learn differently.” She realized that we have to understand their way of thinking in order to be successful; we can’t force them to conform to our way of thinking.

Current Morgan Autism Center Executive Director Jennifer Sullivan said in her recent interview that her program is for students with severe disabilities who are not able to be in the public school system. They require a more intensive learning environment. She agreed that autism is a lifelong disorder affecting speech, social interactions, and behavior.

Jennifer mentioned pioneering Morgan Center parents like Sue Sweezy, who had contact with the late Dr. Bernard Rimland, whose Autism Research Society’s approaches broke ground in the 1960s. He would later refer autistic patients locally to the late Dr. John Wakefield, a psychiatrist on the World Health Council, who looked at environmental allergies and nutritional interventions with great success. Patients like Vanessa who should not take psychotropic drugs could be benefited by alternatives, like nutritional microgram amounts of Lithium in that she lacked the normal amount, for example.

At the time the Spark foundation came into being in the 1980s, awareness of autism was just beginning to grow. Sixty to eighty percent of autistic youth also had some form of developmental delay. In recent times, the autism spectrum has included people with Asperger Syndrome. Asperger individuals have milder forms of the same characteristics as autism with impaired social skills; they are able to communicate and typically do not have cognitive issues. Sullivan said that in the upcoming DSM5 (Diagnostic and Statistical Manual of Mental Disorders) Asperger will be separated from autism, which may return autism to its more traditional definition to the time that the Spark Foundation was formed.

The early parent pioneers had confidence that autistic young people would blossom as they matured, given adequate residential and day services. Last month child and adult



Thomas was 8 years old when he painted this picture for a Starry Starry Night Gala – one of 55 pieces of students' artwork on display.

autistic artists at Morgan Autism Center's Starry Starry Night Gala earned thousands of dollars per piece of art snatched up by local collectors. The autistic artist creates from an unusual interior view that has come to be recognized as extremely "free" by art connoisseurs. One new autism theory is that such individuals have more not less synapses. Thanks to the efforts of Santa Clara Valley autism pioneers who

looked beyond the deficits to the strengths of the autistic, many of these unique individuals are coming to support their own community programs.

Supplemental Information

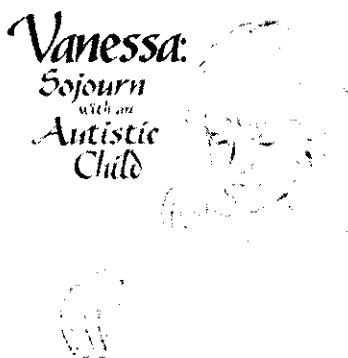
In the following appendices, I offer additional information that supports my essay.

1. Appendix A – A Personal Reflection on Autism
2. Appendix B – Autism Research May Be About To Bear Fruit

Appendix A: Personal Reflection on Autism

Written by Lynn Rogers and fully published in the September/October 1994 issue of Venture Inward magazine; excerpted version presented in this essay.

When I first
beautiful, two-year-old
impaired, I went
grieving, shock, denial,
acceptance. Fortunately,

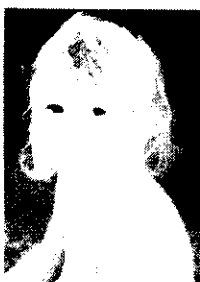


knew about the Edgar Cayce philosophy — that nothing happens by chance, that souls live more than one life, that this was not Vanessa's whole self.

learned that my bright-eyed,
daughter was neurologically
through the typical steps of
bargaining, anger, and finally
even as a young mother, I

Still, that knowledge didn't keep me from an almost overwhelming pain as I gradually faced the fact that my angelic-looking, "perfect" child was impaired for life. At five months, she'd tried to talk. She'd crawled, but on her back, and at thirteen months, she tried to walk, only to fall, over and over, often hitting her head.

I had to face facts at 22 months. She'd stopped walking and fell even when crawling.



