ALAN'S ALBUM

Interview with Sheila Green
by Marguerite Kearns

An additional text to "Alan and the Strange Light"

Photographs by Michael Weisbrot

Sheila Green:

I didn't want to look at the photographs when my brother Michael brought the entire collection to me the day he came with his family for my granddaughter's birthday party.

The photos represented the end of a long journey.

Michael took the first one when Alan was 16 and in the hospital. They followed him through all those difficult years of tension, sadness, and an occasional moment of joy and then ended with the day of the funeral.

When he handed me the pictures, I was struck with how compact they seemed, all neatly presented in an album. I'd seen most of them before, but something prompted me to go into the bedroom. I closed the door. Looking at them brought back so many memories. It was terrible.

Finally I got to the last picture at the cemetery.

I couldn't see how I could go on.

Then I noticed a black page after the last photo. And another picture behind it: a photo of the whole family. My brother, his wife Marilyn and their two kids. My husband Perry, me, our daughter Robin, and granddaughter Rachel. My uncle Lou had taken it with Michael's camera.

I thought the cemetery picture was the end, but the last photo changed that. Our family became the beginning, as if Alan didn't die.

Some people would say that's a rationalization. In our grief, we grasp for reasons to feel better. No matter what I come up with, an essential fact remains. Alan isn't here any more. People die every day, just like Alan did. The loss is felt by close friends and relatives, but usually one's life and death doesn't make much of an impact. I want to think Alan was different-- that what he went through will make a difference.

We'll never know how it would have been without the photographs. They made Alan's and our struggle larger than life. When we became frustrated with letter-writing, phone-calling and dealing with agencies and institutions, the photographs spoke for Alan, much better than I could ever do.

You could lay them out on a table and make everyone sit up in their seats. They weren't pretty. They didn't tell the tale of family members with superhuman strength who overcame the odds. They told the truth; sometimes that wasn't pretty. They communicated the tragedy, the inhumanity, and occasionally a victory. When doors were closed on us, we kicked them open.

It wasn't always like that. I've learned a lot over the years--the hard way. I wish I could take other parents with disabled kids aside and tell them the best way to come through the experience intact, but disabled kids don't come with instruction books.

Sure, there are plenty of articles and books to read about disabilities and parents' rights under the law, plus all sorts of supportive professionals who invite you into their offices to talk about the best services society can provide at this time.

Most often that isn't enough.

As parents, we worry about not being able to get through another day. About what's going to happen when we get old and die. About whether or not our child will suffer if we speak up and criticize a program or an individual staff member working for it. About not doing enough.

There's even guilt, if we steal a few hours to get away from it all.

Alan was unique. Most parents of disabled children say that about their child. Alan's problems were of exaggerated proportions. By late adolescence, his multiple handicaps made him so difficult to place that people were fond of telling me he "fell through the cracks." The programs were designed for textbook cases of one disability or another. Alan was brain injured and had acute medical and behavior problems.

We loved him intensely and wanted him to be happy. That's what kept us going.

I wasn't equipped to handle what we were up against when we started on this journey.

When I was young, it was generally accepted that women weren't the major players. Men were. That's the way it was. You didn't waste time thinking about it or trying to change things. Overall, I didn't look beyond the nose on my face.

In high school I was an honor student; for a time I was even considering going on to college, but I didn't. I got married. I knew I'd be happy being a wife, a daughter and relative of good, honest basic people. And I was. We had a close family of people who liked to do things together.

Raising a family kept me busy. I went through the motions of the day until it was time to sleep. That's the way it is for many people. You believe that teachers are smart; doctors and lawyers are brilliant; and that you should always trust a policeman.

I looked outside myself for the answers for years. You have to do that first. Talk to the experts and professionals. Take their advice seriously. Go to different doctors and get a variety of opinions. Read books. Attend meetings. Talk to other parents. The process never stops.

Sooner or later you reach a point when you discover that what's out there doesn't apply any more and you have to look elsewhere. You must dig deep inside yourself for something beyond the facts, beyond someone else's interpretation of them. You have to call on resources you never knew you had. You have to go places and relate to people that at other times in your life you would have never believed you'd be able to do.

It's lonely at times.

A lot of people, even those who mean well, can't always help.

There are other parents with similar problems, but usually they're just as overwhelmed as you are.

Some days you think you simply can't go on.

But you do.

You're fighting for your own flesh and blood. A rational part of you says everything will turn out for the best, but there's no evidence for that point of view.

You live on faith. Even that's weak sometimes.

That's why I wrote letters and talked to anybody who would listen. Most of the time it seemed as if what I was doing wouldn't make a dent. In many instances, it probably didn't. That didn't matter. We had to push on.

Alan was my son and I had to fight for him.

We lived day-by-day. We had no choice.

The photographs were a path through the wilderness.

* * *

Alan was Perry's and my first child and only son.

I was 19 years old.

What a gorgeous boy! He was smart, blonde and cute. The kind of kid who eats, isn't constantly sick, sleeps at night and does the right things at the right time.

Alan's birth was normal. He was an early talker and reader who sang many of the tunes on television commercials. Probably he was average, but to me he was above average. When we went for walks in Jackson Heights, older women told me how beautiful Alan was. He was pleasant and always smiling. If I read to Alan, he filled in the spaces when I left out words. He'd entertain himself for hours playing with pots and pans. He told time early.

My brother Michael, who was six years younger than me, took on the role of uncle easily. Michael and Perry got on immediately, like brothers. Michael took Alan to the zoo and to museums--even when he went out with his own friends.

Alan was five-and-a-half when he came down with rubella or measles. One day he had a temperature of 106.5. I couldn't get it down and couldn't get a doctor. I followed Dr. Spock's book and my mother's advice. Through it all, Alan just laid there, extremely ill.

For a long time I didn't know Alan had been neurologically impaired or brain injured from the high temperature associated with the measles. His condition was that mild. In 1963, not long after Alan recovered, the first measles vaccine was developed.

When your child starts life in a way that appears normal, you don't always look for evidence of abnormal development. Individual children have good and bad days, plus aspects of their abilities that develop quickly and more slowly. Parents don't always observe as closely as they should. There are opportunities for all sorts of mistakes.

Perry and I made more than our share by being uptight, impatient and overprotective at times. We learned. We were married young. We had a traditional relationship. The first child gets the brunt of your trial and error. We tried to prove that what we were doing was right. We had a big investment in Alan.

It's difficult to be objective.

Today there are numerous programs that give parents the necessary information to evaluate their child's development so they can determine whether or not they should be concerned. You can call professionals over the phone and have your questions answered. Quite often you don't have to pay for testing and consultations. There's a consensus among the experts that it's cheaper and more efficient to identify problems early.

In addition, we have the law on our side. The right to an education is guaranteed. Libraries and stores have lots of books about how the mentally retarded and others with disabilities are people first. Dignity and independence are stressed, as well as finding out how each person learns best and working from there. Numerous courses and guides instruct parents and teachers about what to look for and how to respond to a wide variety of conditions; they provide plenty of checklists and excellent bibliographies.

That's the good news.

The bad news is that doctors, school personnel and other professionals are human, just like everyone else. They have their personal problems and concerns. They can be ambitious and short-sighted and lazy. And they are also wonderful, but not all of them, all of the time. You can't depend on other people to make sure your children get what they need.

Discovering this is an agonizing experience.

By school age, Alan was big for his size. When he was in line with the other children, the teacher put him at the back. His size implied he was more able to cope with school than he really was.

It took a long time but eventually I figured out that when Alan was called on in class, he couldn't answer. He came home from school very unhappy. Not every day, but often. He must have been very frustrated. My husband and I were unaware.

People would say, "He's acting babyish."

It's easy to think your child will outgrow it--that they're going through a stage. More often than not, they are. It isn't helpful for a parent to be obsessive and anxiety-ridden about the predictable uneven stages of a child's early developing years.

We expected a lot from Alan.

I'd get a note from the teacher and I'd respond, "He'll try harder." It never occurred to me that he was doing the best he could. I don't think too many people ever heard about neurologically impaired children back then. It was just assumed they were lazy.

Sooner or later something happens which in retrospect you recognize as a turning point. For me, it was the acceptance that something was wrong and I'd have to rely on myself instead of putting everything in the hands of the experts. They're there to help, but more often than not, even the best ones have their hands full.

I went to Alan's school one day. No one was in the main office so I proceeded to Alan's classroom and stood outside the door, waiting for the appropriate moment to go inside. Because the door was open slightly, I could observe everything.

"Everybody pick up a blue crayon and make a sky," the teacher said. "Everybody--EXCEPT ALAN."

There was an edge to her voice. No doubt but that she was picking on him. I was stunned. Before I even had a chance to figure out how I felt, the principal was standing behind me.

"What are you doing here? Don't you know you're supposed to go to the office first?" he asked.

Immediately I felt terrible, as if I too had misbehaved. It took a while before I realized I was entitled to know what Alan was going through. The changes in my approach to Alan's situation came a little at a time over a long period of time.

I recognized that the teacher was under a lot of pressure and Alan didn't make her job easier. He was awkward, fidgety, and had poor coordination. He resisted when people forced their will on him.

Standardized tests that evaluated his reading ability as higher than grade level made it appear that Alan was a behavior problem, not a child with perceptual difficulties. It was difficult for him to sit still and absorb what was going on.

When the teacher left on maternity leave, another took her place.

She called me in.

"After taking over your son's class, I looked at the old records. I don't understand it. Your boy isn't the same one that's written about in these reports. He's cooperative and friendly."

That's because for the first time in a long time, he wasn't being humiliated. If he was short, thin and pale, perhaps the teacher would have had fewer expectations, but that didn't happen. Alan was made to feel that his inability to do math and throw a ball was his fault.

Without realizing it, we contributed to that.

The old teacher may have handled things poorly, but she created a crisis. Conflict between parents and teachers over children with disabilities is classic. There's an inherent competition when there should be cooperation. As far as many teachers are concerned, parents are too emotional and not objective enough to know what's best for their child. They cite ample evidence.

Some parents are overtly hostile when dealing with the school. They may have had a bad experience like I had or general difficulties dealing with authority figures. They may blame the teacher for the learning disability diagnosis or believe the institution isn't providing relevant instruction. Often parents don't have the energy to get involved with school because they're overwhelmed with addressing the demands of family life. There are many reasons why parents and teachers work in isolation.

