

# Timothy— My Son and My Teacher



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# PREFACE

For many years, I have been involved in presenting programs throughout the United States dealing with the evidence for the existence of God. A question that frequently arises in these presentations is the reasonableness of belief in God in view of the suffering and calamities that befall mankind. No area better illustrates the problem than the case of a damaged child. Why should a baby be born into the world with defects that alter the normal course of life? How can a loving and merciful God allow such things to happen?

I do not pretend to have an easy answer that will satisfy all who ask this question. My own life, however, has been marred by this very problem. To have your own child born without usable sight, retarded, and with a serious neurological disorder forces you to look at the reality of life. My damaged son Tim is now an adult in age. His problems are not over, and we are still learning.

The purpose of this book is to encourage those whose lives have been touched with the problem that we have been wrestling with for over 40 years. If you are in this situation, you will find yourself in these pages—for all who have faced the problem of a damaged child have faced the same frustrations, anger, despair, prejudice, and lack of understanding, as well as having experienced the joy, rewards, peace, encouragement, openness, comradeship, and understanding. We hope you find not only encouragement in these pages, but also some ideas of how to meet the challenges that you face. Perhaps some source of help, some approach to a problem, or some way to get someone else to understand will come through that you have never considered before. There were those who helped us a great deal in our trials, and we hope this book will help you in yours.

We reach out to you offering whatever help we can give you. If you would care to write us or call us we would be happy to listen and help if we can. In many cases we will not be able to offer anything that you have not already learned. We have had a good teacher, however, that has given us many answers to the problem of the damaged child. Not only have we received answers from people and from God, but we have learned a great deal from Timothy—my son and my teacher.

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## Chapter 1

# The Dream

The girl outside my classroom door knocked and held up a pink slip of paper. "These blasted interruptions," I fumed. I opened the door irritably while 28 physics students watched in amazement. I had been broken into three times during this one class period with PA announcements, a kid dropping out of school, a fire drill, and now this. There was no way I was going to get the day's lecture finished.

"I-I-I'm sorry, Mr. C," the girl stammered, "but your wife told us to get this to you immediately." She almost had tears in her eyes knowing I was pretty irritated. I glanced at the note. "Get home quick!!! We get Timothy tonight!!!" it read. All of a sudden my emotions soared. For months we had waited for the right baby to come into this world to be our son. My dream of a baby boy who could run and play ball and perhaps become what I could never be was coming true. My eyes clouded with tears of joy and I looked up at the girl who was backing away. "Thanks," I said. She sighed a relieved sigh—obviously confused by this crazy teacher who grouched about one interruption by a note and got all choked up at the next one.

As I turned into the classroom 28 pairs of eyes were riveted on me. "Uh ah—just some personal news," I stammered. Snickers floated out of the back, but I resumed my lecture. "Now where were we. Oh, yeah! Now this circuit is called a baby...." The room exploded in laughter. "You're a father!!!" my loud-mouthed teacher's aide announced. I nodded. "Yes, we pick up the baby tonight." Quizzical looks floated around the room. "We're adopting a baby boy and we're going to get him tonight." "We'll have a party!!" came the comments from the back row. "Yeah—with cigars and the whole thing." It was immediately obvious that nothing else was going to get done for the rest of the hour so we talked about adopting babies for the last ten minutes.

Today was the culmination of a long wait. Phyllis and I had been married for over three years and had been told by doctors that we would not have a child biologically. We had immediately applied at the "Family and Children's Center," a private adoption agency in our home town. Public agencies were having three-year waits or longer, and we had been told that a private agency could cut through the red tape and get to families that were serious prospective parents somewhat sooner. It had been many months since we had applied; we had



gone through all the interviews, the home studies, and the waiting; and now our wait was over. For me, this was a very special day in another way. I had been an active atheist for most of my younger life. My decision to become a Christian had been a difficult one and a long time in coming. Having been so destructive as an atheist I had felt a great frustration as a young Christian. What could I do for God? I did not have the training to be a preacher or a Bible teacher. I knew very little about the Bible, and a lot of what I thought I did know seemed to conflict with what many older Christians thought to be true. I did not understand the Church and a great deal of what was done in the name of Christianity. What could I do for God? I finally realized that if I could raise a son that could be a great power for God, I might be able to justify my existence as a Christian. As a public school teacher, I saw so many messed-up kids. In the Church, I had seen a few super kids who were really doing something for God. Gradually, I realized that I might be able to produce a "Timothy"—a young and effective preacher of the Gospel that could really be a power for God. My son was to be named "Timothy." I had a dream!

## Chapter 2

# Life With a New Baby

We arrived at the Family and Children's Center out of breath. I had run home, made a quick check on the baby's room to make sure everything was in order, and we had run to the car. Miss Simons was waiting for us when we got to the waiting room and ushered us into her office and into some chairs. "We're going to go out to the home where the baby has been staying and let you look at him. He has been there for about two months, and his foster parents have gotten rather attached to him so we will not pick him up today." I looked at Phyl and saw the grimace of disappointment. Neither of us could wait, it seemed; and yet, we knew that we were not in a position to make demands. "We also want you to think about whether this is really the baby you want!"

Miss Simons went on. "Sometimes people just don't like what they see, and if the reaction of you to this baby is negative we want to be able to make some other arrangement for him." "I don't care what he looks like as long as he's healthy and OK," my wife responded. "I know, but we still want you to think about it overnight," was the reply. "Let's go look at him."

The five-mile drive to a small yellow house near the St. Joseph River seemed like a hundred. On the way, Miss Simons explained to us that the family would like to adopt this baby themselves. "They have had him longer than we like for our babies to be with foster parents when they are to be adopted out, but his natural mother has had a difficult time giving up the baby and the adoption papers were just signed yesterday. They already have one adopted son (and I'm sure they will be getting another child soon), but we don't believe this one is the best one for them. We're waiting for a baby girl for them," she explained. We were so afraid of saying or doing the wrong thing that we did not do or say anything. We sat in silence all the way to the home.

Holding my wife's hand and feeling her squeeze it at regular intervals, I could feel the joy that she was feeling. We finally turned into the driveway and went to the door and the lady of the house ushered us in. Looking into her face, I could see the emotional strain of the situation. It was obvious that she loved this baby. We walked to a small bassinet in the living room and Miss Simons took a small bundle in a fancy white baby nightie and handed it to my wife. This

was Timothy. He had blue eyes and a beautifully shaped head with light brown hair. He looked so much like my own baby pictures that I was astounded. We had been told that they tried to match the baby to the parents, but this was uncanny. There was no doubt that this was our son. My wife looked up through teary eyes and said, "He's beautiful. There's really no thinking to be done." After a very short period of time, a car pulled into the driveway and a very tall, thin man got out, walked to the door and came in. "Honey, this is the couple that is going to take Jamey," came the wife's explanation. "Mr. and Mrs. Geisler, this is Mr. and Mrs. Clayton," Miss Simons introduced us. It was a tense situation, but the Geislars were courteous, friendly, and obviously wanting to help us in any way they could in our new adventure with a new baby—even though their disappointment was apparent.

We made a fairly hasty exit and began driving back to Miss Simon's office. As we traveled, Miss Simons explained to us that she thought it best not to have much contact with the Geislars after we got the baby because of their strong attachment to him. We agreed, but Phyl asked if she would be allowed to talk to Mrs. Geisler at all, to which she was told to use her own judgment, but that they thought we should be aware of the problems this family was having and to try to avoid causing them any more problems. I thought about that and wondered if "cold turkey" withdrawal from someone you are attached to was the answer, but certainly we knew that we did not want to cause any hurt feelings or harm to them in any way and we certainly knew nothing about such things. It was decided that Miss Simons would accompany us to get Tim the following afternoon after school.

The next day of school was one of the longest I have ever had. I had passed out the usual father favors and had advertised our joy and happiness until I began to worry about becoming irritating to my colleagues. After school, I hurried home to a joyous wife—that day, Timothy Stafford (his grandfather's name) Clayton came to be a part of our home and our lives. The next several days were spent in doctors' appointments, an interview with the Family and Children's Center, and our first trip to Church with Tim (where he became more than an instant success). I especially delighted in some of the people who did not know he was adopted saying, "Boy, you sure can tell whose boy he is." He *did* look like me in many ways. As he got a little older and stronger, the resemblance grew. His eyes wandered a little, as most babies' eyes do, but he was a handsome baby in anyone's eyes and showing him off became a preoccupation with both of us. Not only was he a handsome baby, but the best natured you could imagine. By the end of the first week after we had him home, he was sleeping through the night. During the day, he would sleep for 2-5 hours at a time and wake up happy and smiling. Never did it cross our minds

that something might be unusual about all that sleep.

Our house was a ranch style we had bought with mostly borrowed money. Our bedroom was right next to Tim's, and his crib was against that wall. We could hear him roll over or whimper—that arrangement was by design. One night when he was about three months old, I was awakened by a hysterical shriek from Tim's room. Never before or since had I heard such a scream. It sounded like a woman being attacked by some terrible monster. I was out of bed and running before I could think, with Phyl running behind me. As I ran into his room and looked at my son, he was blue—bluer than I had ever seen a human being. He was screaming and moving his arms and legs, but within a minute the blue color was gone and he quieted down. "What on earth happened?" my wife asked. "I haven't the slightest," I said. In the back of mind I wondered if he had not had some kind of an arrest or seizure, but he was fine now and that was what really mattered. I lay awake for several hours waiting for another scream. I went into Tim's room and looked at his face with the night-light dimly illuminating his soft features. Finally, I lay down on the floor below him and listened to his breathing until I fell asleep. Never again did it happen.

A month later, another strange event happened. Every night after work, Tim and I would spend time playing and generally enjoying one another. I would toss him into the air and he would be laughing when he came down and I would catch him. Rubbing my forehead on his stomach brought gales of laughter. It took a lot to get him upset, and he was always in a good mood. A hard day of work was quickly forgotten in my son's world. Holding him on the couch one night, I looked into his eyes and noticed something I had never seen before. As a teenager, I used to catch a lot of walleyed pike in northern Michigan. This large perch had big eyes with a whitish background that looked like a flat surface. I guess that is where they got their name, although they also are called sauger and pickerel and other names in other parts of the United States. As I held Tim that night, I noticed that his eyes looked just like one of the fish that I had known as a kid. The pupil was wide in the dim light of the living room and I could see a white, flat surface. At that point, he said, "Da-Da," and any concerns I had were lost in the joy of his first "word."

At hand was my parent's first visit since we had gotten Tim. They had been in Hawaii where my father was teaching summer school at the university. Time had flown and they were to make their first visit. Phyl's mother had been up and had shared, to a great extent, our joy with Tim. I wanted my own parents to be impressed with our handsome son, and so all kinds of special clothes and arrangements were made. When they arrived, they made all the proper fuss and bother, but I could tell that my mother was bothered by something.



They had supported our adopting children and, even though they did not share our religious views, they were highly in favor of grandchildren. When things died down a little, my mother said, "John, I think there's something wrong with this baby's eyes." "Mom, the baby's been checked out by two different doctors and they say he's fine, so don't worry about it," was my response. She could see that it was not going to be considered by us, so she let it drop. Later I told Phyl to have the doctor look at his eyes again the next time she took him to the doctor. My wife had questioned the pediatrician about Tim's eyes because we had some concerns also, but he had said that it probably was a muscle problem that would correct itself by the time Tim was six months old and that, if not, corrective measures could be taken at a later time. By now, Tim was almost six months old so I knew Phyl would ask again. Things had not improved—in fact, his crossed eyes continued to become more obvious.

## Chapter 3

# Bad News

It was a normal afternoon in October. Phyl had taken the car in order to take Tim to the doctor, and I was to be picked up at 3:15. It was 25 minutes after and I was beginning to boil with male impatience at a constantly late female. "Doesn't she know I have things to do at home," I fumed. As I neared the boiling point, the yellow Studebaker Lark came up the street beside the school and turned toward where I was waiting. "Boy, am I going to tell her a thing or two," I thought. I opened the door and looked at a wife who was sobbing uncontrollably. As she drove toward home she kept trying to speak but the words did not come. I looked down at Tim strapped in the infant seat beside her and could see nothing wrong with him. "What's the matter, Honey?" I implored. "Th-Th-The doctor says Tim can't see," she sobbed and tears flooded her face and coat. I flushed and tried to comprehend the statement. "What does he mean he can't see? We both know better than that," I said. "He thinks Timmy probably has congenital cataracts in his eyes and probably can't see much at all. He's made an appointment for us at an eye specialist for tomorrow morning," was the reply followed by more tears. As we walked into our house, a million thoughts raced through our minds. Phyllis was a diabetic. All her life, she had been warned about the possibility of losing her sight due to her diabetes. She had kept herself under pretty good control, at least partly motivated by her fear of losing her sight. Many times she had said that she could not imagine anything worse than being blind. As she fell into my arms those words came again. "It could be worse," I said. "He could have something wrong with his brain." I am the eternal optimist of our marriage and my wife has learned to ignore such statements, but this time she said "You're right—at least we don't have that to deal with. But the Family and Children's Center won't let us keep him! That's the reason they have a year waiting period. John, I can't stand this!!" "Let's go see what's really going on," I responded. "I'll get Tim from the car." In the meantime, Phyl called Miss Simons. As she came to the car she said, "She wants us to come over after we've seen the doctor tomorrow morning. We're going to lose Tim..." and Phyl's voice dissolved into tears.