**Before her
second birthday,
Vanessa began
falling, and
stopped walking
for a time.**

The early attempts at speech had ceased. I had a dream to take her to an osteopath or a neurologist, who said, "There's something very wrong with this baby." I didn't want to believe it. She's always given the impression that she has glimmers of brilliance mixed with a much more limited mental awareness.

I'd just given birth to her sister and spent the first two weeks of Megan's life nursing her in the waiting room of the hospital where Vanessa lay. I prayed that Vanessa would be healed. She suddenly

picked herself up and began to walk. Again I wanted to believe she was normal. But at home she regressed, banged her head, cried, and stopped walking.

The first time I heard the word "autistic" used to describe my daughter Vanessa, she was four years old. Although one psychologist then suspected she was autistic, other diagnoses were offered, including ataxia, aphasia, and dyslexia. And I was told that autistic children walked on their tip toes and never looked at you. That didn't fit Vanessa. At four, she got speech therapy at a school for the aphasia, but it wasn't enough; by six years she was in a behavior modification program for the autistic, as well.

When autism, a severe lifelong disability affecting speech, mental development, and perception of sensations and people, was first identified by Leo Kanner in 1949's post-Freudian era, parents were wrongly blamed — "refrigerator mothers." It has now been firmly proven that parenting style has nothing to do with the origin of autism.

Current medical science has established autism as a neurological disorder that appears in the first three years of life. It is more common than blindness and is found in four times more males than females in families of all racial, ethnic and social backgrounds throughout the world. Eighty percent of autistic persons are developmentally delayed, though many have distinct "savant" skills in areas like music, mathematics, spatial concepts, and, I have discovered, heightened psychic awareness.

Autism is often misdiagnosed, at first. Although no one was exactly sure what was wrong with Vanessa, over time we learned she did better in an autistic program. At first, we still suffered from the old approach to this disorder. For example, the children's father and I were made to sit on the floor in a glass viewing room with our two little daughters, as unseen eyes watched our every move.

If Vanessa banged her head at home, one social worker at the speech school made us track Vanessa's every move on a huge piece of butcher paper hung on our kitchen wall — until she hurt herself badly in their care. This experience gave us further clues as to Vanessa's condition, because we later learned that self-injurious, repetitive, aggressive behavior is a symptom of autism.

When she was in the behavior modification program, we carried a timer. A bell rang every 15 minutes. We had to give Vanessa a food reward if she hadn't banged her head.

It was no comfort to hear that the divorce rate of young, first-time parents of such a child was over 80 percent. By the time she was six, Vanessa's father and I separated. Other family members on both sides couldn't cope, either. I felt abandoned, except by one person, Jessica Madigan, an early West Coast A.R.E. (Association for Research and Enlightenment) organizer, lecturer, and writer, who had introduced me to the Cayce philosophy.

"Don't put Vanessa aside," she advised me, when others were urging me to give her up. "Vanessa is an old soul, retarded in this one life, for a purpose."

Again and again, whenever I felt overwhelmed, ready to drive off the Golden Gate Bridge with Vanessa — I didn't plan to do it, it just made me feel much better to think there was a way out — I would remember her words.

In this life, now, I was a young mother burdened with an autistic, developmentally-delayed child. After some time, I focused on putting her welfare before my own. Gradually, it became a stepping stone. In the words of Catholic theologian Matthew Fox, I had journeyed from the Via Positiva, the path of joy at Vanessa's birth, to Via Negativa, the darkest night of the soul, when her disability became known. And now I was moving toward Via Creativa, where new insight comes from the depths, and ultimately toward Via

Transformativa, where this insight is taken out into the world to help others. Fox's Creation Spirituality and Edgar Cayce's philosophy — know thyself and give loving service — are not too far apart in my book.

When I truly came to care for Vanessa's suffering more than my own selfish desires, grace entered in.

First, at Jessica's suggestion, I took Vanessa at age six to Dr. Gladys McGarey, who was then at the A.R.E. Clinic in Phoenix, Arizona. She explained that Vanessa's soul wasn't fully "tucked in" her body. Her implementation of the Edgar Cayce healing tools stopped Vanessa's screaming at night and brought greater coordination.