Many parents simply aren't made to feel welcome in school.

We've come a long way toward working together the past few years. Conflict or confrontation is a signal that something is seriously wrong and you must give it your total attention before moving ahead.

After Alan was tested, we realized what had happened.

Coping with that information is extremely difficult.

There's lots of written material about what occurs after parents find out their child has a disability. There's underlying truth to it, although it's also a body of literature used to stereotype us.

Families informed of a disability at birth are at an advantage in some ways. They have the opportunity to come to terms with the information relatively early.

A natural impulse is to deny this is happening to you, hold fast to the idea of a cure, or maintain that the experts don't know what they're talking about.

Maybe they do. Maybe they don't. You have to give it time.

Some parents blame the difficulty on themselves. They withdraw and ride a rollercoaster of negative and positive feelings. They're depressed, sometimes feel suicidal, defensive, or all-around miserable. They expect too much or too little. They have mixed feelings or guilt about deciding whether to keep the child at home or look for an outside program. They can be ashamed, angry, and devastated.

Sooner or later, love for the child becomes the driving force.

Over the years I've experienced a sampling of the possible range of emotions or I've seen other parents agonize through them. There are few things other parents haven't gone through already. If you think you're alone, your eyes will be opened when you read the books about exceptional children written by parents or professionals. Everything we could feel about our child's condition has been fully documented.

When Perry and I joined a group of parents interested in advocating for services for our children, the inevitable subject came up. "WHY ME?" At one time or another a well-meaning friends says there's a lesson a supreme being is giving us through our child from which we're supposed to benefit.

Or they suggest we're being punished for the sins of this or another lifetime.

"God doesn't give you any pain you can't handle," is another cliche that's supposed to make us feel better.

Why us? I'd ask myself that. Perry wondered why he had a serious case of arthritis. Who knows? At a certain point you have to stop asking. Even if you know what went wrong, like a prescription drug you took during the first trimester of pregnancy or a chromosomal abnormality, it's too late to do anything about it. What's the point of blaming ourselves or someone else? It only diverts our attention and energy which we need to get through this experience.

Alan had problems. That was it. We had to dig in and get to work. Life is tough. It is for everybody. Where's the justice? There is no justice. Only the justice that we create. There are so many inequities in this world and so much suffering that if we let it get to us, we'd go crazy. We have to ask ourselves if there's meaning in our suffering. If there is, it's meaning we've discovered or created. It's significant only to us.

At one point during the journey I approached a religious leader in my community to share our situation.

"What do you want *me* to do?" he responded.

He wasn't very skilled dealing with women.

"Nothing," I mumbled. I hadn't expected his response. My sense of desperation must have been powerful. The tone of his voice was almost hostile, as if I was personally responsible for what had gone wrong with Alan. I was only looking for tools to get around the obstacles put before us.

I had no answers. Only questions.

I felt faint. All sorts of feelings I didn't understand swirled up inside me. As I got up to go, I was almost knocked back down again by the force of my reaction. I didn't want him to know what I was going through. With a burst of will power I didn't know I had, I jumped up from my chair and hurried out the door.

It's difficult to say something significant to another person when they're in a great deal of pain. Much of what's said is inappropriate or totally inadequate. There's a tendency to hold out hope that there's a person or agency or program out there to solve all your problems. Perhaps there is, but don't count on it.

It's unsettling to come to terms with the possibility that the answers are **inside you.** So many mixed messages are coming from society.

Christine, another mother, says she cringes each time someone tells her she'll have to "accept" her son Billy's disability and "adjust" to it. If she likes the person, she forgives them. They have good intentions.

On several occasions the terms were used by someone in a position of power to justify why they had said "no" to one of her requests. This infuriated Christine. Because she wants Billy to be fulfilled and live up to his potential, she has difficulties "accepting and adjusting" to certain conditions associated with his life.

Every day Christine thinks about the dilemmas posed by Billy's disability. Over the years she says few people have said things that have made a difference, whereas a hug by a friend and an offer to stay with her son while she went shopping would have made all the difference.

One of her son's teachers once remarked, "I've always had a special place in my heart for people who are locked inside their bodies."

That touched Christine.

She says another friend said, "You'll never regret all the time you spend with Billy."

She never forgot that.

There are books, documentaries and movies made about people whose lives have been improved because of their child's disability. They're about exceptional people who do exceptional things. Christine says that although the accounts are well-intended and even inspirational, they often make her feel inadequate. She says she's only human; sometimes her responses and actions were less than noble, but she hasn't given up trying.

I know what she means.

Do families with disabled children benefit from their suffering? That's a good question.

Until recently it was primarily answered by the cynics who said the perspective that you can "make the best of a bad situation" is a rationalization for what is an otherwise unacceptable and desperate state of affairs.

That has been challenged by families of children with disabilities who acknowledge the stress, but add that their child is a profound source of happiness, strength, pride and fulfillment. Ann Turnbull, a professor in special education who adopted a boy with disabilities, has done important work with her husband in this area. After she crossed over the line from professional to parent, she was able to communicate to both sides the critical need for us all to work together.

Adversity can be an excellent teacher.

I learned a great deal because of Alan.

There's no doubt our daughter Robin was affected profoundly. Even to this day she's working on healing herself because of all those difficult years and the extraordinary tension because of her brother's condition.

Because of our suffering, Perry and I are more sensitive to other people's suffering.

If more regular citizens understood what we went through, other young persons like Alan would have a better life.

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When Alan was placed in a special class early in his schooling, we tried to accept it, as much as parents are able to do about such an disappointment. I don't think Alan was as upset about being taken out of the mainstream as we were, considering that most of his earliest experiences in the classroom were unpleasant. I think he believed he didn't have to be in a special class. The placement was a mixed blessing. The other children weren't as cruel as those in the regular class.

In the new setting, Alan developed at an uneven pace. In a limited number of ways, he was perfectly normal. He was just as interested in contemporary music as his peers. At a family gathering, no one would have noticed Alan was much different from his cousins. He wasn't as well coordinated, but as far as various family members were concerned, that wasn't worthy of comment.

Alan was just Alan.

He showed an interest in the comings and goings of all our friends and relatives. You wouldn't think twice about seeing him sitting at the kitchen table reading the newspaper. He had opinions about current affairs. His speech was slow and at times unclear.

Few of my friends thought of Alan as different; he wasn't treated that way, except at school.

Even though my husband and I scaled down our expectations, there was never a question in our minds that Alan would have a future. It took him longer to do things. That's all. We defined his boundaries differently and worked within the limitations.

In the quiet of the night when Perry and I laid in bed and talked, I sensed Perry's hurt about what had happened. He always wanted a son he could do things with. What father doesn't? Our neighbor's son became a doctor. Why not our's? When we changed our expectations, I was delighted to think Alan might become a mechanic. He loved cars. What difference did it make as long as he was happy?

That was before Alan went into the hospital.

Considering everything, Alan tried hard to do so many things. I wanted his life to be as normal as possible. I would do anything--I MEAN ANYTHING-- to see that come about.

When Alan was still in elementary school, he begged me to join the Stallions. It was like Little League football. Alan was tall and broad for his age. I didn't want to discourage him, so off we went to join up. He was the only Jewish kid among a team of Irish and Italian boys. Every Saturday there was a practice or a game.

Alan looked great in his helmet and uniform. He felt great too. Except for the fact that he and another boy sat on the bench. Always. Alan never got a chance to throw a ball. The coach was so concerned with winning that he never sent Alan into the game to run up and down the field.

Perry and I sat in the stands and cheered-- until one day we had no heart for it any more. I don't think Alan did either. Disgusted, I called up the coach and asked him why. He said Alan couldn't catch the ball and run as fast as everyone else.

"If that was so, why did you take him?"

The coach had no answer.

I asked myself why I had set Alan up for failure. By participating, Alan felt part of something important. He needed that. Just like he needed to be a member of the Boy Scouts and any other community group that would accept him.

That's the agony of being the parent of a special child. You have to go with your gut instinct about what's right and accept that few experiences will be perfect.

It's easier for families of special children than it used to be. There's a continuum. Not long ago, children were labeled "feebleminded" at birth, put into institutions like warehouses and left to languish in dark dirty corners. The citizenry didn't want to know anything about it.

In New York State, a nationally televised broadcast in 1971 about conditions at the Willowbrook Developmental Center on Staten Island finally woke people up. Five years prior, Senator Robert F. Kennedy had called the institution "a disgrace."

Public pressure led to the closing of most of the state's large institutions which have been replaced with smaller residences, usually with a dozen beds.

The majority of disabled children live at home through adolescence and move to community residences or other supervised settings during adulthood. They take advantage of special programs based in their neighborhood schools and communities. Children and adults with special needs have more rights and programs now than ever before in history.

The terminology has changed from retarded and handicapped to "people with disabilities"; the most recently coined term is "challenged." We're hearing a lot about "mainstreaming," "community-based instruction," "integrated settings," "normalization,""work assisted programs" and "least restrictive environments." Ramps for wheelchairs are more common than they've ever been.

It all boils down to treating people with disabilities as whole beings rather than subhumans-- responding to the details of their lives and not treating them with condescending attitudes. A new generation of parents with special children doesn't have to fight the same battles we did because so many rights are guaranteed by law. The younger parents take a lot for granted.

Even with the advances, the mothers and fathers will find that what's available falls short in one way or another. As a parent, you rarely get a rest. There's always one more thing to do-- one more person to educate about disabilities and one more boundary to push back. Sometimes the boundaries are within yourself. Sometimes they're within your child. Often the work is in your neighborhood or community.

I'll never forget the day I heard the term "RETARD" applied to Alan the first time. I couldn't believe it. Alan had gotten off the bus; I was walking to meet him and there it was. That word. I'm sure Alan had heard it before.

I grabbed the kid who said it by his ear and marched him toward his house.

"Let's go home to your mother and have her teach you what the correct word is, what it means, and how to spell it. I'm telling your mother what you called my son."

I was furious. I went on instinct.

The door opened and I did everything I promised.

I wasn't prepared for the mother to deny that her child would do such a thing-- a family where the mother is a teacher and the father, a lawyer. Such big shots in the community and they didn't consider it important to teach their children about something so basic!