The eye doctor's office was in a large downtown building where three doctors worked together. Dr. Thompson was a kindly looking

man. We had been inserted into an already busy schedule but he was very cordial. We laid Timmy on the examination table and he leaned over looking into the baby's eyes with his instrument. "Well, it certainly isn't hard to see what the problem is," was his instant remark. He stood up and turned to us in a very professional manner, his voice one of kindness. "This baby has cataracts," he said. "I would suggest that his mother possibly had measles during her pregnancy. We can eventually remove the cataracts, but there may be other problems. He may have other congenital defects such as a heart problem, a nerve problem, and he could be retarded. All kinds of things can develop from this kind of thing. When there is one congenital defect, often there are others. From a medical standpoint, I have to advise you to let this baby go." He turned back to the child and looked again.

I looked at Phyllis who was sitting in a chair by now, her head shaking in disbelief as she looked at the floor. The doctor spoke again. "Of course, that's just from a medical standpoint. There are other things to be considered, but I am only qualified to give you medical advice." "But they'll take him away from us," I said. "They may," he replied. "There's no question that he has some problems that will be difficult and expensive to deal with. I'm sorry!" His face was kind and compassionate. We talked some more about what could be done, but it was obvious that our world of joy had been shattered.

We drove to the Family and Children's Center in silence, convinced we were about to lose our baby. I felt as I had once years before as I took a dog I loved dearly to a veterinarian to be destroyed—unable to look at Tim again and desperately wanting to get it over with. My thoughts were broken by my wife's words. "They'll never give us another baby. Why did this have to happen?" We sat in the parking lot of the Family and Children's Center for a moment drying our eyes and then hurried into the building to give up our child.

## Chapter 4

# The Tough Decision

Miss Simons was the picture of professionalism. We sat in the lobby and we poured out all that had happened. Finally we stopped talking, waiting for her to say it was over and take Tim away forever. "I talked to Dr. Thompson right after you left there," she said. "He called me and told me all you've said. We have to make a decision about what to do—what is best for Timmy and what is best for you. If you don't think you can deal with his problems, we'll have to find another foster home and maybe a different placement." "You mean we can keep him?" I asked. "Certainly, if you want to; but we can find someone else—maybe an older couple who might be able to take him on. You go home and call me later tomorrow. I'll talk to Mrs. Butler and we'll have some options for you then." We walked out to the car both relieved and distraught. The decision was obviously going to be ours. We had not figured on this—we thought the choice would be forced on us. Tim was his usual happy self as we came home and we were greeted joyously by our family dog Suzie. The pain was gone for a little while as we thought about what had happened. The day had been a whirl. We called our parents and they reflected our own pain and offered sympathy at what had happened. My own parents reflected their confidence that we would be able to get a "normal child" when we gave Tim up. There were no "I told you so's"—only a shared sense of pain.

Our next call was to the minister of our Church. Jim Boyd and his wife Rosalyn were active and dynamic people. The Church in South Bend had done well under their influence and my own spiritual growth had been spectacular under his tutorage. When we had moved to South Bend, I had just come out of atheism. From a world of belligerence against religion and religious people I had evolved into an aggressive Christian worker. Jim had encouraged and supported me as I worked with the teenagers, put out the Church bulletin, taught classes, and even spoke publicly a few times. As I poured out our tragedy to him, he said, "I'll be right there," and within 10 minutes he and Rosalyn were at our door. Phyl fell into Rosalyn's arms in a new flood of tears and Jim guided me to a chair. When we had talked ourselves out, Jim said, "John, I don't have any question about what you should do. This baby may be a tool of God to bring the Gospel



to the blind!" A Timothy to the blind! I had not thought of that! Jim took us to the Bible to John 9:1-3 and read Jesus' answer as to why this man was born blind, "that the works of God should be made manifest in him." We prayed together and were alone again.

Later that evening we went for a drive. Doubts began to cloud our minds. If he were retarded, he could not be a Timothy to the blind! Why should we have to deal with this kind of problem? The Family and Children's Center probably would have something worked out anyway. Our emotions were on a roller coaster and we were definitely on a slide. Phyllis went into a grocery store and I sat there waiting, holding Timmy in my arms, looking into that smiling face with that "wall-eyed" glaze I now understood to be a cataract, looking up at the light outside. I had left a lot to become a Christian. I had turned away from the system I had been raised in. I had lost friends, given up recreations I enjoyed, given up time and even some opportunities to get quite a bit of money. The weight of the situation was more than I could take. As I held Tim, I cried out, "Lord, why me? This isn't fair!" The anger in my voice started Tim crying and stopped my own outrage. By the time Phyl returned I was the cool, composed male I felt I was supposed to be. My parents called again and reflected amazement and anger that we had a choice to make, but were sympathetic.

The next day at school I shared our problem with the people I worked with. Some stared in disbelief with their hands out to console but offering no real answer. Some said "Well, I'd take the baby back and get it done right." Some tried to avoid me when they heard of our plight. I hurried home to find one of our school counselors talking to my wife in our living room. Sylvia Kercher lived right behind us. Her daughter had been in my class the year before. Sylvia was a religious leader in the community, had been a counselor in the high school for a long time, and was only remotely known to us. I knew she was a widow and had been one for some time. As I sat down, I realized she was telling about her own life—about her son. I did not know she had a son. She told how he had been born in a very damaged condition, about all the problems they had encountered as he grew, about how finally he had become dangerous to their daughter to the point where they had to institutionalize him—but they always felt they had done the right thing in keeping him as long as they could. At about this same time, she lost her husband to a brain tumor and so all of this had happened in a short period of time. Here I felt I had been allowed to experience all I could take. This woman had endured so much more and yet had retained her faith, nurtured it, and was always a smiling, happy, positive person. Sylvia became a dear friend and a great influence. She had walked the road we were walking and she knew the pain and frustration. She was the first person who could

really relate to us in a meaningful way because she had been there.

The following day, we went to the Family and Children's Center to meet with Miss Simons and Mrs. Butler. Mrs. Butler was a lady in her 60s. She was the real "boss" of the Center and was greatly respected. We had met her once before, but that was the limit of our contact with her. As we sat down, Miss Simons spoke to us and told us that she thought Mrs. Butler might be able to help us in our decision because she had been down a similar road herself. Mrs. Butler then began to tell us a little of herself and her family. She had given birth to a multiple-handicapped boy nearly 30 years before and, therefore, Miss Simons had asked her to talk with us and perhaps help us with some questions we might have. She told us that Henry was still living with her and her husband, how they had spent many extra hours helping Henry to accomplish things that her daughter had done so easily, and how a boy such as Timmy would certainly put a strain on our lives at times and also provide us with many happy hours just as all children do. She said, "Mr. and Mrs. Clayton, you have a difficult decision to make. I too, had to make such a decision some 30 years ago. We want you to know that we will support you in whatever decision you make. We will be glad to assist you in any way we can if you decide to stick it out with Timmy. We want you to know that you are free to let someone else deal with Timmy's problems. He'll do fine. The decision must be yours and nobody else's." She asked us if we had any questions. One of the questions we had to ask was what would happen to Timmy if we did not keep him. She really did not have any definite answers for us, but assured us that they would do everything they could to get him into a good foster home situation. We poured out the questions about mechanical things, but left basically as we had come in—with a lot of confusion in our minds and no clear options, but grateful for the attitude and concern for both our feelings and Timmy's welfare.

"Neither hath this man sinned, nor his parents: but that the works of God should be made manifest in him" (John 9:1-3). "All things work together for good to them that love God" (Romans 8:28). As I sat on the couch in the living room watching my wife iron a shirt, I kept turning these passages over and over in my mind. How could I let this child go and never know how he really turned out? I had heard from teachers at school how the valedictorian a few years before had been a girl born with congenital cataracts. I could visualize seeing a young man with heavy glasses being honored as a scholar in years ahead and wondered if this were my Timothy. How could I not at least find out what this baby's situation really was? "Phyl," I said, "I really think I know what we should do." "I sure hope it's the same as I've been thinking because I have just come to a decision in my own mind while I've been thinking about it off and on all day

long," she replied. "*We've got to keep him,*" we said in unison—and laughed and cried together. I felt relieved. I was sure the decision was the right one, but I was also sure the decision would be unpopular with my parents and many of my colleagues. The first person I called was Jim Boyd. "Jim?" I said, "we've decided to keep Tim and do the best we can with him." There was a long silence at the other end of the phone which made me begin to wonder if Jim had been having second thoughts about his advice. "Jim?" I repeated. "I'm sorry, John," he replied. "I just got choked up a little there myself. Fantastic!" he said. "I've got to tell Rosalyn." The next person we contacted was Sylvia, who arrived moments later with cookies and an "I knew you'd do the right thing."

Not everyone was enthusiastic about our decision. When we asked our doctor why the diagnosis had not been made sooner, he said the problem must have developed later. Tim did not do things at the proper time in his development, but when we questioned this, we were accused of being neophyte parents who were worry-warts. Our doctor's explanation of Tim's slow development was "of course he can't do anything—he can't see." We began to feel like second-class citizens in the doctor's office because we had a problem we could have avoided and did not. We finally changed doctors, asking the new pediatrician if he thought Tim had any problem other than eyes. This doctor's opinion was reassuring to us because he sincerely thought that, outside of his eye problem, Tim would be fine. (We have never faulted him on that opinion at all because we feel he gave us his best medical "opinion," and, as he has said to us since then, we cannot always know what is in the future for a situation such as Timmy's.) Visits to the eye doctor assured us that the eye situation could be greatly improved as soon as the cataracts finished their development. We also learned that Dr. Thompson, even though from a medical standpoint, he had warned us against keeping Tim, was behind us 100 per cent in our decision. Once we had made the decision to keep Timmy, he told us that he would do everything in his power to do what was best for him. Teachers at school generally reacted with dismay that we would go on with Tim, as did most of our friends and relatives. At a Church in Bloomington, where we had worshipped some years before, we learned that many of the Christians there felt we were making an error and a few expressed it to us. We were told by one dear Christian lady from this Church that it had been discussed in a Ladies Bible Class and most everyone did not think we would keep Tim, but that she "knew we would," because, you see, she too had gone down a similar road with a damaged child several years before. Our circle of friends narrowed enormously, especially those at work and those not a part of the Church. Soon we found ourselves spending a great deal of time alone. Tim's foster parents (for the first nine weeks of his

life) became friends and we shared the pain of his problems together. They had adopted another baby boy three months after Tim had left their home, and we shared many good times together.

Many people sincerely believed the decision was in error. One day, my wife got a phone call from Miss Simons just to check out things and see how we were doing with Tim. She asked, in the course of the conversation, how the grandparents were accepting the situation. Phyl told her that her mother did not like the situation, but she understood and that she thought eventually my parents would accept things even though it might take a while. Miss Simons responded "Well, we were just wondering because we received a phone call from a doctor in Bloomington today strongly reprimanding us for not taking the choice out of your hands. We have been told that adopting a baby is like getting a car; if it is defective, the dealer is obligated to take it back and provide one that is not defective."

It was obvious to Phyl that the doctor had been encouraged to do something about what my parents considered was a wrong decision for us and said that she would discuss it with me when I got home from school. I knew my parents' values motivated them to do what they thought was right for their son, but I did not expect them to do this. We talked to Miss Simons again and assured her that this was not our attitude. "OK," she said. "That's all we need to know. If it doesn't bother you, it won't bother us." "I'll try to stop any further action by my parents," I assured her, "but I don't know that I can."