Vanessa at 13, visiting Dr. Gladys McGarey



Family portrait clockwise around Vanessa: father, stepfather, mother and sister.

I took Vanessa to Dr. Gladys again when she was 13 and could read no alphabet letters at all. She spoke in short repetitive phrases — "Gimme treat." After two weeks of osteopathic

manipulation, massage, music, energy medicine, patterning for the brain injured, nutritional intervention, and love, she began to recognize a few whole words that the clinic staff wrote on huge flash cards — a major breakthrough.

Dr. Gladys explained that brain-injured people don't process information like those considered "normal." They might be hypo- or hyper-sensory, or both, like Vanessa. I understood then why Vanessa took off her

clothes at times — because they felt heavy, like a suit of armor. At other times Vanessa could have a third-degree burn and barely notice.

"The organism is always trying to heal itself," Dr. Gladys said. So Vanessa was banging her head in a misdirected attempt to heal, to get the message of touch to her brain. We could intervene and build new pathways.

Returning home via Los Angeles with my new husband Joe, an older man I had met through Jessica, who was devoted to Vanessa's care, we stopped to see Jessica. Near death after a severe stroke, she couldn't speak. It was the last time I ever saw her.

After our visit, we visited with Jessica's co-worker. He asked Vanessa, "Did you like the clinic?" We couldn't explain to him that Vanessa, with a functional I.Q. just below 50, wouldn't understand his question. But she looked clearly into his eyes and answered, "Yes. It helped my soul." It was a wonderful moment for us all.

We continued the A.R.E. Clinic's home program, with the help of volunteers, for six months intensively, then requested it be integrated into her day school dealing with autism and emotional problems. For example, as often as possible, Vanessa's forearms were gently scrubbed to give her brain the message of touch. Self-injurious behavior decreased. She began to read whole survival words on smaller flash cards— "walk, stop, women's." Today, at Morgan Center School, she associates pictures and words if related to her life. "Today we went swimming and had ice cream."

She was better able to express her feelings, but still had cycles of withdrawal contrasted with flurries of repetitive speech, strange habits like picking lint off a stranger's clothing, turning off all the lights in the house and biting her arms. She needed a structured living program.

Now Vanessa resides during the week at Spark Foundation, a grassroots, parent-founded residential treatment program, an alternative to state hospitalization in our community. Founded by three mothers of autistic sons — one Jewish, one Catholic, one Protestant — it serves young people of diverse social, ethnic and racial backgrounds. Spark takes a positive skills training approach, focusing on strengths rather than weaknesses in a safe, homelike atmosphere where the essential dignity of each person is respected.

From these parents' research, I learned there is a broad spectrum of autistic symptoms including perseveration (repetition) of words or behavior. Because of inner neurological chaos, autistic persons develop rituals to organize their environment. Some were more sociable than others. Now I knew for sure Vanessa was autistic.

At Spark, Vanessa shares activities with other autistic youths, including skills training — like salad making — and recreational activities like therapeutic dancing and swimming. Although autism is a lifelong disability, autistic people do continue to make progress, even into adulthood. Next year she'll begin a sheltered vocational workshop.

Our whole family helps keep Spark alive. I've done fund-raising and community outreach, Joe serves on the board, Vanessa's 19-year-old sister Megan volunteers in the office, and my father edges her group home lawn and golfs at the benefit tournament. The Center for Infinite Growth church in Santa Clara has opened their hearts to Vanessa and supports all these efforts. Our dark night of the soul and karmic stumbling block, as Edgar Cayce might have said, has become a stepping stone to the Via Transformativa as we join with other dedicated parents and professional staff to provide a program now regarded in California as a new approach to autism. Dr. Gladys McGarey serves on Spark's advisory board.