Traditionally mental retardation has been defined in terms of IQ score. Usually it's 70 and under. The professionals say that the condition involves subaverage intellectual functioning affecting behavior across the board in varying degrees of intensity-- mild, moderate and severe.

Often it's not that simple. Brain injuries are unique to the individual and often involve varying degrees of functioning in behavioral and learning areas. To make matters worse, problem children and those who are culturally deprived have been lumped into the mentally retarded category.

The label can be a curse.

It lowers expectations and reinforces stereotypes which is one good reason why some parents resist the recommendation that their child be put in a special class. There are professionals who would like to do away with the mental retardation term completely and replace it with "general learning disabilities."

I'm certain the debate will go on for a long time.

Sooner or later, any new term takes on negative connotations. On the pecking order of disabilities, those involving intellect are not as fashionable as sensory disorders. The professional literature of special education is filled with discussions of the extent of prejudice.

People stared when we took Alan out in public. Regular folks didn't know how to talk to our son. They were awkward, annoyed, or anxious. It's one thing for folks to be ignorant or uncomfortable and quite another to be hostile and ugly. I've seen that more than once.

Ordinary citizens have all sorts of exaggerated fears when a group home is planned for their neighborhood-- from a decline in their property values to fears for their own safety. After the group home is open and operative, usually the attitudes change dramatically. They see that our children are people, just like everyone else.

When you're dealing with it every day, it's difficult to remember how things used to be. In the colonial days of this country's history, there were instances where people with disabilities were accepted. More often than not, they were hidden away in attics or barns. At best, they were neglected. In the worst instances, they were abused.

It took until the 1940s before disabled family members ventured out of the closets. The most dramatic developments have been since World War II. Academics started doing research. Laws were passed which gave handicapped people rights to education and opportunities. Until relatively recently when a retarded child was born, doctors automatically told parents they should be put into institutions for their own good.

During the 1970s there was a move to close down big institutions and put the disabled back into the community. "Deinstitutionalization" was was an important movement. "Mainstreaming" referred to the attempt to integrate special kids into normal public school programs as much as possible, instead of completely isolating them in separate classes and schools.

At one time the developmentally disabled had no rights. Now it's generally acknowledged that they have a right to respect and dignity; to a life free from harassment; a free education, appropriate training and guidance in the least restrictive setting; treatment of physical, mental and emotional disorders; the right not to be sterilized; the right to privacy and marriage; due process; the right to earn a livlihood and live independently in the community.

None of these things are handed over on a silver platter.

We still have a long way to go.

No matter how we sugarcoat the reality, our children aren't fully accepted. Discrimination is still a serious problem in our schools and communities. A catch-22 situation develops. The special kids are rejected. Feeling the full extent of the rejection, many become aggressive and hostile. They become more difficult, and as a consequence, even more isolated and misunderstood.

That's why parents must take a visible and assertive role.

Over the years we have. Many of the privately-run professional agencies serving the needs of the developmentally disabled exist today because they began as grassroots associations of parents trying to give their children services that weren't otherwise being provided. Many of the laws in effect on the state and federal level were lobbied by parents' groups.

Even though a new generation of parents with disabled children has emerged on the scene, it isn't as sophisticated as the older generation of parents that I represent. The political times are more challenging. There's more competition and debate in the public arena about how public money should be spent.

Despite the advances, we're still fighting fundamental battles every day. It wasn't uncommon for Alan's sister Robin to hear from other children at school, "Your brother's a retard--an idiot."

One day I assume it happened just before I looked out the window to check on the kids coming home from school. Alan turned around and wacked one boy on his nose. The mother (a different one from before) went off the deep end. She called the police. I couldn't believe it. Such a reaction!

Alan was terrified.

"Hide me," he begged after he ran into the house.

The mother called on the phone. I told her what happened and used the episode as an opportunity to bring about some positive change.

There were times when other kids yelled names after that, but not that particular kid.

He never went near Alan again.

When Alan was almost ten, we went to a reform temple for the studies for his bar mitzvah. I worked at the temple as a volunteer. Two times a week.

Yes, the other kids in the class picked on Alan. He was slower, although he eventually mastered the work.

The day of the bar mitzvah finally arrived for Alan and two other 13-year-old boys.

Alan went up to the altar and started his speech, for which he had practiced so hard and long. Three words into it, he faltered.

I held my breath and waited.

He looked at me intently, went back to the beginning, and read it perfectly. Then he gave me the O.K. sign.

The party was held the following day. All his friends and members of our family were there.

Alan looked great. As part of the preparation, he had taken dancing lessons.

That day he danced with everyone.

It was one of the proudest days of his life.

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Then the heartache began.

Alan got sick.

We didn't know what was wrong with him in the beginning. The doctors didn't either. Everything had been going so well. There was an organization not far from our home that was founded as a parents' group to provide recreational and other services to the families of brain injured and mentally retarded young men and women. They sponsored dances and other social functions.

It was wonderful to see our son play basketball, attend Boy Scout meetings, camp and hike. He had friends and was beginning to enjoy life. Even though we were all aware of Alan's heart murmur, our cardiologist advised us that it wasn't necessary to curtail him in any way.

He went away to camp, rode horses and bikes. Every year when he had a physical, our doctor told us he was doing well.

I remember the first time Alan complained of blurred and double vision. It was the end of summer vacation. The doctor prescribed some medication and said he should be put to bed to rest.

The next day he felt fine.

A few days later he said his shoulder was extremely painful. I called the doctor. Again, an examination and no clear diagnosis.

School started. The problems were compounded with exhaustion, loss of appetite, a fever. There were blood tests, more examinations and medications. This went on until Alan had lost 27 pounds. The doctor even suggested Alan might be emotionally upset due to school.

About a month into Alan's illness, he cut his hand with glass and needed stitches. When it came time to have them removed, our doctor commented on how poorly Alan looked. He listened to his chest and heart and recommended that Alan see a pediatric cardiologist. Arrangements were made to put him in the hospital-- immediately.

When I took Alan home that night, he could barely breathe. He walked with considerable effort. He was a grey color, as if there wasn't any blood in his system. He could barely walk up the stairs without lieing down right away.

Alan was 16 years old when he went into the hospital for what we thought was a short stay. He was diagnosed as having bacterial endocarditis, which is an infection of the heart chambers. The condition called for heavy doses of penicillin over a long period of time.

Alan was terrified, frustrated and upset by this prospect. Who wouldn't be?

We were told that all the previous symptoms were caused by embolisms shooting through his bloodstream; his spleen was terribly enlarged; and the pain was caused by all the clots.

After a month or so, Alan was sent home. There was a hospital strike underway. He still had a swollen spleen, fever and poor color. It was difficult for him to walk a short distance and he had a hard time catching his breath. Still no appetite, exhaustion, and pains all over his body.

He was hospitalized two more times.

In January of the next year Alan went back to the hospital for the fourth time to be catheterized to determine the damage to his heart. By the time the verdict was in, the severity of the infection was dramatic enough so that two of Alan's heart valves were damaged. They needed to be replaced with plastic valves.

Open heart surgery was performed on Alan in early February of 1974. The aortic and mitral valves were replaced and repair work was done on the rest of his heart. The operation took eleven hours.

We were told Alan might be lost to us forever, but they were able to bring him back.

After two weeks in the intensive care unit, Alan looked newborn. His color was wonderful and healthy. His appetite had improved. His sense of humor returned and he was able to help himself.

There he was-- going to the bathroom alone. He was healing well.

What a blessing!

One afternoon in March, I left Alan's hospital room to get cake plates for a little party. There was something to celebrate. He'd moved from intensive care to the adolescent unit on the main floor and he had asked for a chocolate cream pie. Alan's aunt and uncle were there with Perry and me that day.

When I came back, my sister-in-law Eileen stopped me.

"Don't go in there," she said.

That didn't stop me. Nothing ever has.

Alan was in cardiac arrest.

Perry and Eileen had been talking to Alan when he blanked out, as if he'd drifted off to sleep. It was very sudden.

Alan was slumped over so Perry lowered the bed and I did the first thing that came to mind after the emergency call had been put in. I put my mouth down on Alan's and breathed until someone came.

The force was so dramatic that I broke Alan's front tooth. The medical team administered an electric shock which brought Alan back.

Throughout it all, Alan's monitor never sounded an alarm.

When Alan was wheeled back to intensive care, he was conscious and spoke to me.

"Why are you so sad?" he asked. "Are you all right?"

That's the way Alan was.

I braced myself for the next interaction with the doctor. There was a great deal I wanted to know.

I was told that Alan had taken a mix of medications that had "played havoc with the electrolytes in his body."

I was insistent.

" How could this have happened?"

I prodded and pulled.

"It's a fluke. A once in a lifetime occurrence," I was told.

Then the doctor admitted that one drug wasn't administered in the recommended dose. There were certain risks associated with the treatment; in this instance, the worst had happened.

I was heartsick. We should have known. We should have spoken up.

It didn't seem right that Alan's monitoring equipment was often in poor working order. We had never asked why the machinery wasn't in the hallway or connected to a central monitoring device so that the medical staff could keep an eye on it.

If we hadn't been visiting Alan the day of his cardiac arrest, would they have been able to save him? I doubted it. We had to notify the doctor. There was no alarm. No sound came from the machine at all.

A few weeks passed.

One day when I was visiting with my mother, Alan compained of a stomach ache.

We told a nurse who got some medication. Alan vomited and said he was very tired.

The weather was so bad, I left early; my mother stayed until after Alan's dinner. He didn't eat much. My mother begged the nurses to keep an eye on Alan.

At ten o'clock that night a doctor from the intensive care unit called to say Alan was there again. He had suffered another cardiac arrest and was in a coma. We were told to leave home at once.

Things didn't look good.

For a long time we sat beside his bed and waited. We went home and returned the next morning.

We prayed.

Every day I sang to Alan. I taped photos on the guardrail next to his bed-- pictures of the family dog and family members.

Over and over, I read an inspiration poem to him that I'd clipped out of a newspaper. I've carried "Just for Today" around with me for years. It's thin for all the use it's had.

Just for today, I will try to live through this day only, and not set far-reaching goals to try and overcome all my problems all at once. I know I can do something for 12 hours that would appall me if I felt that I had to keep it up for a lifetime. . .