## Chapter 5

# Surgery and a Sister

Tim began walking at a fairly normal age and took great delight in looking at lights and listening to things. We worked hard to overcome his handicap. Musical toys, rattles, a record player, and reading to him by the hour occupied our time. We would put a record on the record player and Tim would lie down on the floor in front of it holding his hand between himself and the picture window and wave it back and forth so that the shadow flashed across his face. The Christmas tree lights were a special joy to him, as were the candles on his first birthday cake. Tim's favorite activity, however, was taking the lids of saucepans in the kitchen (or saucers or shiny peanut butter jar lids, etc.) and spinning them on the floor. Hour after hour, he would spin these lids with such finesse that you would not believe he could do it. They would spin and he would rest his head on the floor and watch them until finally they would come to a stop. There was no way I could duplicate what he did nor understand how he did it. The only time we have ever seen anything like it was about 17 years later when Phyl was watching a television show about the autistic child and they showed a sequence in the show where the child was duplicating what Tim did in his spinning sessions.

Tim continued to be a happy child and to develop. He began talking a little later than most children, and it was much later than most before he began to put words into phrases and sentences. He was totally trained (no night diapers nor any accidents ever) from the time he was 3 1/2 years old. In fact, he picked this up in about one week once he knew what we wanted him to do. Phyl felt all along that Tim *would* do whatever we wanted him to do if he could. He was an extremely cooperative child.

Our family life became fairly normal and we decided to apply for a second child. Just after Tim's second birthday, the most beautiful baby girl I'd ever seen lay in a bassinet at the Family and Children's Center with us looking on. "If you'd like to go into the other room and talk over whether you'd like to take her as your daughter, you may," Miss Simons said. I looked at Phyllis and said "There's no reason for that. She's perfect!" We all laughed and Cathy became our second chosen child—for better or worse like any other. Cathy was as fast as

Tim had been slow, and we began to realize just how much Tim had not done. By nine months, Cathy was walking and climbing—into everything! Tim's progress became agonizingly slow and, by the end of Cathy's first summer, we had real concerns.

Thus began a new series of tests. Some doctors said he was retarded and had petit-mal seizures which showed up on electroencephalograms while other doctors (especially our own pediatrician) minimized his problems. No one seemed to be able to tell us what we were dealing with. Finally it was decided that Tim was ready for his first eye surgery. After the surgery, Tim was to remain very quiet for a couple of weeks in the hospital and then continue to be watched for a couple of months so that he would not fall down and cause harm to the operated eye. How were we going to keep a 2 1/2-year-old child quiet and keep him from falling when he walked (for he was a very wobbly toddler at the time)? The answer was a record player. Hour after hour, Tim listened, moving his hand back and forth up in front of his face. Phyl and I stayed with him around the clock. I came in after school, having picked up our five-month-old Cathy who was being cared for during the daytime by some fine Christian friends by the name of Mondel and Louise Benson. I then would bring her up to Tim's hospital room; then Phyl would take her home for the night. The next morning, Phyl would drop her off at the Benson's house before she came to the hospital, and I would go to school. During one of these switches, Dr. Thompson came in around 11:00 P.M. (which shows the kind of hours this fine doctor had to keep) for Tim's daily checkup. "Who's this?" he asked looking at Cathy in my arms. "This is our daughter Cathy," I answered. Dr. Thompson took out his instrument and looked into Cathy's eyes. My heart raced as I wondered if he saw something. I looked at Phyl and saw her biting her knuckles as she watched. The room was deathly quiet. He finally straightened up and smiled. "Never saw a better pair of eyes," he said. We virtually collapsed in relief.

## Chapter 6

# Misdirected Stress

Soon Tim was home with a metal patch over his eye and a tube of medicine. We put drops in his eye constantly and guarded his steps. Still nagging at us was the question of what other problems Tim might have. We talked about it, prayed about it, and worried about it. Phyllis began to get hives on her body and extreme diarrhea. A trip to the doctor, X rays, and other tests said "nerves." Medication was prescribed—tranquilizers on a regular basis. Equinil became part of her diet. She lost weight as her emotions became more up and down. She was clearly on an emotional roller coaster. We were working actively with the Church during all of this. Vacation Bible School was starting, and I had been asked to be in charge of it. The Boyds had moved to Tennessee to get away from the South Bend winters that were having a bad effect on Jim's sinuses. The new minister, Ernest Scarbrough, was a kind and thoughtful man. We had spent many happy hours together working on a variety of projects. He and his wife Shirley had a family of five children and Shirley wrestled with nerve problems herself.

One day Ernie came to visit us at our house. Sitting at the dining room table, Ernie expressed his concern, "John, you're going to have to do something about Phyllis and Tim," he said. Phyl had almost lost consciousness during Vacation Bible School that morning. "This problem isn't going to be solved until Tim is taken care of in some other way," Ernie said. "Would you like me to talk to the Family and Children's Center, explain the situation, and free you two to pick up and go on? I could try to cut out some of the red tape and you can work on re-building your life." I flushed and stammered. There was no question that Phyl could take no more. Was I to choose between my wife and my son? "No! We have to find some other reason for my problems!" The voice was my wife's. "John, I can't give up Tim!" she said.

"Lord, help me deal with this," I implored. "I need your help." We saw an article on cyclamates and their relationship to cancer and intestinal problems. Phyl, being diabetic, drank as many as half a dozen bottles of dietetic soda a day. "Phyl, do you suppose your problem could be diet pop instead of Tim," I asked, holding up the newspaper. The idea was too preposterous to be true, but too coincidental to be

ignored. Had God led us to a solution? We decided for Phyl to cut out the diet pop and, within three days, she was 100 percent better. All of us had blamed the wrong cause for her problem, but Phyl and I had known real love and sacrificial concern from a brother in Christ and we would never forget Ernie and his concerns for our family.



## Chapter 7

# Learning a Reason

As we rose from this latest crisis, we found doors opening in our spiritual life and opportunities we had never dreamed of. I was teaching a class concerning proof of the existence of God, which was basically a summary of those things that had led me to become a Christian. This class had been taught at our local congregation and I had been impressed with how many people really had problems with this issue. A preacher from a congregation in Logansport, Indiana, named Jay Wilson had visited our Church one day when I was teaching the class and asked me to come to his congregation and present a one hour presentation to a youth rally they were having. I did this by telling how I had left atheism and the scientific evidence that forced me out of atheism and into Christianity. A man named Virgil Lawyer from Harding College was in attendance and asked me to make the presentation at their Thanksgiving lectureship. Three people who attended that Harding Lectureship asked me to make presentations at their congregations. That was in November of 1968. In 1969, I gave these programs in Youngstown, Ohio; in Newport, Arkansas; and in Schenectady, New York. From this beginning, a whole area of work for God opened up which caused us to devote virtually every weekend to lectures all over the country on the existence of God. As we began to see people becoming Christians through this work, we felt a real purpose and value to our lives. It was also at this point that we could see a way God could use our experiences with Tim.

One day I was going through the mail and I came across a letter from a friend of mine named Fred Alexander. Fred lived in Pontiac, Michigan, where he worked with a congregation and with a Christian college. Fred's letter told of a young couple that had found their newborn child to have many of the same problems Tim had. Fred talked about how frustrated he was in trying to help this couple. He told me how they were talking about how unfair God was in doing this to them and that they were actually talking about turning against God. Then he totally blew my mind by asking me to write them and help them!

As I read Fred's letter I felt a sense of anger and frustration. How could I help someone else when I had not understood my own situation? How could Fred pry into my private problem? For several

days, Fred's letter sat on my desk inviting emotions from resentment to guilt to anger to sympathy. Finally one night I sat down at the desk to do something else and I saw Fred's letter. I tilted my head back in frustration and saw a stack of small note cards and envelopes my wife had left beside the desk. I grabbed one and decided to dash off a note which I could mail and throw away Fred's letter with good conscience. As I started to write a typical I'm sorry for your misfortune letter, I thought of the things we had been through. I reflected on Jim Boyd's advice about the child being a possible preacher to the blind. I thought of my study of John 9:1-3, and "Neither hath this man sinned nor his parents: but that the works of God should be made manifest in him" came into my mind. Cathy came bouncing up to the desk to get a piece of paper and I thought of Dr. Thompson's "look" at her eyes and how much we had treasured her and her freedom from the problems Tim had. Then I thought of the day we learned of Tim's eye problem, and I realized that the only person who had been able to really understand what we were going through had been Sylvia Kercher—a lady who had been there and really *did* understand. Maybe I *could* offer a little something extra.

I began to write on the little card, but my mind flooded with experiences, with people who had helped, and with ways we had learned of helping Tim. I took out an 8 1/2 by 11 inch sheet of paper and began to tell this young couple of how God could bring something good out of this rotten experience. I spoke of the special loving nature this kind of child seems to have and about how my wife and I had been drawn closer because we faced these things together. I was able to describe the even greater joy we had in our child who had no physical problems because of our experience with Tim. I spoke of the government, private, and Church programs available to help in whatever problems they faced. Above all, I was able to say "Don't let your baby go! You didn't ask for this situation; you don't like it; you wish and will continue to wish it hadn't happened; but you will find joy and love and special blessing in this child."

By the time I finished the letter, I probably had a dozen pages in addition to the 3-by-4 inch card which I stuffed into the envelope and mailed. I did not expect to ever hear from the couple, I just wanted to help them. I understood what they were going through. Years later I was doing a lectureship in the Pontiac area. I told our story about Tim as I did every weekend, including the writing of the letter. After the services were over and while I was collecting my material, a woman came walking down the aisle leading a little girl. The girl had a leg brace like Tim's, a hearing aide, and thick cataract glasses like Tim wore. "Mr. Clayton," the lady said, "I'd like for you to meet Carolyn." "Hi Carolyn," I said. The girl's face lit up in a happy smile much like Tim's when he was getting attention. "I'm the lady you wrote that let-

ter to years ago," she said. "That letter has been on my refrigerator all these years, and I want to thank you for writing it. If you hadn't written it, I might not have made it." You never know what the Lord can do with your feeblest efforts. That experience taught me one of the greatest lessons of life a Christian has to learn. We are here for a purpose! We are not an accident! We have a job to do—people to reach with the Gospel of Christ—and we cannot do that job if we are isolated from the realities of life. God never promised diplomatic immunity from problems. For the first time in my life, I realized that experiences are a talent. Tim taught me that I had something unique that I could share with others.

As if to underline that understanding, I had an experience the very next weekend that gave me an opportunity to use my talent. I conducted a lectureship program in Schenectady, New York, and two different members of the Church there had been faced with a child born with multiple birth defects. I found I could share in a unique way with those who were walking the same road I was. As we talked we found that even though we were comparative strangers, we had a closeness and an openness that we had with no one else. On the plane returning home I found my seat mate had a child in her lap that obviously had Down's syndrome, and we were able to talk with such familiarity that before the plane landed in Chicago we were studying the Word of God.

I have a talent through my experiences with Tim that has opened a myriad of doors and enabled me to share with people that only those who have experienced the heartbreak of a damaged child could understand. As Phyllis and I continued to study and talk, we began to see that Phyl's diabetes could also be used. I eventually got her to write a book about her half century of living with insulin-dependent diabetes. Over the years literally dozens of people afflicted with diabetes in themselves or their families have been helped by my wife in a way I could never relate to. We all have the gift of experience that we can use to allow the works of God to be made manifest in us.

## Chapter 8

# Adjusting to More Problems

In the spring following our fresh understanding of some of these things, we built a house outside of town with room to raise our children. Money was tight and we had to work to make ends meet. I worked in a photographic studio part-time, and one semester I worked nights as a night watchman and taught in the daytime. We borrowed on our insurance, took out a mortgage, and borrowed from the contractor to get the house built. The intensity of Tim's problem dropped, but opportunities continued to come. One of our dear Christian friends in South Bend had a daughter born with Down's syndrome. We grew closer as brothers and sisters in Christ because we shared a common problem. In my travels, I found many hurting people we could help. It was not long, however, before it was our turn to hurt again.

Tim's operated eye had settled down, and a day I had looked forward to since his birth arrived—the day he would be fitted with glasses. In my mind, this day was to be the rebirth of my son. I had the opinion that Tim would now be normal, able to see with glasses, and all our pain would be over and we would live happily ever after. Tim had progressed very slowly since he was two years old. He had fallen behind the kids in Bible class and in the neighborhood. Our doctor had said, "How can he do it? He can't see" and dismissed us as neurotic parents concerned over nothing. Tim's behavior in public had been good but uninhibited, no matter what was said or done. If Tim's clothes got wet for any reason he took them off. One time we went to a Church family camp in Wisconsin for a week. After the first day or two, we were asked not to allow Tim to go to the children's class because he was not "normal." The teacher of the class was wringing her hands and nearly in tears as she described the habits she could not tolerate—spinning of lids, waving of hands, holding his mouth "funny," etc. More and more, we felt the distrust and disdain of our child by the world around us.