My life has come full circle. Though she will never fly to college in France or attend A.R.E. Youth Congress as Megan has done, I've learned greatly through caring for her and from her unique, fresh, approach to life. She loves unconditionally, and can break from the frustration of her condition into a radiant smile, joyous just to see the face of a friend.

She is highly intuitive and reads the essence of people. For example, she knows ahead of time when someone will drop in unexpectedly to visit. "Where's Rob?" she repeats for an hour before he arrives, unannounced. If people who otherwise love each other argue fiercely over inconsequentials, Vanessa laughs. But if someone rejects Vanessa behind a superficial smile, she becomes extremely agitated.

Once I dropped in at her group home on a day when I had experienced a sad personal loss. I masked my feelings and the staff didn't notice I was ready to cry. But Vanessa and three of her roommates who are usually in their own autistic worlds, all stopped their perseverative behavior and came quietly toward me in the living room. One girl who almost never makes eye contact — she says "pizza, pizza, pizza" when I visit — touched my shoulder and faced me with eyes full of compassion. I've come to believe that although autistic and developmentally delayed people don't have all of their cognitive abilities, their soul, or intuitive force is very strong.

When I recently received a phone call from Vanessa's teacher Clare, I was afraid it was bad news, as Vanessa had been in one of her down cycles for weeks. "Vanessa clicked today," Clare said. She had run the 100-yard dash with people preparing for the Special Olympics, and in the class had read two pages from a book, *The Grumpy Elephant*. I couldn't believe it. Vanessa's never read a book in her life. She got stuck once, the teacher reported.

"What does 'o-w' spell?" Clare asked Vanessa. "Ow," she answered correctly.

"Vanessa," Clare exclaimed. "You can read!" "Yes," my daughter answered with a big smile.

Vanessa delights in simple things. She tries harder than anyone I've ever known, making so much of so little. While other young adults worry about the right clothes and college choices, Vanessa kisses her Miss Piggy doll's nose and sorts the same memory cards over and over, studying each picture as if it were new.

When Megan's friends, home on college break, rush past Vanessa to chat with Megan in her room, Vanessa beams and repeats, "I saw Megan's friends," long after they have all left her behind to go out.

Vanessa forgives those who lose patience with her and doesn't envy her sister's abilities. She, in the definition of Creation Spirituality, a true mystic, or, in the philosophy of Edgar Cayce, an old soul. She is my greatest teacher.²⁶

Addendum: For anyone interested in gaining further insight into hope for autistic children, I have two recommendations which I personally had reviewed for *Venture Inward* magazine's January/February 1996 issue: *A Child of Eternity* by Adriana Roche and Kristi Jorde and *Son Rise: The Miracle Continues* by Barry Neil Kaufman.

²⁶ "Vanessa: Sojourn with an Autistic Child," *Venture Inward*, September/October 1994, 26-29

Appendix B: Autism Research May Be About To Bear Fruit

Paraphrased from a very timely article written by Mike Stobbe of the Associated Press and published on Monday, April 9, 2012.

More than \$1 billion has been spent over the past decade researching autism with a focus on everything from genetics to the later age of the father, the overweight of the mother, and how close a child lives to a freeway. Some in the field are seeing a wave of scientific reports that should strengthen some theories, remove others and perhaps herald new drugs.

"I do think over the next three to five years we'll be able to paint a much clearer picture of how genes and environmental factors combine" to cause autism, said Geraldine Dawson, a psychologist and chief science officer for the advocacy group Autism Speaks.

The effort has been infused with new urgency — a recent federal report found autism disorders are far more common than was previously understood, affecting 1 in 88 U.S. children. Better diagnosis is a part of the numbers, but health officials said there may actually be more cases of autism, too.

If autism's causes remain a mystery, "you're not going to be able to stop this increase," said Irva Hertz-Picciotto, a researcher at the University of California, Davis who is leading a closely watched study into what sparks autism disorders.

Finding the causes of autism — an umbrella term for a variety of disorders that delay children socially or intellectually — remains daunting. The causes are believed to be complicated, and not necessarily the same for each child. Autism is a small word for a wide range of illnesses. In many cases, autism can be blamed on both genetic problems that load the gun and other factors that pull the trigger. It has been a growing public concern for two decades, as studies have found it to be more and more prevalent.