Just for today, I will adjust myself to what is. I will face reality. I will try to change those things I can change, and accept those things I cannot change. . .

Just for today, I will be unafraid. I will gather the courage to do what is right and take the responsibility for my own actions. I will expect nothing from the world, but I will realize that as I give to the world, the world will give to me.

It was difficult watching him fall apart. I drove every day from our home in Long Island to the hospital in mid-town Manhattan. That alone was exhausting. I was constantly at Alan's side. Our relatives came as much as they could. My mother was there for me, just as she always had been.

Michael's photographs speak more vividly than any other form of communication about what we went through. There's a sense of helplessness when you put someone you love into the hands of a big institution like a hospital. You want to trust the doctors and medical personnel, but a part of you doesn't.

If you're there long enough, you notice that nurses and doctors are overworked; they don't spend as much time as they should with each patient; they overlook things; and they don't know everything about every condition.

Love is lacking in large sterile places.

When he finally opened his eyes, it was clear Alan was paralyzed. Over a several week period he began to make tiny movements with his toes and fingers. We rubbed his limbs and toes to keep the circulation going. He was fed through a tube in his nose.

Alan fought that. It was horrible.

As he improved, he sat up a little. Then we were able to put him in a chair. As he got stronger, he was taken to the physical therapy unit. Finally when he stood up, Alan was a skeleton of what he had been before he got sick. One hundred pounds versus 170 pounds at six-foot-three. He cried and was agitated quite a bit. A teacher came to see him but he couldn't do any school work of significance.

By early summer Alan was told he'd be allowed outside for an excursion. Everyone in the family looked forward to that. A simple victory: Alan in his wheelchair with all the family members taking a walk in Central Park.

We didn't dare think about his future.

* * *

After Alan came out the coma, he was dazed. He was aware immediately of the close call he'd had with death.

His life wouldn't be the same again. We all knew that.

"Does it hurt to die?" he asked me.

He wanted to talk about the operation, a lot.

"I remember when I was lying on the operating table. There was nothing but blackness, like when you close your eyes. I was afraid-- afraid I wouldn't make it."

He told me about the young girl he'd made friends with who'd died in the adolescent ward right across the hall. There was a stir in the middle of the night. In the morning, he described the empty sheet pulled around her bed.

That made a big impact on Alan.

Around that time on a visit Perry and I made to the hospital, Alan was sitting on the edge of the bed in a state of terror.

"I'm dead," he announced.

It was almost humorous if it wasn't so serious.

We had to pinch and tease him to demonstrate he was perfectly all right. Alan was so used to the life-support machines being operative that when they were turned off, he had assumed the worst. No one told him otherwise.

The next stop for Alan was a medical rehabilitation institute where he underwent physical therapy so he could walk again. After four months he was able to come home.

The medication continued. I had to administer the standard series of pills. He had to be lifted to go to the bathroom. He was able to partially dress himself. The rest we did. Most of the time he was in a wheelchair.

After Alan came home from the hospital, all our relatives called and asked what they could do. I told them how much better he looked. I knew that wasn't true, but I wanted to spare them. I couldn't let people know the extent to which we'd suffered.

"It will be better tomorrow," I said.

I lied through my teeth.

I didn't think. I kept moving. Activity for its own sake. There were so many things to do.

Alan couldn't feed himself. He could barely hold a cup.

Before Alan went into the hospital, he was learning to drive a car. Now it was evident he couldn't, then and most likely not in the future. He was miserable and frustrated.

The burden of it fell on me.

The next five years were awful. The stress was constant. We had to find people to help Alan and a program to accept him. Alan went in and out of programs as if they had revolving doors. Either the program we agonized to get him into didn't provide what Alan needed, or he didn't fit in and his behavior resulted in his expulsion.

Most of the time he was simply refused admission. He wasn't eligible.

There are several shopping bags still in my closet full of copies of letters, notes, news clippings, and miscellaneous documents about that period of time. There are so many memories and feelings brought up when I review those records.

Michael continued taking pictures.

We applied to residential schools, rehabilitation centers, nursing homes and psychiatric institutes. Anything, if we thought it would help Alan.

Where do you start?

I became Alan's advocate. When I started, I found out quickly that there aren't any rules. There is no beginning or end. From the start, you have to believe you're a good person and you deserve help. This is very important because closed doors can reinforce the negative.

If there aren't services to meet your needs, that doesn't mean there shouldn't be. On the other hand, you can't expect government and the social service apparatus to be totally at your service. Advocating for your child is a complex and serious matter.

It's your job to visualize the ideal situation. Then go out and get it.

Sounds like a career, doesn't it? You're probably thinking you don't have the time or the skills to do what's needed. That you need someone by your side. Look for an advocate. Maybe you'll find one or two. Eventually I found people to help me and they acted as advocates, but I was still Alan's primary advocate.

When administrators and bureaucrats saw me coming, they wanted to hide. They knew they'd better have some answers.

They saw Alan's face when they saw mine.

In the end, we got what we wanted.

It was a long and painful process.

There was a lot of trial and error, searching, hoping, waiting, anticipation, disappointment.

It finally dawned on me to sit down at the typewriter and write something to speak for Alan when I couldn't be there physically to represent him. Maybe you don't have a typewriter or know how to use one. Probably you feel intimidated about putting words on paper. I was in the beginning, but I found out quickly that Alan's needs and his story developed a momentum once I got started.

Most people have access to a copy machine and a camera. You don't need a typewriter or a family member who's a professional photographer. A handwritten note reproduced many times and some snapshots of your child and family will do just as well. Whatever you need to communicate should be made part of a permanent record that you keep.

You won't get results right away. Maybe you will, if you're lucky.

Your problem might be the need for placement. Or poor conditions at a program your child is attending. A medical problem. A service you feel you deserve. The way you're treated. A move of your household which means a transfer to another school district and you want the same level of services continued for your child.

Whatever it is, the need and the associated feelings must be communicated. If you want something badly enough, trust that there are people out there who care.

You may not find them right away. If you're persistent, you will. They may be overworked and have limited tools with which to help you. You can't measure success by the quality of their response. You may not be using the right approach or arguments. They may not be aware of your rights under the law and you'll have to educate them. You may be asking the wrong person. You may be asking for the impossible.

Do and learn. That's what I did.

Never give up, even if you get what you want. Your needs will change.

My active advocacy didn't start right away after Alan came home from the hospital. I was too overwhelmed. I was still looking to other people to help me. I was extremely busy dealing with the immediate demands of Alan's care to relate effectively with agencies and systems.

When Alan came home from the rehabilitation institute, we made arrangements to have him tutored at home with instructors from our public school district. That was difficult because his attention span was short. Whereas he was minimally brain damaged perviously, now the problems were much more severe.

Alan was finally able to travel on a school bus. Plans were put in motion to have him enter a cerebral palsy program not far away. That was a poor choice, but we were in a difficult situation. He was still in a wheelchair. Attending the program was distressing for Alan because he felt he didn't belong there. He couldn't relate to the other young people.

Because he wasn't allowed out of his wheelchair during the program day, he became frustrated and belligerent. He threw temper tantrums. He was able to walk a little but not very well, and only with assistance. When he came home from school, his legs were weak from sitting all day. It took hours to get used to standing and moving again. The school sent reports about his poor behavior.

That summer Alan was admitted into a special day camp for disabled young people. He didn't take the wheelchair. What a miracle! And he got exercise by walking and swimming. Of course it wasn't without effort. We could see the progress. He was socializing with others his age, but his behavior never returned to what it was before he got sick. He became a volunteer aide and worked with disabled children younger than he was. While on one hand he was functioning better and contributing, Alan still felt inadequate.

Starting in the fall, Alan went to a series of schools designed for young people with emotional and behavior problems. There he got into so much trouble that the staff recommended psychiatric help. His frustration had developed into rage. It was impossible to know how to handle him.

One night we took him to the emergency room of a local hospital; the next day he was taken to a psychiatric hospital. The physician in charge told us we'd better put him in a state hospital for the rest of his life. No name was given to Alan's mental illness-- only that it was related to the second cardiac arrest.

No words can describe how I felt.

The photographs tell the story. They speak volumes.

Signed into an infamous state mental institution that has since been closed, Alan was severely medicated and left defenseless to deal with some of the other young patients who had been raised in the inner-city. I could see in his eyes when I visited how they'd bullied and tormented him. I'm sure Alan gave them a hard time too.

The institution was understaffed and underfinanced.

It took a week before I couldn't stand any more. We packed Alan's clothes and took him home.

I was depressed.

Even if we couldn't give Alan the proper care, he was safe at home with us.

He was loved, in spite of the tension created by his presence.

* * *

I cried, picked myself up and moved forward. I forget how many times that happened. We went through some awful times. All hope for a normal family life was out of the question.

For my own sanity, I went shopping when I had free time with a woman friend.

I never bought anything I couldn't afford. It was a way of spending time away from the house, far from my duties and responsibilities as a mother and Alan's advocate. I didn't hear anybody complain. It was a way of releasing the tension.

Shopping isn't necessarily the answer for other mothers. Some women I know hate shopping. For me, it was something simple I could do to feel better without going to a lot of trouble. When you're under constant pressure, it's short-sighted not to think the situation is getting to you.

Writing letters was also an important way of unloading stress.

I've written some pretty nasty letters to people.

And I've been so intimidated that some program wouldn't accept Alan or would kick him out that I've almost bitten off my tongue. It's difficult. You have to do what you think is best. Be open to constant reevaluation.

Once when Alan was 18 and at home without the prospect of a program placement, I went for an appointment at the Social Security office for his recertification of benefits. There's was lots of snow and ice on the ground. The office was quite a distance away.

Alan was sleeping a lot then. I had the choice of getting him dressed and into the car (no small feat) or keeping him home. I was terrified about leaving him alone, but since he couldn't walk and hurt himself, I decided to get back as soon as I could.

After I arrived the office, I sat and waited for what seemed like a long period of time before my name was called.

The interviewer was abrasive.

"Well, where is he?" she barked.

I slid down in my seat, that is, until something snapped inside me. Which way would I go? Buckle under or stand up?

I raised my voice-- the voice that had always been so timid.

There was nothing to lose. I said the first thing that came into my mind.

"Who do you think you are? If you want to know why he isn't here, come to my house and find out."