To us, Tim was the warm and loving Tim. He amazed us with his sense of direction and memory. We would drive by the river and Tim, who had been lying in the back seat of the car since leaving the house, would point to the North and say "wa-wa" (for water). I would take pride in asking him which way our house was, or the Church building, or New York, for that matter. Without looking at his surround-

ings or making any reference, Tim would point right at the requested item—even if it were 1,000 miles away. When he was five years old, we took him to the Children's Memorial Hospital in Chicago for an EEG and other tests. Five years later we turned on to the Chicago Toll Road to go to a nearby town. Tim said out of the clear blue, "This is the way we went to go to the hospital and saw Dr. Baccus." My wife and I looked at each other and shrugged. We had forgotten the doctor's name, but had remembered that Tim was right once he had mentioned the name. "Who is Dr. Baccus, Tim?" we queried, wondering how much he really did remember about the trip. "He put sticky things on my head," Tim replied. "And he hit my knee with a hammer. We ate lunch near the lake and we had Kentucky Fried Chicken." It was incredible to us, but Tim was correct in each and every detail. Ever since that time, when we want to remember something, we tell Tim to remind us about thus and so—and he always does.

There had been many good and bad times, but today when he would get his glasses, I felt everything would be "good times." All the strange behavior and slowness would be gone forever. No longer would the doctor say, "Why should he do it. He can't see!" Dr. Thompson measured and fitted Tim with his glasses without a word. Finally the glasses were put on his face. Tim tightened, looked at the lights in the corner of the room and began waving his arms. I pinned his arms to his sides, and Dr. Thompson tried to get Tim to read the eye chart. Even when Tim tried, he could not do it. "Can't he see?" we asked. "Yes, he can see in a tunnel," the doctor said. "But there may be other problems. Remember that I told you that he might have brain damage?" He put a kind hand on my shoulder and guided us out of the office. "I have a new technique I want to try on the other eye," He said. "You mean you want to keep working on him?" I asked. "Of course," he said. "We'll get him all the vision we can and you'll be able to help him develop whatever he has to work with. Tim isn't any different than when you brought him in. He's just a child with special needs." I turned to thank him but could not find the words. He hugged Timmy, and we went home in silence. With what we had been told, along with the continued lack of progress, we were beginning to realize that Tim did have some of these additional problems we had been warned about by so many doctors.



## Chapter 9

# Schooling

The social worker brought Tim into Mrs. Butler's office, and he immediately went to the toy box in the corner and began to play. A group of papers were placed on Mrs. Butler's desk by Miss Simons without comment. We searched Mrs. Butler's face for an emotion that might tell us what Tim had done on the IQ tests he had recently taken. There was no sign at all. Finally she quit reading, looked, and smiled. "Well, Mr. Clayton, you know all about IQ tests, don't you? They don't mean much, do they? Especially when there's a vision problem." "Oh Boy," I thought to myself. "It must really be bad." "What is Tim's IQ?" my wife queried. "Oh, we really don't know; you see these tests..." This was the old IQ-doesn't-mean-anything routine, and everyone in the room knew it. I knew that all this was true and certainly true when a vision problem existed, but I also knew that thousands of hours of personal stimulation had been given to Tim. Finally I said, "Mrs. Butler, we know the limitation of IQ, but we would like to know what the test did say. What was Tim's score?" Mrs. Butler sighed, looked over her glasses and said "52." I had worked with a child in my science class the first year I taught who had an IQ of 52 on his record. He was a disaster in the classroom socially and educationally. Tim could not be like that—and yet as I thought about it, he had been like that to most people outside our family. My racing mind was interrupted by Miss Simons. "Now we know what we're dealing with," she was saying. "We think you ought to contact St. Joe Hospital Nursery School. Tim needs to get started on his education. They have classes and specialists, and they can do wonders." She handed us a name and a number, and we were on our way home.

When we got in the car I faced an angry wife. "It's easy for them to tell us to do something about Tim," she said. "They don't have to hear the cutting remarks and deal with all the problems. Why did Tim have to have everything wrong?" At that moment Tim threw his arms around her neck and hugged her. This spontaneous outpouring of love was normal for him. "Mommy hurt?" he asked. I had to pull over until one of us could get composed enough to drive home.

The next 10 hours were ones of total depression. Neither of us could sleep. We had both said the only thing worse than blindness

was mental retardation, and we had *both* to contend with. The next morning, Phyl checked out the nursery school that had been recommended to us and he went there for a year or two, three mornings a week. The next school we checked into for Tim was Logan School for the Retarded in South Bend. As we stepped in the door, we saw three adults working over a 10–12-year-old girl who was in an epileptic convulsion. “Can I help?” I asked. “No! Terri will be OK in a minute,” the lady smiled. It was obvious that Terri had Down’s syndrome. She also had thick glasses and a hearing aid. In a few minutes she was up and walking around. “Are you her mother?” I asked. “Yes,” the lady replied. “We go through this three or four times a day, but I guess you know about that, don’t you?” I looked at Phyl and both of us realized our feelings had been altered by this experience. “No,” I said. “We don’t have that problem.” “Oh, well, we’ve all got our own things to deal with,” the lady said and she left.

While we waited to talk to the director, we saw children Tim’s age in wheelchairs, in diapers, with braces on their legs, with no legs at all, with no arms or misshapen arms, etc. Phyl later remarked that she almost literally became sick to her stomach the first time she observed all these extreme cases. However, her next thought was that the parents of these children loved them and saw their beautiful nature just as we saw Tim’s—not the “strange” behavior that so many other people saw in him. We left Logan School that day thinking “We really don’t have much of a problem,” but later I had to admit that I asked myself all over again, “Why should our Tim have *any* problem?” Then I was back to square one. At Logan School, he had a teacher, Miss Kessler, who really made him work. He had some speech therapy and made great progress.

We traveled extensively, living in a tent camper and conducting workshops during the summer and doing weekend programs on the existence of God in the winter. Tim and Cathy traveled and camped like little troopers. They would settle down in the back of the wagon and play for hours or sometimes sleep. It was a good time in our lives. One time we were driving on an interstate highway near Denver. The camper was working well and I had paid little attention to it. Suddenly, Tim said, “Daddy, there’s something wrong with the camper.” I looked in the mirrors and saw nothing amiss. “What makes you think something’s wrong, Timmy?” I asked. “I hear the inside flapping,” he said. Tim’s sense of hearing was too good to ignore. I pulled off and went back to look. When I got to the back I found that all of the clips holding the top down had pulled loose. About three feet of canvas was hanging out through the opening, having been pulled out of the inside by the wind. Another mile and the top of the camper would have undoubtedly popped up and been caught by the wind. Whether I would have been able to control the car on that busy highway is problematical. In all likelihood, Tim saved our lives.

## Chapter 10

# Another Baby, Another Rejection

About this time came another big event for all of us. In October when Tim was 5 1/2 years old and Cathy 3 1/2, we were thrilled to bring a baby girl home six days after she was born. Wendy Kay was a new experience. Night feedings were new to us because Tim and Cathy had been nearly off of the night bottle by the time we got them. What a joy it was—to hold that bundle of warmth in the dead of the night and, in that quiet, marvel at one of the most incredible of God's creations.

Tim had another eye surgery on his second eye which was done by needling the cataract in one surgery and flushing out the material in another. Tim was home in three days after each of these surgeries and did not have to be held down this time due to the different surgery technique. It did mean more eye drops and more patches. Dr. Thompson was not very optimistic about the results. He noticed a pallor in the optic nerve which indicated that the eye might not be too healthy. As it turned out, this did not get any worse throughout the years and Tim could see pretty well out of the eye in a narrow tunnel, and we were relieved.

As Tim finished his last year at Logan School, we became acquainted with more and more parents of damaged children. We went to recreation programs for the kids, meetings to raise money, the Special Olympics, and also spent a lot of time talking. One day at a picnic we were talking about having friends—really close friends. “I don’t really have many friends since Jerry was born,” one lady said. “I used to have a lot of Church friends, but when I had a retarded child who was deaf, they didn’t want much to do with me.” “Yeah, these churches don’t want anything to do with people with problems,” enjoined another lady. “They’re afraid we’ll pollute their holy sanctuaries.” I wanted to jump up and scream. “That’s not true! Real Christians want to help! They’ll care and understand!”

Recently, however, we had gone through an incident that had cemented in my mind the fact that it frequently was true. We had been active in our local congregation of the Church of Christ ever since coming to South Bend. We formed friendships with members of the congregation and worked hard. I directed the youth program, both of us taught in Bible School, we visited quite a bit and had a pretty

active social life with the members of the Church. The Church of Christ is a unique religious organization. Its primary doctrinal goal is to restore New Testament Christianity as it existed in the first century. "We speak where the Bible speaks and we're silent where the Bible is silent" is the biblical philosophy.

The officers of the Church are selected according to biblical principles. One of the official positions in the Church is that of a deacon whose duties and qualifications are spelled out in the New Testament in Timothy, Titus, and in function in Acts. Among those qualifications is that the home and family not be unruly or poorly disciplined. In age, wife, experience, and desire, I was qualified to be a deacon. Prospective candidates were visited by an existing deacon and an elder or bishop, who was the real overseer or leader of the Church, again as defined in the Bible.

The elder who visited to talk with us was Charles Hoggatt. "Grandpa Hoggatt" was a spiritual giant. He was always in control. His wife used to tell of a time when she left a large canner on the top step of the basement stairs so that she could carry it down the next time she went. Grandpa Hoggatt had told her repeatedly not to do that as someone might trip on it. Suddenly she heard a yell, and a series of thumps and crashes came from the basement steps. She ran to the top of the steps and in great fear looked down. Grandpa Hoggatt was sitting on the floor at the bottom of the steps with the canner in his lap. "Grandma," he said calmly, "I have asked you many times not to leave things on these steps. Please don't do it any more." He stood up, wiped off the dust from his pants and limped over to the shelf to put the canner away. He never said another word. That's the kind of Christian man Grandpa Charles was.

When he and one of the deacons came to the door I was excited. For a former atheist to be appointed a deacon within a few years of leaving atheism was quite an accomplishment in my view. I really wanted to serve God too, and being identified as an official worker with areas of responsibility was something that held great potential to me. Charles came in and sat down and we exchanged niceties. The kids all ran to him and hugged him. He was "Grandpa" to every kid in our congregation. I could see that he was troubled. We talked about the need for deacons and about the qualifications. "John," he said. "do you think you're qualified to be a deacon?" I wanted to say "Yes," but that did not seem too humble. "Well, I've tried to be a Christian," I said. "I've tried to raise my children the way they should be, but with all Tim's problems not everyone can understand why he waves his arms and spins things, etc." "You're right!" he said. "People might not understand. I think it might be better if you didn't take on the role of a deacon. We'll announce that you don't

think you're ready," and he stood up and pulled on his coat. "Ready to go?" he said to the deacon with him—and they left. I was hurt and depressed.

All of that circulated in my mind as I heard the condemnation of churches by these parents of multiple-handicapped children. Suddenly I found myself speaking. "You know, folks," I said, "I know exactly what you're talking about, but I think it's important that you don't throw the baby out with the wash. People act that way, but that's not God's fault. God cares, and a lot of people care—they just don't know how to react because they don't understand—they've never been there. I'll bet that if we were to go to our Bible school people and suggest a special class for children with disabilities they'd be delighted to do it." "Not at our Church," one man said. "They already told us they couldn't spare a room for our boy." This discussion prompted me to push a little on some previous thoughts some of us had discussed at our Church. A few of our fine Christian ladies were ready and willing, and within a few short weeks some of these ladies had managed to begin a "special" class in our cry room which was vacant during Sunday school time. There is still a terrible need for an aggressive program in reaching out to these children, but many congregations are beginning to see the need and the opportunities.