The lion's share of money for finding a cause has been spent on genetics, which so far experts believe can account for roughly 20 percent of cases. The earliest success was in the early 1990s and involved the discovery of the genetic underpinnings of Fragile X syndrome, a rare condition that accounts for just 2 to 4 percent of autism cases but is the most common form of inherited intellectual disability in boys.

Dozens of risk genes have been identified, and a half-dozen drug companies are said to be working on developing new treatments.

"We've made some very significant progress on the genetics end of this search," said Dr. Thomas Insel, director of the National Institute of Mental Health.

New drugs include a small, white, strawberry-flavored pill that is so experimental it doesn't have a name. Developed by a Massachusetts company called Seaside Therapeutics Inc., the drug is aimed at a problem area in the brains of autistic children, where neurons connect and conduct signals through the nervous system.

The drug made a striking difference in small groups of Fragile X children, causing hermit-like youngsters to start hanging out in the kitchen to chat with their mothers, said Dr. Paul Wang, Seaside's vice president of clinical development.

Now it is being tried in a preliminary study of about 150 children with a range of other autism disorders, including Asperger's. The results are expected to be presented at a scientific conference in the next year.

"It's going to be an exciting time, we hope," when those results come in, said Dawson, from Autism Speaks.

But even genetics enthusiasts acknowledge that genes are only part of the answer. Studies of identical twins have shown that autism can occur in one and not the other,

meaning something outside a child's DNA is triggering the disorder in many cases. Some cases may be entirely due to other causes, Dawson said.

That broad "other" category means "environmental" influences — not necessarily chemicals, but a grab bag of outside factors that include things like the age of the father at conception and illnesses and medications the mother had while pregnant.

For years, the best-known environmental theory involved childhood vaccines. But there are other possible candidates. In all cases, these are "association" studies — they don't prove cause and effect. They merely find connections between certain factors and autism. And sometimes these conclusions can be skewed by other things researchers failed to account for. Some study results expected within a year:

— Hertz-Picciotto's study of 1,600 children in Northern California is comparing autistic children, youngsters with other developmental disabilities, and those who have no such diagnoses. Some results have been released already, including the recent finding that suggests a link between autism and a mother's obesity. An earlier part of the study found that children born to mothers living less than two blocks from a freeway were twice as likely to have autism — presumably because of auto exhaust and air pollution, the researchers speculated.

—A study by The Centers for Disease Control and Prevention involves 2,700 families nationwide. The researchers are interviewing parents and poring over medical records to look for common threads among autistic families, as well as doing genetics tests and checking hair samples for mercury. Much of the focus is on illnesses, medications, nutritional deficiencies or other problems during pregnancy.

—A study by Pennsylvania researchers involves 1,700 families in various regions of the country. Scientists are doing brain-imaging to look for changes over time in the brains of infants who have an older autistic sibling.

—A large Scandinavian study is examining patient registries in six countries for prenatal risk factors.

As study findings are reported, researchers are hoping to see repetition — confirmation, that is — that certain factors are playing significant roles.

Said Coleen Boyle, a CDC official overseeing research into children's developmental disabilities: "We're at the infancy of just understanding how these factors relate to autism."²⁷

²⁷ Mike Stobbe. "Autism Research May be About To Bear Fruit. *Associated Press*, 9 April 2012, <http://news.yahoo.com/autism-research-may-bear-fruit-213713663.html> (accessed April 11, 2012).

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Bibliography

Articles, newsletters and interviews unless otherwise noted are from the Rogers/Haddox Autism Archive.

1. "Vanessa: Sojourn with an Autistic Child." *Venture Inward* 10, no. 5 (September/October, 1994): 26-29.

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1. Numerous photographs and images were scanned 5 April 2012 from various newspaper and newsletter sources from the Rogers/Haddox Autism Archive.