I told her every detail.

She backed down. From that point on, I never had a problem.

I learned to assert myself. It took a while, but I did it.

Here's an early letter I retrieved from my shopping bag file that Perry and I wrote jointly and sent to the director of a state organization of parents dealing with mental health concerns.

Dear Mr. _______,

I'm writing to you on behalf of our son Alan who's 19. In 1974 he suffered subacute bacterial endocarditis, underwent dual valve open heart surgery, suffered two cardiac arrests, the last which left his brain damaged and his physical condition badly debilitated. In May of this year he was placed in a local hospital (WE ALWAYS CITED INSTITUTIONS AND PROFESSIONALS BY NAME) because of the changes in his behavior.

We thought the stay was helping him, but after three months the staff evaluated him and said he needed further hospitalization. In discussing Alan's future health, they felt a long-term facility was needed and we began to search for one. They recommended a psychiatric hospital and then proceeded with court action to have Alan placed there involuntarily. Even the judge questioned the proper placement for him , due to his vast medical problems. The doctors maintained that this kind of psychiatric placement was necessary so that's where Alan was sent.

When we arrived at the psychiatric center, the psychiatrist who examined Alan told me that he didn't think this was the proper setting for him. Medical facilities are almost non-existent for a person with Alan's medical problems and behavioral complications. Nevertheless, he was *placed in Building 25.*

We then found out that Building 25 was a geriatric ward-- certainly not the place for a 19-year-old who was ambulatory. Alan was supposed to be getting assistance so he could get better. So I objected. They were in complete agreement to get him to a better-suited hospital where he could be treated for his medical and emotional problems. He was put into another building.

That wasn't the end of it. I had made it clear that in order for Alan to get up and down the stairs or in and out of showers, he needed another person at his side. That wasn't the case when he used the stairs, so he lost his balance and fell, bruising his arm. I was told that the second building didn't have the staff either for a person in Alan's physical condition during the week, let alone the weekends.

How could medical center personnel, who are supposed to be concerned about people's welfare, do this to a young man who could be helped with the right and proper placement?

We really believed in their judgement. Now we have lost all faith.

I implore you. Please help us get the best care and attention, both physically and emotionally.

He is worth the effort. We are all people.

Sincerely,
Sheila and Perry Green

To write letters like that, you can't care what other people think. I wrote so many, I lost count.

It isn't hard.

Communicate the truth and ask for help.

The mother of a disabled boy I've known for years could never imagine herself writing a letter like that. She's afraid her advocacy would be held against her son. Fear is common among family members. It feeds on itself.

All of us need to exercise caution. That's common sense. There's no point unnecessarily alienating people who are there to help you. I did that many times, but Alan's situation helped me learn. I allowed myself another chance; most people will give it to you.

I asked myself often, "Did I handle that as well as I'm capable of doing? How can I do it better next time?"

I was hard on myself. I made many mistakes. I had a job to do and couldn't wait.

Fear is pervasive among parents of disabled children because the system of services is so overwhelming. Many parents are afraid of going up against the system because they don't know how to make it work for them. They're scared to ask questions. They'd never suggest their child deserves something better.

They mouth-off at home, but are like mice in public.

I think many professionals would be surprised to hear that. Many assume that if you don't say anything, that means you have no problems. It's also relative. Many parents are so happy to have their child in a group home, for example, they don't dare speak up.

No matter how good things are, they must be made better. You have to consider yourself on a new wave of change in the field. This comes about from a partnership between families of the disabled and the professionals and to an increasing extent, the disabled themselves. We tend to forget that they can speak for themselves and they're part of the necessary teamwork.

Self-advocacy is a movement that has emerged during the past decade or so which supports the idea that people with disabilities should represent themselves and improve the quality of their own lives. The principle is actualized by means of citizen advocates who are teamed up with a "protege" or disabled individual. It's a necessary part of the process of achieving independence so great care is exercised to make sure the advocate and client don't assume the parent-child relationship. The ideal is for one citizen to advocate for another.

Many parents are so used to advocating, they lose sight of the fact that their children must do things for themselves.

Alan couldn't advocate for himself, but he knew what he liked and didn't like, and he wasn't shy about expressing it. I hoped a day would come when I could step out of my advocacy role.

We have to believe in our children. That sounds easy when we've had to fight so long for the most basic things.

We have to hold public officials accountable.

Be careful that you don't get caught up in the superficial details and internal politics of the handicapped agency machine. You're just passing through.

Keep in mind that public officials need us to justify their budgets. If we can help them document or illustrate a need, they can lobby more effectively for us.

Many people tried to help when we reached out. Even though we didn't find a program that suited Alan for a long time, people and places existed where we could turn for assistance. More often than not, they were limited in their effectiveness.

It's our job to make the system work to serve us.

In order to be an advocate for your child, you must have your house in order. If your marriage is on the rocks, you have to deal with that. If the roof leaks, take care of that. Advocacy of the type I engaged in assumes that certain essentials are in place. You can engage in outreach even if there are loose ends, but only in a limited way.

Some people are really independent-minded and wouldn't think of asking for help. They feel they have things under control and can handle everything. Perry and I tend to fall into this category. We tried to be on-top-of-everything and we revealed our vulnerability seldom. It would have been helpful to have obtained individual counselling (professional therapeutic help) along the way. We didn't for whatever reason. Pride. I don't know. It might have helped. Who knows?

No matter how competent you are, you always need to learn more, whether it's from individual therapists, group therapy, or guided involvement with professionals who are there to help.

Books are useful. So are special workshops and retreats. The self-help industry is booming. It boils down to knowing where you want to go and getting help to get there.

If you try to make it on your own, you might make it. You might not.

There may or may not be the right professionals out there to help with your particular needs.

Don't close doors on yourself. Too many people are closing them on you already.

Some people have so little confidence in themselves that they're totally dependent on outsiders. Dealing with their child's disability makes it seem like they're in a big deep hole and they'll never get out. If this is the case, sign up for all the help you can get. See it as a stage you're going through. You're there to learn. Take your time.

It's possible to choose different types of individual, group and family counselling. Some of it's free and a great deal is offered on a sliding scale according to ability to pay. If one type of approach doesn't feel right to you, keep looking. Be critical. Some programs are set up so parents can test different behavioral methods with their children to see what works best.

A community, state or national organization specializing in developmental disabilities can give you a list of places and people to check out. There are many different groups which have united under the national banner of the National Association for Retarded Citizens. Are you a member? Do you attend local meetings and read their literature? Check out the fine print.

Some organizations catering to the disabled prefer parents to function in supportive rather than active roles. They don't say that outright, but in practice that's the way it is. If you're pressured to become involved in busy work committees for fund-raising dances or public relations events that enhance the egos and images of professional staff members and do little else, watch out. You need to budget your time wisely.

These groups and associations are perfect for some families. Others feel stifled by putting their child in a retarded or disabled track from which they believe there's no return. Some groups provide advocacy training sessions and staff who perform advocacy services; many can't because operation of a service system and advocacy pose a conflict of interest.

This happened on several occasions when Alan was in the group home. Certain employees put their loyalty to the clients before loyalty to the agency. At least one former employee I know believes she was fired because of complications caused by this essential conflict. I wasn't there to know if that was the whole story, but there's enough basic truth in her story to mention it here.

Parents have a complex emotional relationship to their children and for this reason they're not in the most objective position to act as an advocate. In addition, the role of advocate by its very nature puts you in a position to be more protective and overbearing than you might otherwise be. Advocacy can promote dependency.

Sometimes we don't have a choice. If we don't advocate, no one will.

It's good to keep all these factors in mind.

You'll know what feels right. You won't need me or anybody else to tell you what's appropriate for you and your child. In time, you'll know. And in time, you'll have the confidence to know that you know.

That took me a long time to develop. I wish it hadn't taken so much effort, but it did. My difficulties in making personal breakthroughs stems from my relationships with authority figures going back to childhood. I was in awe of the experts. If a doctor told me something years ago, I took it as gospel. The professionals have formal training in subject areas, but that doesn't mean your knowledge about your child and your experience isn't valid.

Parents are partners, not children, in the process of education and medical care. It sounds simple, but I didn't know that in the beginning. I was naive.

After I became disillusioned, I may have overreacted at times. In my state of frustration, I was frequently overbearing, arrogant, and abrasive.

I went over the deep end and from one extreme to another-- total trust to no trust at all.

You will do things you'll think differently about later.

Trust that people will understand.

Arthur Y. Webb, commissioner of New York's state agency for the disabled, says parent power is the primary reason why public funding for the disabled has become legitimate and reliable. He says our field wouldn't be where it is without parents, who he says share a lack of understanding about how government works. Dealing with government is "a lesson in patience and diligence." It's complicated. He should know.

Parents don't have a clue about the possibilities as well as the limitations of the system that provides services for their child. In addition, there's a great deal of pressure on agencies to be accountable concerning how public money is being spent. Often the state or federal legislation makes stringent rules and you fall outside the guidelines.

Keep trying. Parents have developed strong sophisticated advocacy groups. Our input and participation can only make them function better.

There are instances where even if someone in a position of power says "no," another person could have a different interpretation of a guideline or a statute and say "yes."

One "no" and some parents become bitter and angry. They're so difficult to deal with that no one wants to help them.

Even if you make a mistake in your approach, it's possible to rectify it. Give professionals the benefit of the doubt.

Expect the best and you might get it. That requires being flexible and mature. If you're pushy and opinionated, accompany it with a sense of humor.

You're going to win. Eventually.

Victories come in all sorts of shapes and sizes. You have to recognize them for what they are.

My guardian angel was Lila Liebman. Lila is dead now, but she was with us in the long-term effort to find an appropriate program for Alan. She worked for a county family service agency as a social worker. Most of the cases that came in the door were short-term: immediate things like clothing, shelter, food.

Lila saw me coming and didn't see me as a problem. I was a challenge. Alan won her heart and for years she worked diligently for Alan. Even with Lila in our corner, he still fell through the cracks.

One of Alan's favorite songs was "I'm Gonna Win" which is sung by the group Journey. I was never one for pop music of the type the kids like, but I could easily see why Alan liked it. The lyrics had messages for Alan that didn't come from any other source. The Journey song had a driving beat that addressed the kind of obstacles Alan was up against.