## Chapter 11

# Success in School

The following fall began Timmy's public school career. He was placed in Grissom School not too far from our home. A school bus picked him up and brought him home, although he did have to catch the "early" bus that came by our house at 7:00 A.M. which we thought might be a little early for an eight year old to get up. However, Tim was always up by 6:00 A.M., ready to go to school. For the first time, Phyl was not spending an hour or two a day driving him to and from school. Grissom was a disaster! The kids made fun of this little fellow because he was small and weird. Grissom was grades seven, eight, and nine. Tim was eight years old, still waving his arms and spinning lids. The teacher of the class was compassionate and loving, but of the opinion that Tim was incapable of learning—and in that climate, she was right. The previous teacher had worked so hard on getting Tim to walk down the halls of the school without waving his arms, etc., but all his former teachings seemed to no avail. At home we read to Tim by the hour and tried to work with him. It was obvious, however, that he was not making any progress. There was a teacher replacement at the end of that year who was a much better teacher for Tim, but that teacher left at mid-term because of a pregnancy. Thus, Tim had three teachers in two years! The following year he was sent across town to Walt Disney School, a school that was an elementary school so he came in contact with younger kids and he did not get ridiculed. Phyl had to drive him, but was paid a little gas money by the school system. Tim enjoyed attending this school, but again made very little progress.

Our neighborhood reacted well to Tim. People either treated him well or ignored him. Bob and Lucille Geisler, Tim's original foster parents, lived across the street and down a few doors, and we spent many hours together. Tim would spend hours with their son Corey, but Tim really did not play. He was in his own world, but he got love from the entire neighborhood. Our girls did not have a lot to do with Tim although he and Wendy would play together for hours in the basement when she was between two and five years old; but outside Tim was alone. If someone tried to make fun of Tim, Cathy would put a stop to it; but she was an athletic, active child in her own world as well. I tried to get Tim to play ball, but he had no interest. He could



Tim and John when Tim was 10 weeks old. You'd never find a happier, more "normal-looking" baby.



Tim and Phyllis when Tim was three months old. At this age, there was no reason to believe Tim had any problems. Three different doctors had declared him a "normal newborn."



Tim and Phyllis when Tim was seven months. This picture was taken shortly after we had been told that Tim had severe problems. Just looking at the picture, you can see why it was difficult to believe.



Tim at 20 months, looking at Christmas-tree lights. We put up lights for every occasion because Tim could see them through the cataracts in his eyes and was ecstatic with anything like that—especially when he saw them for the first time.





Tim on his second birthday straining to see the candles on his cake.



Tim on his third birthday and also after his first eye surgery



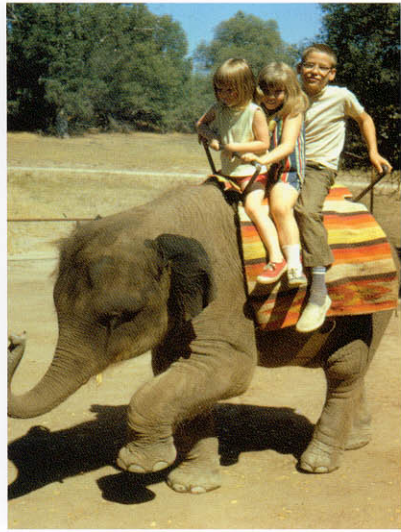
Tim observing a fish for the first time. Notice he is using his touch more than vision



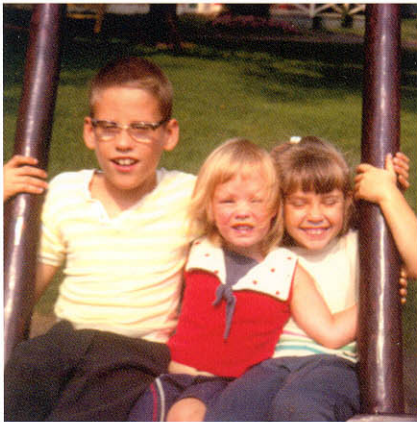
Tim in his "graduation" cap and gown after a Vacation Bible School program.



Tim, with his sisters, Cathy and Wendy, and his mom, Phyllis, following his leg surgery



Wendy, Cathy, and Tim riding an elephant.

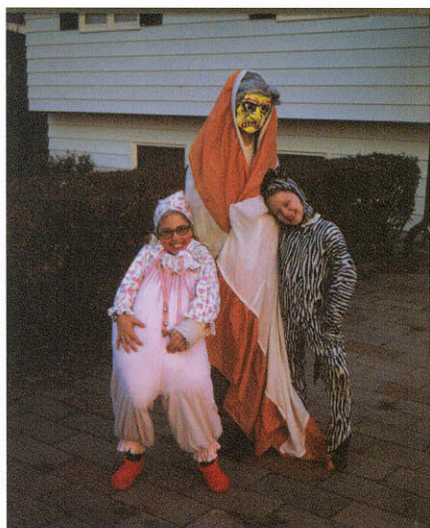


Tim, with his sisters, Wendy and Cathy, having fun on a swing.



Tim and Wendy had picked some flowers for their mom in the woods behind our house.





Cathy, Tim, and Wendy enjoying Halloween costumes together.



Tim, with his friend, Rob. He is from Tonga and met Tim when we were in Hawaii, during a **Does God Exist?** lectureship. Rob climbed up a coconut tree and let Tim drink milk from the coconut.



Tim at nine years with a *church building* he built in the basement. Ingenuity and interest in spiritual things have never been a problem.



Tim at 18 years of age with his going away party cake as he left us to live in a group home. He was so anxious to be *on his own*.



throw a frisbee 50 feet with an *overhead* throw—not side armed the way you are supposed to. Tim did everything different. He enjoyed playing alone in the sandbox and spent a lot of hours just looking at the trees and sky as he waved his arms and sang songs. He learned to ride a tricycle when he was around 11. Phyl wanted to buy him an adult three wheel bike when he was 14 or 15 because he was certainly much too big for the large-sized child's tricycle he had been riding. She finally found a used one at a pretty good price and we got it for him one year for his birthday. We did not know whether he would be able to control that large bike with coaster brakes instead of wheels just turning backward as they do on a tricycle. Within a week, he was riding it all up and down our street which was not at all heavily traveled; and when a car would come by, he would hear it and ride four to five feet off the side of the road and wait for the car to go by. Tim was extremely careful of cars when one did happen to come by, so for several years he spent many happy hours riding his tricycle.

The following school year, Phyllis decided enough was enough and attempted to find a better answer for Tim's schooling. "What you really need is a visually impaired, mentally retarded class," the assistant superintendent in charge of special education told her. "But we don't have one." Realizing that Tim was not getting the needed education in the mentally handicapped classes he had been in, the man began to search for a better answer. There just happened to be a new class starting for visually impaired children in the South Bend school system. This was a brand new class, but it was decided that this just might be the better answer for Tim. In fact, they even arranged transportation for Tim—he was to be picked up by a cab which also was going to be picking up three or four others prior to Tim. He was the last one on the route before going to Marshall School. This was the best possible arrangement for Tim and for my wife. Marshall School was not far from our home, even though it was in a different school system. Arrangements had been made for three local school systems to be able to take advantage of this visually impaired class if they had children who met the requirements. The class consisted of nine children—all with visual problems and one or two children who were totally blind. The teacher told Phyl the first day that she would do the best she could with Tim, but most of her children were of normal intelligence and she did not know whether Tim would fit in or not.

As it turns out, this was the best possible place for Tim. He took off like a shot. In the first weeks, he learned more than he had at the two previous schools combined. By the end of the first six weeks, he had learned to read a primer. Phyl was moved to tears the first time she had a parent-teacher conference when the teacher played a tape for her, handed her the book that Tim was reading from, and she

heard Tim reading for the first time in his life as she followed along in the book he was reading from. He went on to learn to add simple numbers and developed a soaring interest in other countries. They had large print encyclopedias which we feel had a lot to do with his developing interest in books. We bought books like mad. The teachers grew to know Tim as we did, and it seemed that they took a special interest in Tim. Even the cooks at school became Tim's friends and the principal knew him by his first and last name. Those three years at Marshall School in the visually-impaired class were the best years of Tim's childhood.

## Chapter 12

# Teenage Body, Child Mind

There is something about American education that causes educators to get concerned when things are going too well. After three years at Marshall, Tim had grown. He was almost six feet tall and powerfully built in his arms and shoulders. His upper body strength was incredible. Tim was no longer a small child. He had made great progress in his school work due to a lot of hard work from some really dedicated teachers. He was reading at about second grade level, could groom himself fairly well, and improved verbally (through speech therapy) to the point where a stranger to him would not have felt he was retarded much at all. His familiar hand waving and spastic type of facial expressions were still there, but they were voluntary and even that was improving. One of his teachers at Marshall was Mrs. Mary Wehr, a media specialist. In Mary's eyes there was nothing that Tim could not do. She taught him to do up the zipper on his coat when everyone had agreed he could not do it; she taught him how to dial the phone and used her own number as a homework assignment. For years Tim would occasionally pick up the telephone and deliberately call Mrs. Wehr and carry on a brief conversation with her. After his brief talk with her, Tim would hang up—proud and satisfied that he could do it. Mrs. Wehr's love and interest in Tim was a sustaining force in his life.

After his third year at Marshall, however, the school system decided that it was time for Tim to move to another class. "He's too big for an elementary school," we were told. "You're not allowing him to be with kids his own age so he can develop socially," we were admonished. No amount of argument was going to change this decision. Tim was going to be moved. While we fussed and worried about the outcome, due to our previous experience with classrooms for the mentally handicapped, Tim was complacent. As long as he could keep calling Mrs. Wehr, he would move peacefully and happily.

It was decided that the best place for Tim would be Grissom School. This is the same school that he went to when he was eight years old, but now he was the tall, lanky teenager that fit more into the Grissom student environment. He was allowed to visit the classroom the spring before he was to make the transfer. The teacher was very congenial and very student oriented. Phyl liked him right away although she

had some very deep misgivings about whether Tim would be able to do even a small portion of what the students were doing. They were working with tools in the industrial arts classroom, using saws, hammers, etc. The answer that she received from everyone she expressed her concerns to was that she was observing these students after they had been in Mr. Nowicki's class for at least a year—that she would be surprised how much Tim could learn in a year in that class. The educational level as well as the mechanical level seemed to be out of Tim's grasp, but she was satisfied that maybe Tim could improve that much in a year's time—after all we had seen a rapid thrust the first two or three months at Marshall School, she remembered. Tim's eagerness to go to school dwindled a little a few weeks after he started at Grissom. He kept saying how much he wished he were back at Marshall, although he never did say he did not like it at Grissom—he just kept talking about how much he missed Marshall.

During the first parent-teacher conference, it was decided that we should ask for a review of Tim's placement. The teacher had expressed some concerns, as had we; in fact, he made the statement that if Tim were his child he would want a change made as soon as possible. It seemed to us that Tim was working to his limit and barely reaching the bottom rung of the ladder of success; he desperately needed to be able to at least compete successfully within his special education class. More testing—and again indefinite results. We were told that he could possibly be put into another classroom; however, since both we and the teacher thought a lower functioning class would meet his needs better, arrangements were made for a transfer to North Side School. North Side School was a one-story brick ranch as far from our house as you could get and still be in the city of Mishawaka, but bus transportation was available, and Tim went. He liked the school a lot. The following year, that class was transferred to a middle school (North Side had been an elementary school just like Marshall) called John Young School. There Tim became fast friends with the principal, the assistant principal, the physical education teacher who took a special interest in Tim, the cooks, and his teacher—but not with the kids of his age. Once again we were faced with Tim being ridiculed and called names. It bothered us much more than it did Tim because we could see that the alleged purpose of moving him was not being accomplished. Tim associated with adults—not with the kids his age.

Even more disturbing was the fact that his learning had seemed to be at a low ebb. His reading level, math ability, and communication stood still and perhaps even regressed somewhat. When the class talked about airplanes, perfumes, or foreign countries, Tim was all ears. Otherwise, he floated above it all—being no problem to anyone, but getting very little out of school. His teacher took advantage of

Tim's interest in other countries and would show films every so often and let the class discuss these countries and allow Tim to participate in the discussion and show his knowledge to the other class members. But still, Tim was interested in only the things Tim was interested in, and nothing seemingly would alter this. As Tim began his third year at Young, his personality began to change. More and more, there were harsh words toward both his sisters and us. Tim was 17 by now, very strong and tall. Cathy—our oldest girl was 15 and very small for her age. One night Phyl and I went out for a while, and when we came home Cathy came running to us in a mixture of fear and anger, "Tim picked me up and shook me and hurt me," she said. I looked for Tim while Phyl tried to console Cathy and finally found him in the basement in the corner sitting on the floor holding his hands over his ears and rocking from side to side. It was as if he was going to block out the words he knew would come and did not want to hear. Before I could even speak to him, he said, "I'm sorry! Cathy wouldn't let me pour my tea. I'm sorry! She wouldn't let me! I'm an adult! I can pour my own tea! She wouldn't let me!..." Tears were flowing down his cheeks and he was shaking all over.