It had a vision of what could be. Alan needed that. So did I.

Getting Alan into a residential school in New Jersey at age 20 was a major victory. It was the only one we could find that dealt with the entire package of Alan's problems: emotional, mental, physical and medical. It was an opportunity for him to learn about independent living. He made friends and was active in the school program. He loved the extracurricular activities such as woodworking and ceramics.

He called home every week to tell us how happy he was. Finding the school had been time-consuming, but it was worth it. Around the same time we also initiated a suit against the hospital for malpractice. We had to do it. It was an investment in Alan's future.

Our optimism relative to Alan's placement at the residential school was short-lived. After just six months there, Alan turned 21 and was no longer eligible for an education at public expense. In the terminology, he had "aged out." Special schools like this one cost more than a college education, except that at the end of a certain period of time there's no college degree. Just more of the same.

The public's responsibility for Alan ended, even though his education had just begun.

Alan was sent home. He was miserable.

So were we.

I rolled up my sleeves and went to work. Part of my drive came from the sense of outrage I felt. When you have nothing, you have nothing to lose. It's easier to be courageous. At times I didn't think. I did what I had to do. Lila went into action. We were an effective team.

Advocacy isn't easy. It's one of the most challenging and frustrating things I've ever done. At times, it's confusing. There are moments when you think you'll never win. That you'll lose control, go off the deep end, cry in public, and scream at the top of your lungs.

If that happens, view it as predictable. No one ever said you'd get what you want and need immediately. If all else fails, tears cut through sticky situations. They can also put more distance between you and the person you're trying to reach.

Just keep going. Trust in yourself.

One parent I know advocated for her son at one of the state's special hearings set up to determine their need for services. When she ran into a brick wall, she began to cry. She said the hearing officer listened and then replied in a condescending tone, "Do you have a drug or alcohol problem?"

She wasn't ready for that. The humiliation of the experience set her back for years. I think she went into the hearing expecting that the system of appeals was put there for her benefit and all she had to do was ask for the right things, be persistent, apply pressure at the appropriate times and everything would turn out fine.

There are instances where it's that easy, but it costs a lot to educate handicapped children these days. Even though the law is on our side, many people in positions of power are looking for reasons not to spend money. There's a limited amount of money. There may not be enough to pay for your child to attend a residential school when the officials can make due with something else, even if it doesn't serve your needs. People in administrative positions are most often far removed from the direct experience of dealing with a disabled family member.

We have a sense of urgency; they don't.

Remember that the fight may take several rounds. Remember that you're a good person and you're supposed to be doing what you're doing. It's difficult to make change. You're a warrior in the front lines.

The process can make you think you're losing your mind. All families with a disabled family member feel the vulnerability at one time or another.

Doubts arise. You ask yourself, "Am I crazy? Am I unrealistic? Am I asking too much? Should I be satisfied? Am I a chronic complainer?"

You're afraid to be viewed as a cry baby or an unreasonable bitch. You're afraid your visibility will put your child or family member in a bad position--that some staff member will take out their feelings toward you on your child.

The wait for a decision or for someone to answer your letter or phone call seems forever.

Be patient. Your advocacy develops a life of its own in time. If you're pleasant, spirited, and serious at the appropriate times, sooner or later people in the right places will recognize and respect you. Think of it. You're really what they want and need. They might view you as a threat in the beginning, but that's subject to change.

Parent power as a movement is sweeping the country. Educators and other professionals are just beginning to appreciate its potential, although it's good to keep in mind that they have a vested interest in the status quo even though the social services profession says it's squarely behind advocacy as a integral ingredient of change. Carried to its logical extreme, advocacy has the potential of revolutionizing the entire system of care for the disabled. Many professionals don't really want that.

Under the present system, the experts and professionals get paid and promoted whether or not your child is serviced in the way you think you deserve and is most suitable to your child's needs. The big shots on top spend a lot of time taking long lunch hours, going to meetings and carrying out administrative duties unrelated to your child. No wonder I feel resentful when I go to their air conditioned carpeted offices to beg for something on my knees. I think about my offspring 24 hours a day. The handicap bureaucracy doesn't.

Parent power demands a balanced mix of personal and political power. It means developing yourself personally and interacting effectively inside and outside your home. It also involves working closely with many different types of people--both parents and professionals.

You have to know what you're doing. Along the way you'll learn what to do.

There are instances when you go as far as you can and still get no results. Consider working in concert with several other parents. Persistent organized effort of three or more people over a period of time can be extremely effective. Books and pamphlets are available which tell you how to do this.

Or consider legal action. If you prepare yourself for the most extreme action, such as going to court, you may never have to do it. If you're afraid of court action and try to avoid it, you're operating from a position of weakness. The agency or organization you're dealing with picks up on that. We had a good attorney who specialized in cases of disabled children who "fall between the cracks" of service delivery systems. That was extremely helpful.

Even though the developmentally disabled are beneficiaries of advances in civil rights, we need as many people on our side as possible to guarantee and extend those rights. Don't limit yourself to certain professions to support your effort. You'll find sympathy even in the most unexpected places.

Approach ministers, teachers, doctors, lawyers, social service professionals, neighbors, relatives, representatives of organizations, and politicians. You'll be surprised how willing they are to speak up on your behalf.

Write letters to local newspapers. Print up a fact sheet about your situation and what you'd like to accomplish. Give it out.

Be creative.

Be confident.

If you aren't, take time out to build your confidence. If you don't have money for an attorney, look into legal services for people with limited incomes. Even if you don't meet the income guidelines, that doesn't mean you can't consult with someone from that office. Very often someone there specializes in disability advocacy and they're only too happy to explain your rights and give you the literature you need.

Educate yourself.

It's one thing to exercise your rights and quite another to find out that you don't have any. That's what people told us time-and-again relative to Alan after his 21st birthday. He was too old for participation in a program for it to be paid for at public expense (and that eliminated some things) or he didn't meet eligibility requirements.

Debbie Zaiff sat behind Lila in the family service office all the years she worked for Alan. Debbie, who is much younger and has since inherited Lila's job, remembers Lila being impressed with how "gutsy" I was.

In another county agency, where the top administrator wouldn't answer my phone calls or respond to my personal visits, I was considered aggressive and unreasonable.

I wasn't trying to win a popularity contest.

Lila never got never got tired of her advocacy work. Maybe it was because Perry and I did so much on our own. We enhanced Lila's efforts. Our needs were immediate and complicated, but they weren't a bottomless pit.

With a little bit of help, we went far.

Debbie believes that Lila needed to be challenged intellectually. She was always looking for a missing piece of the puzzle to help Alan. She never lost sight sight of the goal.

We got as far as we did because Lila never took "no" for an answer.

Our approach amounted to trial and error. We tried anybody and anything: local representatives, senators, congressmen, organizations and agencies of all types. Several times I even wrote or called the news media.

When you decide you want something you deserve, view it as a process that will take time. Define the problem, talk to people and gather support for your position. Anticipate obstacles you'll run into and arguments you may encounter from people who stand in your way.

Build a file. It can include a scrapbook about your child with photos, drawings or anything that makes it compelling and personal. It can contain news clippings or letters from important people. It should demonstrate that you've prepared yourself and know what you're doing.

Read the appropriate state and federal legislation. See the Education for Handicapped Children Act (P.L. 94-142); Section 504 of the Rehabilitation Act of 1973 (P.L. 93-112) and the Vocational Education Act Amendments of 1976 (P.L. 94-482). You can get copies from parents' organizations or your federal representatives.

Brainstorm every possibility. Look at the situation from all sides. Talk to as many people as you can. Then decide on your best course of action.

Break down the large steps into smaller ones. See if you can get someone else to help you with the smaller pieces. If you take one small thing each day to accomplish, at the end of the week you will have moved your effort forward significantly. One small action each week is better than nothing.

If you know the overall strategy, you don't have to concern yourself with the details of it on a daily basis. The ideas from one good planning session by yourself or with a friend or advocate can last for quite a while. If you send out a letter, it often takes up to several weeks for a reply. Meanwhile, you can do other things.

Occasionally evaluate your course of action. Be objective and as critical as you can about your approach.

I can't say this enough: NEVER GIVE UP.

Even if you think you have no chance of getting what you want.

Things can change. An impossible dream is often realized.

That's what happened with the group home. We were told that there wasn't enough money from the state to build them fast enough to meet the demand; it seemed like an impossible dream. We got so many denials from programs and schools for Alan that I lost count.

Eventually we turned to a county organization, the ACLD or the Association for Children with Learning Disabilities, that had been founded about 25 years ago by parents concerned with providing services to their special children. It's now run with a professional staff.

This pattern has repeated itself all over the nation. Parents get together and form a grassroots group. They get it rolling, hire professionals who in turn obtain funding, and in time the parents take a secondary role. The ACLD staff had its ear to the ground enough to respond to Alan's needs. Finally, when it became evident we weren't getting anywhere, ACLD said it would start a day treatment program for young people with hard-to-meet needs like Alan's. They called it WIN.

Special federal funding was available to get it off the ground.

That gave us hope again.

Thanks for helping, Lila.

* * *

Over the years, Michael took about 500 rolls of film of Alan. When you consider that he's probably shot about 5,000 rolls overall during his career as a professional photographer, that's not many.

The photos were a part of normal family life. Michael didn't line us up for a photograph. In fact, he's so good, you hardly noticed he was taking pictures. Alan was photographed at birthday parties, on holidays, and during visits. Wherever Alan happened to be at the time-- whether he was in a hospital or at home-- Michael had his camera.

The time Michael spent with Alan always meant something.

It's difficult to explain. His presence was a gift to Alan which contained an intangible quality connecting Alan with reasons to live.

That was the unspoken message behind the photographs.

They were a link to Alan's future.

It was never easy for us to interpret them.

When the work-in-progress was exhibited in a group show at the Brooklyn Museum when Alan was about 23, the body of work contained proportionally more images of Alan in the hospital. It didn't show Alan in his recovery phase.

Every month he showed signs of significant progress.

The exhibition and its content was the last thing on our minds. We were excited and couldn't wait to go. Alan was all dressed up.

As Alan stood in front of the slide presentation, a young man stopped him.

"You look so familiar. How do I know you?" he asked.

I was amazed he couldn't make the association with Alan standing so close.