I went back to the kitchen where Phyl was holding Cathy. "Daddy, I came into the kitchen and Tim had poured a whole pitcher of tea on the floor," she began. "I told him he couldn't pour the tea and he grabbed me by the two arms and lifted me at arm's length a good foot or two off the floor. I said 'Tim, don't and he dropped me! I fell flat on the floor. Daddy, he scared me.'" Phyl and I immediately agreed and told Cathy "We won't ever leave you and Wendy alone with him again. We're so sorry it happened." We could understand what Tim was thinking, yet we were keenly aware of the fact that he could have hurt Cathy and realized that we could no longer leave her in charge. We had entered adolescence in a retarded child.

As I thought about what had happened, I could visualize how it took place. Tim viewed Cathy as bossing him, and Cathy viewed Tim as unable to do what he was trying to do. He could have hurt her seriously, but he was better than that. I could see the conflict—a body and motor part of his mind that could not do what his thinking mind told him he should be able to do. What lay ahead?



## Chapter 13

# Teen Body, Child Mind, Adult Pressure

The answer to that question was not far off. We were heating our house with a wood stove. A dear friend had helped us find wood which I would dump in the driveway from a trailer then rack up on the back patio and along the back fence to use as we needed it. Sometimes Tim would use a small two-wheel cart to haul wood to the patio where he would stack it. His stacks would not stand because he would do them crooked, but that was no problem on the back patio—they would fall over and I used them as they were. Nearer the door, however, it would be different. Not only would they block the door if they fell, but they might hit a person. By the time I got home from school on that day in March, Tim had hauled a dozen carts of wood onto the patio and dumped them. They were blocking the door and would have to be restacked. I hurried upstairs, changed clothes, and ran out to re-do them. As fast as I could, I moved the wood from the jumbled heap to an orderly stack. Suddenly, a new load of wood tumbled onto where I was working. “Tim, don’t bring any more until I can get this stacked,” I requested of Tim. “I’m an adult! You can’t make me stop!” he said. I stood up and faced Tim whose face was red and whose hands were trembling badly. “A soft answer turneth away wrath,” I said to myself. “Tim, you’re getting to be an adult and you’re really helping Daddy a lot, but I can’t have you do this if you block the door,” I said. He looked, turned, and sulked away. Suddenly, there was a crash which I realized was the slamming of the kitchen door followed by stomping which went through the kitchen and up the steps. I ran to the patio door to see him slam the door to his room.

Phyllis met me at the door—wide eyed and incredulous. “What happened?” she asked. Then we heard nearly hysterical crying from Tim’s room. “I’m an adult. No one can tell me what to do.” “He’s *never* like this,” Phyl said. “What’s happening to him? Let’s go and talk to him.” We knocked on the door and I heard Tim sit up in his bed. We went into the room to see him sitting on his bed with a towel over his head. “Tim, who told you you’re an adult?” Phyl asked. “My teacher. He says I’m an adult and I can do what I want.” Phyl had discussed this problem with his teacher, and the teacher also had noticed the same resistive force when he asked Tim to turn off a light, for example. But, he had no suggestions or help

for us—just the same observations we had. His teachers at Church were also getting the same treatment from him. This was so different from the Tim we had always known, for he had always been positive, cooperative, polite, and helpful to everyone. We tried to reason with him. “Tim, even Mommy and Daddy have to listen to what others say to them sometimes,” Phyl was saying. He was not listening. He had his fingers in his ears and was sitting with his head between his knees rocking from side to side.

The following spring this behavior became progressively worse. If I did any outside job, I did it too fast. If Tim spilled tea or coke and someone told him to be careful, he would scream “You can’t tell me what to do” and put his fingers in his ears. His toilet habits became difficult as he would use enormous quantities of toilet paper or even get the bathroom in a mess because of his inability to clean himself. The final straw came that April. Tim had a radio he enjoyed listening to. He would plug it in and listen to music, the news, or anything else he could find. I came into the garage from working in the garden and found Tim sitting on the floor of the garage listening to his radio which was plugged into the freezer socket. The freezer plug was lying on the floor beside him. “Tim!” I said quite severely, “you cannot unplug the freezer! All our food will be ruined.” Tim was on his feet instantly in a rage. “You can’t tell me what to do! I’m an adult,” he stormed. “Yes I can, Tim,” I said. “When you damage something that belongs to me—I can.” He moved toward me in a menacing way. “No!” he screamed. “You can’t! I’m an adult.”

What do you do when you are confronted with an insolent abusive eight-year-old child? You discipline—right? But what do you do when that eight-year-old mind is in a six-foot-plus body that may be stronger than yours? I guarantee that you will think twice. “Tim, you don’t talk to your father that way!” my wife’s voice came from the kitchen doorway. Suddenly Tim yanked his radio from the floor snapping the cord halfway to the plug and ran toward the front yard, crying hysterically. “What are we going to do?” my wife said. “I don’t know,” I said, “but we do need some help. We’d better see if we can find some help somewhere.”

## Chapter 14

# We Cry for Help

Tim was never formally adopted by us for his own good. We did not have the resources he needed for both medical and psychological help. As far as we were concerned, Tim was our son, but legally he was a ward of the state. By this time he was 18. The school system had said they would not allow him to come back after the current year and Phyllis was spending long hours trying to get him into the Sheltered Adult Workshop. All kinds of programs existed, but none of them really met Tim's needs. Being 18, the Family and Children's Center had no obligation or jurisdiction. We were on our own. For the first time in our lives, Tim was becoming a problem that we did not know how to deal with. The girls could not bring friends home because Tim hovered above them like a bird of prey and would not let any of us tell him anything. Always before, he had allowed our girls to have their own friends and perhaps meet them, say "hello" to them, and leave them alone.

As a couple, we could never get away from things. We could not leave the kids alone because Tim would become angry if the girls told him *anything*. We could not invite people over because Tim would dominate the conversation and, if we said anything to him, he would say "It's OK. I'm not doing anything wrong." The company would then usually say something like "Really, it's OK," to which he would repeat, "See, they say it's OK." Blow-ups became more and more frequent as we tried to be extremely careful about the way we asked Tim to do anything. Finally, I got to the point where I would tell him to go outside the house when he would go on one of his rampages. All of this was always over something so simple that would never have caused a problem with most kids—i.e., the freezer cord incident. It seems to me that we must be careful in pushing retarded adults into thinking they are responsible adults in all things. I realize that Tim's reaction was to the extreme and one which no one would expect, but he did not know how to differentiate between what he could and what he could not make decisions about. When Tim would finally come back, perhaps 30 minutes later, he would be chagrin and quiet. Many of these times when he would leave, he would go across the street to Bob and Lucille Geisler's and stay there. They were very cooperative with us and would talk to Tim until he finally decided maybe he should

come back home. One time, however, Bob had to order him to leave the room when they were eating, to which he received the same reaction from Tim that we had been getting. Bob tried to tell Tim that he sometimes did have to listen to others, and that in his house, he had to listen to him and ordered him out of his house. Tim's Sunday School teachers at Church were also getting some of this "different" behavior from Tim than we had ever seen in his past. We had to do something. We could no longer deal with Tim and his problems.

For years we had heard of a program called "group homes." These were residential homes in which three or four retarded adults lived together in an apartment with supervision. It seemed like an ideal answer for Tim. He could live "on his own," we could keep in contact with him, and he could have the home of his own he kept telling us he wanted. Phyl began to call. The response ranged from "impossible" to "in four or five years we might have an opening." One lady told Phyl-lis to "Forget it! He has a home. We've got kids that will be sleeping in a gutter if we don't take care of them." When I came home on that day I was confronted with a nearly hysterical wife. Not only had she been told there was no hope, but Tim had made a terrible mess in the bathroom—all over the walls and floor and then slammed the front door so hard he had broken a wall decoration as he ran outside into a snow storm with no coat on. This seemed to be another part of Tim's rebellion to listening to Phyl—when she told him to put his coat on, that made him more determined to leave without one on.

"Who have you been talking to," I demanded. She handed me a list of several people she had talked to from various agencies. "Who's in charge of the residential homes?" I wanted to know. "Dan Ryan is the director of the residential homes," she said. "But I've talked to him and, although he was very nice to me and seems to realize our problem, he says they have a waiting list and that he can't give me much hope." The strain and frustrations were etched in her face. She had been so strong and through so much, but now it was really affecting her health. A bottle of tranquilizers was on the table plus a bottle I had not seen before. "What are the new pills?" I asked. "Dr. Erickson was one of the ones I talked to today, and I asked him for something to help Tim sleep," she said. "John, he isn't sleeping at night at all."

This was true. All night we would hear him walking around the house—flushing the toilet, going to the kitchen, and sometimes even going outside. We had tried warm milk, exercise, Valium, and even a few commercial sleeping pills. Nothing fazed him. "I don't know where to turn. Everyone seems to understand that we have a serious problem, but no one can tell us anything we can do about it or anywhere to go for help. Are we going to have to continue to live in this type of situation forever? I don't know how much longer I can take it," my wife said. "I'm calling Dan Ryan," I said.



Dan Ryan's voice was pleasant and compassionate. "Mr. Ryan, I've got a desperate situation," I began. I explained the temper tantrums Tim was having, the desire to be on his own, Phyl's health problems (including the diabetic problems she had battled all her life), and the negative effect Tim's presence was having on our girls. He listened sympathetically and made copious notes. "I'm desperate," I concluded. "Everyone tells us there is no chance, but we've got to do something! Is there some way we can get help?" "Yes, Mr. Clayton, I believe that we eventually might be able to help by placing Tim in one of our resident homes. It would have to be on a trial basis, however, because we are financially unable to assume a major medical problem, but if you'll take the responsibility for him until something else could be worked out if we ran into a problem with him that we could not handle, then I'll talk to our staff and see what might be worked out." I was both stunned and elated. "When do you think this might be?" I asked. "Oh, it would be several months, I'm sure," he replied. Could we tolerate the situation several more months? Still, perhaps there was a solution on the horizon.

Barry Chamberlain was a young man who cared for five retarded teenage boys. Dan Ryan had given his name to us as a possible help for our situation. After talking with Barry, we were given permission to leave Tim at Barry's as a respite from our daily contact. Barry also needed permission from the Council for the Retarded since he was keeping some of their boys. I also was extremely concerned about leaving Phyl with Tim for the weekends when I was away on lecture-ships, and Barry came to our rescue here also. We left Tim a weekend or two while I was out of town to give it a try before we left him for a longer time. During the summer we left Tim with Barry while we traveled to Nova Scotia to conduct several **Does God Exist?** lecture-ships. Tim was enthusiastic. He did not want to go with us, and he wanted to stay with Barry. I was 100 percent sure that leaving Tim with Barry for two weeks would be a disaster. "Barry may have Tim in jail by the time we get back," I told my wife; but when we returned Barry was raving about how good Tim had been. "He doesn't relate to the other boys much," Barry told us, "but he talks to me a great deal. He wants to talk about God a lot," Barry said with a smile. Tim enjoyed religion. He had always enjoyed going to worship and was active in his prayers and devotions at home. He was baptized when he was 16 years old and was always ready to share religiously with others. As Barry talked about their discussions, Tim smiled. "It must be us," I thought. "He gets along fine with others." As we drove home, Phyl expressed the same feeling. "The group home will really be the answer for Tim," she said—and we all agreed.



## Chapter 15

# Violence

The summer of 1980 offered a special opportunity to the Clayton family. In addition to the lectureship series in Nova Scotia, I was invited to go to Hawaii to present our lecture series. All three kids and my wife's mother were excited about going, so we saved our money so we could all go. Tim was especially excited because he marveled at the exotic cultures so dominant in the Islands. Tim's relationship to us improved and his outbursts diminished, as we kept reminding him that if he was going to go he would have to behave. All of his life, Tim had attended my lectureships. He enjoyed meeting the people we worked with, and everyone was very kind and supportive of him. We arrived in Honolulu and began our work and sightseeing. Phyl took Tim everywhere, and his eyes were filled with joy as he visited the Polynesian Village, the Kodak Show, and all the other attractions.

After a week, the Mike Wiggins family from California arrived to join us. These Christian friends were like family to us and had worked with us in our Church work in many places. After a beautiful 10 days in Oahu, we flew to Kauai where we saw the more primitive part of Hawaii. One day we went to Waimea Canyon. After driving to the end of the road Tim, Phyl, and I walked for over a mile up a beautiful wooded path. The exotic vegetation and clean air were beautiful and we enjoyed just being together. I felt as though our real problems with Tim were over.

Our next stop on our schedule was the island of Maui. I was to give a two-day series at a very small congregation there that had done a lot of work in preparation. As the 11 of us got off the plane and walked into the baggage area, several members of the congregation came up to meet us. It was a surprise to all of us and was an especially gracious thing to do. Not realizing myself that they would be there, I had not told Tim they were going to be there, so he was some 20 feet away as they introduced themselves. As Tim heard them introduce themselves, he rushed up to them nearly running over Mike Wiggins and pushing Phyllis out of the way as he went. Phyllis, wanting to save embarrassment to our host, took Tim's arm and pulled him gently back so that Mike and our host could shake hands. Tim grabbed Phyllis, shook her sharply and shoved her away, telling her that she could not tell him what to do. As I saw tears coming from her eyes

and saw her grab her arm in pain where Tim had shaken her, I decided that Tim had to learn he could not do that to her. We had already had an incident outside the auditorium in the Pearl Harbor Church building when he pushed her back against the wall, telling her he could do whatever he wanted. This was in response to her attempt to get him to stay with her instead of bothering others, especially visitors. Deciding that this had gone on enough and Tim needed to realize that he could not continue this type of behavior, I stepped up, pulled him away from Mike and our host, and cuffed him sharply across the back of the shoulders. "No, Tim, you can't do that," I said. Suddenly Tim was a blur of pounding fists as he lashed out at me, swinging wildly and crying. My bags had long since dropped, so I blocked his punches rather easily, and after five or six swings I was able to say, "Tim, stop it!" between each swing. After perhaps 20 swings I said, "Tim, please stop it. You're going to hurt someone." He straightened up, cried out, and suddenly began pounding on himself with such force I cringed at the impact. He hit himself on the head and then slapped his own face with such force that I grabbed him to keep him from damaging himself. Putting my arm around him, I hugged him. He bent over and began crying hysterically. With my arm around him, I walked him to a bench where we sat down and he cried his heart out. For the first time, I looked up at the astonished crowd looking on. Mike was explaining to our hosts what the problem was, and the rest of the group was consoling a tearful Phyllis who had bruises already forming on one arm.

After that terrible day, our time on Maui was one of great joy. Tim and I went swimming in the surf on the beach near our room. For hours we enjoyed body-surfing the waves to the beach. The power of that water and the beauty of our surroundings dulled the hurt of our violent experiences. When we asked Tim why he had done what he had done, he would not answer. "I don't know" was all we could get. Mike had several friends on Maui who had been to Tonga, a place Tim had often read about. These great Christian men showered Tim with attention and showed him how to climb a coconut tree and open the nut and get the milk. One of them brought an eight-by-six-foot piece of actual cloth from Tonga which he gave to Tim. When Tim saw the huge sheet with the exotic Polynesian designs on it, he gave out a squeal of glee and for the moment was the wildly excited little boy we could remember of years before as he would look at the Christmas tree lights through his cataract clouded eyes.

## Chapter 16

# The Group Home

We returned home, to school, to work, and Tim to the adult workshop. One night in October, the incident in Hawaii was repeated but worse. Phyllis had told Tim to quit shoving around one of her kitchen chairs—a little thing that he became upset about. Suddenly, he seized her by the arms and began shaking her like a large dog shaking a groundhog. Phyl was screaming for help and I was there in an instant and tried to pull Tim away. Finally, in desperation, I gently cuffed him on the back of his head to get him to let go of my wife. He let go of Phyllis and turned toward me. “Tim, you can’t hurt Mommy,” I said. He advanced toward me, raising his hand in a threatening way. “Tim, I’ll have to hit you if you try to hurt me,” I said. He stepped toward me and swung his fist in my direction. I slapped him gently on the cheek. He took another step and I pushed him back, hitting him again. He advanced again and the process was repeated. After five or six cycles, he finally sat down on the step. “I hate you all,” he cried. “I don’t like this house!” “Tim, you can’t do this in *any* house,” I said. “They’ll throw you out of the group home if you act like this.” Tim collapsed in tears, and Phyl and I joined him.

Those violent reactions were so strong and bizarre with Tim and so different from the Tim we had always known that we truly did not know what to do. We had never experienced physical violence with any of our children. As we sat together later that evening, Phyllis and I talked about what to do if he became violent again. We finally decided we would order him out of the house and tell him not to come back until he could behave. Barry had mentioned one time in a conversation with us that this was what he would consider doing. “If he won’t leave and especially if he gets violent again, we’ll just have to call the police,” I said. “He’s getting dangerous, Phyl—you can’t take the risk!” “He’s not really so bad when you’re gone,” she remarked. “He says he’s the man of the house while you’re gone and he will help me.”

Things got so bad that Tim finally refused to go anywhere with us—especially me. He would frequently not even go to Church with us but would conduct his own worship in his bedroom. He continued to follow a similar pattern by telling us that we could not make him go to Church with us; and if he did psychologically get talked

into going, he would tell everyone at Church that he really did not want to come but that we made him. We began calling Dan Ryan and residential home staff on the assumption that "a squeaky door gets oiled first." It got to be almost a nightly routine that Tim would begin screaming at us, be ordered to leave, and would run out of the house only to return in 10 minutes to an hour as if nothing had ever happened. Finally we got a call that there was a place for Tim in a residential home, and Tim prepared to leave. He packed the things he wanted to take with him and we took him to his new home—a group home on the north side of town.

The group home was a very nice place. I was amazed at how clean and neat the place was. There were two Down's syndrome boys who had grown up in a state hospital but were now living in the group home. One of the young men happened to be a brother of a neighbor of ours and he was very nice to Tim. Tim had his very own room which he could fix up as he wished. We helped him get his things put away into his own bookshelf unit and dresser that we had taken out there for him. We left him sitting on his bed looking out his window. It was an emotional time for us, but for Tim there was no sign of concern, worry, or loss. As we left, the lady who was supervising the homes said to us, "Please don't make any contact with Tim for awhile. We want him to get used to us and the routine here. We hope to push him to become as self-sufficient as possible. In fact, down the road some where, maybe he can move out and function even more independently." "It'll never happen," I thought, but this was what Tim wanted. We had done our best and now we had to let go.

Coming home to a "Tim-less" house was a real change. Cathy began to have friends over for the first time. Phyllis and I were able to go out and do something together. Even more comforting, we could sit down in front of the fireplace together without Tim joining us and starting an argument over some little something that was on his mind. Tim had been such a domineering force in our lives for the past two years that we had not even realized how he had controlled our lives. It was a new and exhilarating freedom. For many weeks, all we heard from Tim was an occasional phone call. Things sounded fantastic every time he called. He spoke of parties and trips and meals at McDonalds. He told of helping fix supper and helping to clean the house. He even painted his room, with Elizabeth helping him. After several weeks, we made a visit to Tim's new home with my mother, father, and younger brother, who taught emotionally disturbed children in Bloomington, Indiana. We had checked with the authorities at the home and they felt this would be a good contact to make—for Tim to be able to show off his new room rather than have Tim come to our house to see them. It was our first visit also, and it was impressive.

Not only did he seem happy, but he had learned to make up his room, do his chores, zip up his coat, and (according to workers there) even to tie his shoes—something we had never been able to teach him. It looked as if Tim had really found the home he wanted and needed. All of our contacts with people in charge indicated they were really pushing him, but that he was doing fine. What more could we ask?



## Chapter 17

# More Pressure

A couple of weeks later, Tim made his first visit home. He was only in the house for a few hours—less than 24—but by the time he was scheduled to return to the group home, he was ready to leave. Later, we got a call from the resident supervisor saying that Tim was having a hard time. “We don’t think you should have any more contact with him since he seems to get upset when he’s with you.” She was tactful and polite, but basically we were told that it would be better for Tim to not have any contact with us. We were a little hurt, but we could not argue! Being around us did seem to upset Tim. What had we done to produce such a traumatic reaction toward us? We had pushed him to learn and to do the best he could, but we had not demanded more than he could do. We comforted ourselves by agreeing that we were glad he liked where he was. The people at the group home had already told us that usually if they were going to have trouble with a new client, it would be after about six weeks. That was about the length of time he had been there. “I sure hope he makes it! We sure have pushed it as far as we could go!” I said to Phyl as she related some of her concerns to me.

One night in Tim’s seventh week in the group home, he called his mother on the phone. They had told us that they would allow Tim to make contact with us if he pushed for it, but did not want us contacting him, which made sense so we had gone along with this. “I don’t like it here. It’s too hard,” he said. “Tim, you must talk to Elizabeth about it. Maybe she can help you.” (This also was the way they had encouraged us to respond: let them work out his problems for him—not us—so that he would get used to going to them.) “That’s your home now. You’ve got to work it out at your new home because you weren’t happy living with us and you don’t want to have to come back here either.” He responded by saying “OK” and that maybe it was not so bad—he liked his new home OK. As she hung up the phone, Phyllis said “They’re pushing him too hard. He can’t do all those things they expect him to do, John. We pushed him as much as we could and they’re trying to get him to do much more. He can’t see well enough to get his clothes on right side out without help, run the washing machine, and fold his clothes and many of the other things that the other boys are expected to do.” Her face was actually fearful,

and there was an element of desperation in her voice. "Honey, they know what they're doing out there," I replied. "Let them deal with Tim." "He just can't come back here, John," she said. "And God knows that! It'll work!" I comforted her. In my own mind, I wasn't all that sure it *would* work, but I believed strongly God would provide an answer. All of Tim's life, there had been answers. Sometimes they were not what I expected, but they were always there. The fact that "all things work together for good to them that love God" had been shown to me by Tim too many times to doubt it now. How God would work it out, I did not know or what might happen between now and the solution, I did not know—but there always is an answer given that prevents us from being pushed past a spiritual breaking point. God would not let us be destroyed spiritually by Tim's problems.

God is faithful, who will not suffer you to be tempted above that ye are able; but will with the temptation also make a way to escape, that ye may be able to bear it (1 Corinthians 10:13).

As the weeks passed, we heard more and more of problems at the group home. Tim was beginning to give them the same verbal abuse that he had given us. Our feelings of inadequacy as parents were further reinforced when we were told that Tim really was not retarded. "Are you trying to tell me that Tim is environmentally retarded?" my wife asked. "No, I wouldn't go that far," was the reply, "but he certainly can learn much more than he has been taught. He's learning things so easily around here—with one attempt at teaching him, he has it down pat the next time he tries." I thought of the endless hours of reading we had given Tim. I thought of our travels with him, the literally hundreds of books, the trips to the library, and the battles with the schools. All of this had *caused* Tim's problems? "God, am I blinding myself because of my pride?" I asked one night. "Am I damaging my other children in the same way? Can I *really* be that *bad* as a parent?" It almost seemed that all our years of trying with Tim had been wasted.

Several more weeks passed, and one morning Phyl received a phone call from one of the people at the group home. During the conversation, she was told, "Tim tried to commit suicide last night." She was asked if she thought he would try to jump out of his second story window and hurt himself that way. Phyllis said that she did not think so, but then she did not think Tim would do what they were telling her he did the previous evening either. He had tried to kill himself by drinking some bubble bath oil and then came downstairs and told the person in charge that he had committed suicide. "Is he all right?" Phyl asked. Yes, he was fine. They had called the poison

control center and had been told that it probably would not do any damage at all except perhaps possibly diarrhea because of the fact that it had been soap he drank. They wanted Tim to see a psychiatrist and see what was causing him to be so upset with himself and with everything else, and they needed Phyl to sign a release so that they could take him to this psychiatrist. Phyl was too stunned to object, but when I came back from a weekend trip I was skeptical. I reminded Phyl of the time Tim had come at us once in anger with the statement "You're causing me to commit adultery!" He knew he was angry and he knew committing adultery was wrong, so he put the two together in his mind and made that statement to us. I suspected a similar thing had happened there, but I was not going to interfere. Visits to the psychiatrist came and went without much comment. As time wore on, we continued to hope that Tim would make it in the group home.

## Chapter 18

# The Mental Hospital

The phone rang, and Phyllis answered it. It was Dan Ryan, this time calling to tell us that Tim would be calling in a few minutes, but that he wanted to talk with her first to let her know that Tim was being put into a psychiatric ward of the hospital in La Porte, Indiana. He had gone berserk the night before and had jumped on the kitchen table and threw cans in every direction. It seemed that he was not trying to hit anyone—just saying, “I have had it and you can’t make me do all these things.” They had already informed us that they could not allow a violent person to remain in the group home so my wife knew, “Well, that’s the end of it! He’s not going to make it.”