Alan was flattered.

"That's my picture in the slides," he replied.

The young man paused.

"It's fascinating how much you suffered," he responded.

I was listening and wasn't prepared for what happened next.

All of a sudden, Alan could no longer stand. He fell into the nearest chair. Two women who walked by also recognized him and said how glad they were he was doing better.

I decided to leave and take Alan with me.

On the way to the car, Alan started to shake and breathe heavily. It never occurred to me that he would react so strongly. He fell apart, like his entire world had collapsed in front of him. I guess it had.

He was terrified.

"Was I really like that?" he asked me. "With all those tubes?"

After we got home, Alan went straight to bed.

It took him a long time to develop some objectivity about the photographs.

By the time the images were featured in an issue of *American Photographer* in 1980, Alan had developed a perspective. He was proud of the photos. When he showed them to people in the programs he was involved in, they were impressed.

Alan and I were taken a little more seriously.

That wasn't true when the early photographs were exhibited in the reception-area gallery at the offices of a commercial parents' magazine based in Manhattan.

When the exhibit was cut short without any notification to us, I flew into the administrative offices and demanded an explanation.

That was the new Sheila. What people thought didn't matter.

I was told the subject matter of the images was too intense.

Apparently the executives preferred happy children.

Michael wasn't surprised.

I was.

My brother was always different than me. Whereas I embraced American middle class culture, my brother indicated by everything he did that he was critical of it. Now that I'm older and have more perspective, I see differences like that between siblings in other families.

My father and both Perry's parents were European Jews, very much connected to their past, yet they worked extremely hard to become part of the American mainstream.

Perry's parents were born in Hungary. My father was born in Lodz, Poland. My mother was from the second generation born in this country. Her mother was born in Russia. Little was known about my grandfather.

My father, Irving "Teddy" Weisbrot, was a truck driver.

My mother, Lena "Lily" Gertner Weisbrot, worked in factories.

Her favorite job was selling handbags in Manhattan. She grew up under conditions we would find difficult handling today.

My mother's father died when she was young, which left my grandmother to raise a house full of young children-- a difficult task for immigrants on the Lower East Side of New York City before the turn of the century.

My parents were proud of their accomplishments, their children and grandchildren. My mother was quiet, helpful, compliant, and a survivor-- qualities she passed onto her children.

Mother went through some pretty hard times with us over Alan.

I inherited the quality of strength from my mother even though it didn't manifest itself for years. In the beginning of the struggle with Alan, I was intimidated. When my mother became a role model later on, I was able to emulate some of her qualities.

On the opposite side of the spectrum, like most girls my age, I inherited from my mother the belief that my identity as a woman could be found in my marriage.

Alan helped me discover the larger world.

My brother and I were always close, although our lives went in quite different directions. Visiting him was always stimulating. He liked to expose me to ideas, people and lifestyles I would have never come in contact with otherwise.

Michael was about 29 when he made his first photo of Alan in the hospital. His style of photograhy had developed slowly over years. Eventually he became a commercial photographer, although a part of Michael always resisted making images for commercial gain. He started a stock photo agency from his home in upstate New York State after his second marriage to Marilyn. They have two children, Joshua and Lila, and now he works mostly from his home, doing occasional freelance jobs, family portraits, and supplying big publishing houses with pictures of real people which are in a big demand for college textbooks and special interest publications.

Years ago when Michael's first wife Joan went into a psychiatric hospital, Michael went and photographed her there. He never made a distinction between being a photographer and a regular person. He just took pictures of what was happening around him. His photographs contain an incredible amount of information and feeling about the experience.

Photography isn't separate from his life.

Some people might see the work about Alan as family photographs and personal experiences.

They go further than than.

I believe they're works of art representing the human condition.

That's probably why the New York State Council on the Arts funded them one year as part of their grants to individual artists and why the work-in-progress has been exhibited at various galleries and featured in a variety of publications.

The art world though has a difficult time with documentary photography with a social theme. So many questions are raised by haunted faces looking out from inside frames under glass. I was one of those haunted faces.

Alan, Perry and I needed a forum.

That happened in October 1983 when Alan was 26.

The photographs and accompanying story were given considerable space in *The Newsday Magazine,* the Sunday supplement for Long Island's daily. Newsday is the second largest paper in New York State.

The article was written by Marguerite Culp, who's a friend of Michael's. At the time she worked for *Woodstock Times,* an upstate newspaper and she wanted to see the work published. The subject matter was important to her. Before changing careers, she was a certified special education teacher with years of experience.

The article focused on "aging out" and our attempt to get services for Alan.

When Marguerite came with Michael to visit and do interviews for the story, we were all on our best behavior. I was in the kitchen fixing fresh codfish for the broiler. Linda, who was Alan's companion and home health-aide, was playing the card game Uno with Alan at the kitchen table. Lila and I had worked for a long time to find someone responsive like Linda to help with Alan in the afternoons. He needed a great deal of attention.

Alan proudly showed off a black-and-white elementary school composition book containing daily notes written by Pat Burton-Eadie, his instructor at the day treatment program. Every day his progress on the road to independence was documented. No group home existed to take Alan, however.

We were happy with what was available. Our goals were immediate. Alan had to learn to control his anger and carry out simple tasks. It was possible that someday he'd have a job in a sheltered workshop.

In the previous months at the day treatment program, Alan had learned how to shop, carry the groceries, wipe the table, pick up crumbs from the floor, concentrate on work, "stop pretending to hyperventilate," play Uno, do multiplication, take a walk and file his papers.

Alan had a "To Do" list. After he learned each task, he wrote "DID" on the paper displayed on the refrigerator.

He showed that to Marguerite. She took extensive notes about what we'd gone through.

Marguerite asked Alan what the photographs meant to him.

In one of his few lucid moments, he told her.

"I've come a long way, haven't I?"

* * *

The Newsday article made an impact--but not right away.

We were patient.

Alan continued his participation in WIN, the special day treatment program created for him initially but which was subsequently opened up to other hard-to-place young adults.

Waiting lists for group homes were so long and state money to build them so limited, we were told not to count on a group home as a realistic possibility for Alan right away.

As a condition of Alan's participation in WIN, we were asked to join a parents' group. Perry resisted that in the beginning. He wondered why, when life was already so difficult, we were asked to do one more thing. But we had no choice.

Before long, I enjoyed participating in the parents' meetings. It took a while for everyone to feel comfortable talking. We all needed a safe place to vent our feelings about growing old, about drudgery that never ended, about dealing with bureaucracies and professionals.

The big institutions were being emptied and a considerable proportion of the state's attention and resources were devoted to accomplishing this monumental task. It was clear to us that families who kept their children at home had a double burden of care. Family support services were nothing compared to the total spent on deinstitutionalization.

A solidarity between us developed.

I spoke a lot. Our experiences with advocacy for Alan were helpful to other people.

Perry and I sent the Newsday article to everyone who came to mind-- including Mario Cuomo, our governor.

Aaron Liebowitz, the executive director of ACLD, also circulated it.

We counted on the fact that a human interest story is more effective than a factual presentation about a particular issue. Seven years have passed now since the article appeared, yet I still hear comments about it. Someone said to me recently, "I remember that big article about Alan in Newsday. That must have been a terrible time for you."

The article opened doors. The photos of Alan made the plight of young adults who had "aged out" dramatically visual. In addition, "aging out" had already been determined as a serious problem throughout New York State and it had been made a funding priority.

After large institutions for the developmentally disabled emptied out starting in the 1970s, it was necessary to open numerous community residences and small residential Intermediate Care Facilities (ICF). ICFs are similar to group homes or community residences except that they provide for more severe degrees of handicaps and medical complications.

Families who keep their children at home through adolescence compete for a limited number of spaces with those being phased out of the large institutions. It has taken years to respond to the need.

Alan took his place in a long line.

Each time the photos were exhibited or published, Perry and I used the occasion to launch a new offensive. The Newsday article was a valuable piece of communication. I imagined the governor reading Alan's story and picking up the phone.

I'll never know that he did for a fact, but the governor's representatives made calls to Perry, me and Aaron. A series of meetings were scheduled, to which we took additional photos of Alan. Wherever Alan went, he carried the article as well.

It would be silly of me to think that the piece brought the state to its knees. Hardly. The restlessness of parents had been building for years. Alan's story made the problem of "aging out" accessible to the public in a very sympathetic way.

During the prior two years, the state had enacted legislation to improve care for those young people "in transition" as they sometimes referred to the disabled who had turned age 21.

A task force on "aging out" was formed after a delegation of parents visited Alfred DelBello, the lieutenant governor, at his office. DelBello had high visibility when speaking out and holding hearings on the issue.

In his "Message to the Legislature" the January following Alan's story, Governor Cuomo pledged 1400 new beds for the 1984-85 fiscal year.

Within 18 months, six new group homes in Long Island were created. One of these buildings became Alan's new home.

Alan played a significant role in its creation in more ways than one.

Aaron from ACLD says that in the aftermath of the article's publication, the way was paved for him to go to Albany, meet with state officials and propose an innovative way of opening group homes faster than we dreamed could be possible.

Perry became president of a parents' corporation which initiated the process of finding a group home. Our parents' group easily shifted into this role. Perry was a natural for the job. As an architect, he'd spent considerable time as a consultant for the state doing feasibility studies of group homes for young adults like Alan. Many of his ideas were implemented, although none of his architectual plans developed into actual buildings.

My husband is very opinionated. He's dead set against closing large institutions and building group homes which become like mini -institutions. Because of Perry's argumentative style, he stepped on quite a few toes. His career as consultant with the state was short-lived, but he didn't care. Things were moving ahead for his son.

We were extremely effective working on the local level.

Around this time, the malpractice suit was settled against the hospital where Alan suffered cardic arrest. A trust was established for our son's future. As part of the large settlement, we promised not to reveal the hospital's name. Payments would be made for the remainer of Alan's life.

We agreed. It was time to move on.

No amount of money could compensate Alan for all his suffering--for all the blood transfusion needles put in his arms, the number of times he stumbled during physical therapy, and the tears that fell because he remembered what life was like before the massive brain damage.

Most of the money went to pay attorneys and to reimburse Medicade for what had been paid out on Alan's behalf during the time we were waiting. Some of the settlement went for seed money to facilitate purchase of a group home in Oyster Bay. All the parents put up several thousand dollars in development money.

That's not usually how it's done, although in this instance it was because of the arrangement ACLD worked out with the state. Otherwise this home and the others like it wouldn't have been possible. Some of the development money came out of the parents' pockets; some was raised through other sources. The parents in our group were fortunate to be in a financial position to raise most of the money ourselves.

There was hostile opposition from the people living in the neighborhood where the group home was planned. It was the first group home in the area and the reaction was almost predictable. They saw our children as threatening or pitiful and feared for their property values and safety of their daughters. Town officials argued that the street was used as a "raceway" by local youth and questioned the safety of locating a group home there.

The local newspaper, which came to our defense in an editorial, noted that safety was the town's responsibility and drove the point home about how the traditional definition of family consisting of a father, mother and two children was changing. The residents of our group home comprised a family unit, just like any other on the street. In our house, the family members had handicaps.

A majority of people in comparable situations might not be able to get a group home off the ground financially in the same way we did. It's still a viable option and worth looking into. If we hadn't done it that way at that time, the group home at Oyster Bay wouldn't have opened. No guarantees of placement were given to the parents in the corporation, as the process of application and acceptance were out of our control.

Few of us would have gone ahead, however, without some reasonable expectation of having a place for our child. We knew that in time, vacancies would open up in our house and other needy young people would fill the beds. We were paving the way for others in the future.

Even as I write this, about 12,000 young people in New York State are on waiting lists for beds in community residences.

In the fall of 1986, our group home opened.

After Alan left us and went to live there, he only came back to our house for short visits.

He made it clear to us that Oyster Bay was his new and only "home."

That was difficult.

Imagine me standing and watching him fold his laundry. It took him forever-- not like when he was home and I'd ask him to help but end up doing most of it myself. The standards were different.

It didn't matter how well he did it or how long it took. He was doing it himself!

That went for a wide range of skills associated with living in the new setting.

It wasn't easy for us or for Alan, but especially for me. I realized how close we'd become.

I had spent more time with Alan than with any other person in my life.

I missed him. I missed the music he played that we danced to in the living room--anything from rock to classical. He had special affection for Tasha, our little dachshund, who had a slipped disc and was for all practical purposes, handicapped.

Alan loved her. He understood what it was like.

When Alan went to live at the Oyster Bay house, he became an adult.

Group residences are intended as way stations for individuals on a journey to the next level of independence. He visualized himself living in an apartment someday with a roommate. Perry and I never dared think about romance or marriage for Alan, although I'm sure he did.

Every morning he woke up at seven o'clock and took medication for his heart, as well as mood-altering drugs. He used the occasion to make jokes with the staff. He was well-known for that.

His jokes weren't particularly good.

Nobody cared.

By 7:30 he was at the table eating breakfast. If the meal had an orange, Alan made a pun.

"Knock, knock," he'd say to the person next to him, prompting them to reply, "Who's there?"

"Orange you glad I asked?" he'd say, laughing.

Alan liked to make light of everything. Even in the worst of situations, his jokes made me forget, if only for a moment.

At 8 a.m. he brushed his teeth and washed his face.

What accomplishments!

Between 8:15 and 8:30, he made his bed. That was a major production. Then he waited for the bus to go to the day treatment program which was scheduled daily, five days a week, from 9 a.m. to 3 p.m.

Each day the staff at the home and at the day treatment program pressured him to become more competent in a wide variety of skills. That was their job. The day treatment program had a model apartment and there were activities that taught money, interpersonal relationships, attention to tasks, essential math and reading, and how to use leisure time.

By 3:30 p.m. he was back home.

Dinner was at 5:30.

Everyone helped set the table and shared in general housekeeping chores.

Alan hated mopping the kitchen floor.

There was television, music and socializing until it bedtime.

Weekends were different. In the beginning everyone had great enthusiasm for making the new house a real home.

As time passed, the freshly-painted walls became dirty. The washer and dryer broke. The stresses of daily life made tempers short.

I suppose that's to be expected.

As parents, we had to learn how to cut the apron strings.

For someone like me with such highly-developed advocacy skills, keeping my mouth shut wasn't easy.

I saw a lot going on I didn't like.

Whenever it really started to bother me, I looked at the photograph of Alan posted on our refrigerator at home which showed him before going to the group home next to another one after he had moved away.

Alan stood tall and looked so much more mature.

Perry and I wrote a letter to the group home's staff to say thanks.

* * *

Away from home, Alan had his good and bad days. Even after his placement, a week never passed when I allowed myself to completely relax.

The phone rang.

Alan hit a girl or a member of the staff. Hard.

Later he won their hearts by saying he was sorry.

My shopping bag file is full of neurological, psychological, and behavioral reports. So many forms. So many experts giving their opinions. Some were sympathetic and others made me downright furious.

Alan is a tall, well-developed 25-year-old Caucasion male. He has brown hair, blue eyes, freckles, giving him a Huck Finn-like appearance, and is ambulatory with an awkward gait. He is currently functioning within the borderline range of intelligence.

Alan is mostly independent with respect to self-help activities, but does require some supervision in those skills demanding coordination of fine motor and gross motor muscle groups (getting into bathtub, completing thorough toothbrushing, cutting food with a knife). He demonstrates independent living skills by being able to travel by bus/subway to familiar places (he doesn't often manifest this skill), use the telephone, cook and prepare simple foods and assist with domestic chores (making bed, setting table, washing dishes). Alan is fully ambulatory (walks awkwardly), verbal (speaks in complex sentences), and has some academic abilities (he reads at about 7th grade level and does simple arithmetic problems).

Behaviorally, Alan exhibits a number of maladaptive traits: temper tantrums (yelling, banging on walls, furniture, hitting himself), hypochrondriacal tendencies (excessive worries about dying, complaints about experiencing a heart attack, hyperventilation attacks). Many of Alan's behavioral difficulties appear to be attention-seeking in origin and have decreased in frequency through a plan emphasizing awarding tokens for appropriate behavior, ignoring the negative behaviors, and time-out from positive (removing Alan from the group contingent upon manifestation of negative behavior). . .

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My examination revealed a tall, well-developed young man with a sallow complexion. He had a prominent, but well-healed, midline sternotomy scar on his anterior chest. Auscultation of the chest revealed the loud clicking of an artificial valve. The patient's face had a rather bland and immobile expression, typical of patients on high doses of Thorazine. There was a prominent swelling over the right elbow, which appeared to contain some fluid. The patient was 72" tall and weighed 185 pounds.

Neurological examination revealed that the patient was well-oriented in all spheres. He recited the days of the week and the months of the year in proper sequence. He was able to give his address and phone number without hesitation. he knew that the capitol of New York State was Albany. He was able to spell his last name backwards correctly, but could not spell "world" backwards, offering "dlow." His performance of mental arithmetic included 100-3=98, 100-7=?, 5 x 5=25, 6 x 7=?, 8 x 8=?.

The patient knew that a person with breast cancer requires "a mamogram and a biopsy." He was right-handed, right-footed, and right-eyed and correctly identified the laterality of his own and the examiner's body parts. He was able to cross the midline. In a somewhat perseverative manner, he kept repeating "I want to see Linda again," apparently referring to a patient he had known while a patient himself in the hospital. When asked to explain his current medical situation, he offered, " I have behavioral problems. I get angry when girls won't go out with me. They don't want to go out with me because I act crazy sometimes." When asked to state three wishes, he wished for chocolate, a pretty girl and a Mustang (automobile)...

At the group home his dislike for going to the beach was well known. He liked slow dancing, did well with situps in the exercise program, and hated getting up for his midnight medication. His special friend was Lisa, who also lived at the house. One day at a flea market he bought a teddy and gave it to her.

Alan was generous with what he had. My mother taught that to him early in life. If he had cookies, he insisted you took several. Once after I bought a special comforter for Alan's bed, I went to his room and couldn't find it. I didn't tell Alan I checked around. He had given it to another boy who was cold.

You couldn't criticize him for that.

There was never a question but that the staff at the house and the ACLD loved Alan. They told me so many times and I could see it in their eyes. The people who worked the closest with him are the real heros and heroines of this story. They had a difficult job to do for which they were well qualified and paid relatively little. No wonder the turnover was high. The working conditions were difficult.

Alan suffered when one of his favorite counsellors was fired. I never understood why. The front-line staff received the brunt of inter-agency politics and power struggles.

Everyone meant well.

We did our best. We could have done so much better.

Alan died on September 19, 1988 when his heart stopped.

Earlier that afternoon at the day treatment program he had complained of not feeling well.

Things hadn't been going well for Alan the months leading up to his death. We were warned that if Alan's behavior didn't improve, he might not be able to remain in the house. Perry and I signed a contract to this effect. As part of the behavior modification program, Alan had to sit by himself at the dinner table and he wasn't allowed to use the recreation area with the other young men and women.

On the day he died, he complained of not feeling well. A nurse at the day treatment program checked him out and couldn't find anything wrong. After drinking a glass of water, he returned to the activities of the day.

When he got back to the house, he laid down and complained of not feeling well again.

Adrienne, one of his cousellors, was alarmed.

"I feel like I can't breathe, like a fog on my throat," he told her.

Calls were made. The incident had to be filtered through a chain of command.

There are different stories about what happened and in what sequence. It took a while before the ambulance arrived and I was notified. One of the supervisors told me to go to the hospital, but not to hurry; it wasn't serious.

I wasn't with Alan when he died.

The building was packed with people at the memorial service. They said so many eloquent and moving things, plus they sent a mountain of cards and letters of sympathy.

Perry took care of all the funeral and burial details.

I couldn't deal with any of it.

What's left now?

More than memories and a tombstone.

I wish we lived in a society where Alan hadn't been made to feel inadequate-- where people labeled him, imposed low levels of expectations, and then blamed him for not reaching higher.

His handicaps weren't his fault.

He was innocent and trusting. He played his music, told jokes and tried to please us. When we didn't understand, he became frustrated and angry.

We tried everything we knew--new evaluations, behavior modification, therapy. We tried to find out how he learned best so he could be happy.

But we never really figured him out.

In return, Alan left us a legacy.

He was a teacher. He taught us compassion and patience and so many more things.

He taught us to look at ourselves.

Thank you, Alan.

We love you.