The next two weeks Tim underwent every conceivable test. When we visited him (as they had asked us to do on his birthday), he was agitated but quite happy with his situation. “They don’t make me tie my shoes or do things I can’t do here,” he had said. It was Tim’s 19th birthday, but we could bring him almost none of his presents due to the hospital’s restrictions. It was not much of a celebration because there was not much to celebrate.

Two weeks later the medical report on Tim was in. Exhaustive testing had shown all the things we knew about plus cerebral palsy, a form of muscular dystrophy, and schizophrenia. Over 10 separate disabilities were identified—with the note that Tim could not be expected to function in society in his present status. “He threw the cans to say ‘I can’t do what you expect of me here,’” the doctor had said, and that he had a problem forming close personal relationships. Because he had threatened suicide, he could be admitted to the state mental hospital at Logansport and bypass the waiting list. Phyl went with Karen Francis, one of the supervisors in charge of the residential homes, to take Tim down. He was put on Mellaril to help the schizophrenia problem and the next time we saw Tim, he was so doped he hardly recognized us. His eyelids sagged and his motions were slow and deliberate. He slept constantly. Three weeks later, he was nearly a vegetable and seemed to be losing control of even his personal habits.

Tim’s stay was to be 90 days. At the end of that time, he would either be sent back to the group home (which was highly unlikely), put into a state institution for the retarded, or kept at Logansport. A

nursing home in South Bend was a remote possibility. It was summer time, and we were planning a long trip to New Mexico and back with lectures in several states along the way. After a month at home we would go to the West Coast on another trip, returning just a few weeks before the decision on Tim would be made. The Wednesday before we were to leave on our first trip, we went down to see Tim. He was in a ward with 30 other men behind a locked door. All beds were visible from the central desk. We were able to take Tim out on the grounds and he ate part of some zucchini bread that Phyl had made, but within minutes he was tired and ready to go back to the ward, asking us if we would visit him "in a month." We left a drooling, pathetic young man in a facility like the one we had refused to send him to as an infant.

As we left Tim at Logansport, I told my tearful wife, "Honey, we have to realize that Tim may die. He's lost weight; his personal control is not very good; he can't even feed himself. We did our best so let's leave him to the doctors here." We left South Bend on our trip with heavy hearts, fearful we may have seen our son for the last time. When we returned from our trip and went through Logansport on the way home, we found Tim vastly improved. I suspected they had taken him off the Mellaril, but I was wrong. We had been told that he would improve as he adjusted to the drug he was being given and that this kind of reaction is not uncommon with this type of drug. We later were told that the medication had not been changed at all since he was admitted; he was still on the same dosage as he came into the hospital on. The only other thing that those in charge could come up with was that he had been removed from all external pressures at the hospital. When we returned after our next month-long trip in August, we found Tim to be a different person. He had gained weight, regained control of his eating and personal habits, and had a renewed interest in his books, radio, and the world around him. His only complaint was that he had not been allowed to attend any kind of church services.

Now we had another crisis to face. What would be done with Tim. We desperately wanted him in South Bend where we could visit him as he wanted us to, and where we could continue to love him and help him as much as we could in his spiritual and material needs. But the group home had no interest whatsoever in considering his return there. His room had long before been filled with someone else who needed a place to live, as some other homes were discontinued due to financial funding. Returning to our house was something that neither the doctors, we, nor Tim wanted. Phyllis checked around town and found that some rest homes would take on retarded adults, and she found one just a mile or two from our home named Melrose Manor that we felt was the best answer for Tim. It was much smaller than



many of them, had a very personable staff, had relatively little turnover in their staff, and had an excellent reputation with the Council for the Retarded for how they had handled some previous clients who had been living there. They had some retarded adults there who had been in state hospitals earlier in their lives and seemed vitally interested in helping us if they could. Phyllis made contact with the social worker at Logansport and suggested that this might be the answer for Tim. There really was no room for Tim in Logansport for a permanent arrangement and they indicated that would be OK with them if that is what we and Tim wanted. And so Tim came back to South Bend. Within a month he was the same Tim of a few years before. Happy, satisfied, wanting to worship God, and functioning very well since he was free of the pressure. Where he would be without my wife's constant searching and work I cannot say, but God truly worked all things to the good of Tim.

## Chapter 19

# The Melrose Answer

The years at Melrose Manor were good years for Tim. He was accepted at a sheltered workshop in South Bend where he worked in a supervised, safe environment and made a little money. There were occasional outbursts at supervisors or workers that picked on him, but they became less violent and less frequent. Tim would get up, eat breakfast, and then be picked up by a van that would take him to the workshop. He would work or do a structured activity at the workshop and then be picked up around 4 o'clock and returned to Melrose. After supper, Tim would look at his books, listen to his radio, or talk to the nurses. He had very little interaction with the other retarded adults living there. I would pick Tim up once a week after I left school and take him to a nearby fast food place and most Sundays, he would go to worship services with us.

Melrose Manor was a care facility for retarded adults. Many of the people living there were bedfast and required very high maintenance. Tim was probably the most ambulatory of all of them, and his desire to talk to adults had him following nurses, maintenance people, and supervisors around with a constant flow of questions about where they went to church and what they believed religiously. For some, this was an irritation, but a vast percentage laughed it off. One of the most positive of these workers was a young Catholic named Paul. Paul's patience with Tim's constant questioning of the Catholic Church was amazing, but he never offered to take Tim to a Catholic service.

One day, Tim heard on the radio about a healing service at a Pentecostal Church, and he started badgering Paul about going. The next time I came in to take Tim out to eat, Paul confronted me saying I should take Tim to this service. I told Paul that I did not agree with all of the doctrinal practices of that church and that I was concerned about confusing Tim by taking him to one of their services. Paul let me know he thought my position was wrong, so I told him, "Why don't you take Tim yourself? I have no objection to that if you want to do it." I really did not think this young Catholic devotee would go to a Pentecostal service, and I figured if he did, I would have lots of things to discuss with Tim. To my surprise, Paul said, "OK, I'll take him."

Paul arranged to check Tim out, saying he expected the service

to last about an hour. He told the supervisor, "So don't worry if we are late." The service began with vigorous singing and an eight-piece band with lots of clapping and shouting. This was followed by a 90-minute service which was highly emotional and in which people were invited to come forward if they wanted to be healed of their diseases and problems. Tim heard that people could be healed, and he took off for the front, towing Paul and expressed his desire to have his leg healed, his sight made perfect, and his retardation removed. Paul, who was used to a 20-minute mass, was in shock. They shuttled Tim and Paul off to a side room, and after a quiet prayer escorted them out of the building. Two days later when I came to pick up Tim, I ran into Paul. Tim was bubbling over about the clapping and the band and the shouting that had been part of the service. I turned to Paul and said, "Well, Paul, how did you like it? Are you taking him again?" Paul looked a little sheepish and said, "Let's put it this way: if he is going back to that service, you will have to take him."

## Chapter 20

# Blindness

In the summer of 1987, a new chapter and a new affliction were added to Tim's story. One consequence of cataract surgery is that, after about 25 years or so, there is a high probability of the retinas detaching in the treated eyes. One of Tim's eyes was treated before the other and so the retinas of first one eye and then the other came loose—both in the period of a year's time. Ordinarily, the surgery to reattach the retinas can be done with a high degree of success, but with all of Tim's problems and past treatments, the tissue refused to hold. The doctor said it was like trying to sew wet tissue paper to something.

After seven grueling surgeries which Tim endured with hardly a word of protest, his visual world ended in August. We went down to take him to the doctor for the last confirmation of the prognosis and Tim said, "It's like nighttime all day. When will I be able to see my books and flags again?" Choking back our tears, we tried to explain that he would never be able to see them again and that we would try to find other things he could do and enjoy. Later, as I helped him eat, he raised his head from his food and said, "When I die, I'll be able to see perfectly, won't I, Dad?" Like all crises, this problem brought our family closer than ever before. As our girls matured, they grew in appreciation of Tim's strength and resolve. Tim's faith in God did not waver in this new problem. He still talked nonstop about God and people's attempts to serve God. No one meets Tim without being told, "I love you." His enthusiasm for life and for the world in which he lives has not dampened. Several days after the bad news, my wife took Tim to a fast food place to eat. Two rather seedy teenagers wearing large earrings, long hair, and gangster-type hardware were in front of them as they entered the restaurant. Tim had learned to put his hand out in front of him to avoid hitting doors and the like, so he did this as he and Phyl approached the door. The two boys noticed this, opened the door, and ushered Phyl and Tim inside. There was a long line, so rather than replace the boys who had graciously opened the door, Phyllis said, "Go ahead in front of us. You opened the door for us and that was nice, but it put you at the back of the line." One of the boys looked at her and said, "No, you go on. That's the least we can do."



Melrose Manor adjusted quickly to Tim's blindness. He got a cane, began getting tapes for the blind and continued pretty much at full speed. There were a lot of problems with his going full speed. Anyone in a wheelchair was likely to get run over by Tim. Changing furniture anywhere would produce a collision and an angry response from Tim. At workshop, there were problems with Tim banging into people and machinery, but they taught him how to use his cane and worked on him to slow down.

Through all of this, Tim never complained or felt sorry for himself. In all his life, Tim has never expressed anger or self-pity for all he has had to endure. There have been times when someone exploited his blindness by stealing things from him, and that has precipitated anger at the guilty party, but never at his situation or at God. Everyone who knows Tim has commented on his positive spirit—something that has been an inspiration to us all.

One day I came to pick Tim up, and he was unusually agitated. In the car as we drove toward the restaurant where we were to eat, Tim said, "Dad, Rasha touched me in my private parts and that is not nice." "What do you mean, Tim?" I asked. "What did she do?" She touched me in my penis and that isn't right, is it?" "What did you say when she did that?" I asked. "I told her it wasn't nice and that God didn't want us to do things like that," he said. "Did you tell anyone at Melrose?" I asked. "No, because Rasha said I would get *her* in trouble," he said. "I'll take care of it, Tim," I said, gripping the steering wheel tight enough to rip it off the dashboard.

When I got home and told Phyllis what had happened, she immediately called Melrose. "This happens now and then," the head nurse said. "We'll take care of it. She was a substitute for us, but I will guarantee you that she will not be back." Rasha never had contact with Tim again, but the willingness of adults to exploit the disadvantaged never ceases to amaze me.

## Chapter 21

# Group Home Success

Tim had been at Melrose for 12 years, and during those years, the home became more and more oriented toward severely retarded adults who could not walk or care for themselves in any way. One day at Tim's yearly review at the adult workshop, one of his supervisors said, "We believe Tim needs to move out of Melrose and into a group home." All of the fears of the past suddenly came rushing back to both Phyllis and me. "Why do you have to change things?" Phyl asked. "We worked so hard to get Tim to where he is; and if you put him back in the group home, he may very well end up back in the state mental hospital." No amount of pleading on our part would dissuade them. We were introduced to Linda Rafinski who was the director of the Dungarvin system of group homes. This was a private corporation that owned a number of homes in which eight retarded adults who were reasonably functional lived together. Linda explained the program and how much better it would be for Tim to live with people he could talk to and relate to. All we could think of was "what happens to Tim if he can't handle it? There is no way we want him back in the state hospital." "We don't either," Linda said, sympathetic with our concern. "But we are fairly certain that Tim can do this." "What happens if he can't?" I asked. "He will," she responded. "The first time he blows up on you, you'll have him out of there," I said. Linda rolled her sleeves exposing some bruises, cuts, and what I later found out were bites. "This is what one of the clients did to me last week," she said. "So what happened to that young man?" I asked. "He's still with us," she said. "Tim will make it." She was right, and we were wrong.

Tim was excited about the move. There would be new people to talk to, a kitchen he could be a part of, and the whole group who would go to Church together. There were four men and four women. The first time I popped in on Tim to see how he was doing, he was sitting in a chair and a wheelchair-bound girl named Linda was reading to him from one of his books. The house they lived in was in a residential neighborhood and had four bedrooms with shared baths. Tim's roommates got along well with him, and he adapted quickly to the new surroundings and to doing his own laundry and keeping his room more-or-less picked up. The group went out to eat frequently, took trips to movies and amusement parks, and went to a Methodist

Church. Every time we visited Tim, there was a new report of something they had done together. Tim's interest in foreign countries and especially religion just grew and grew. No one missed being told about God and what the Bible said about everything from baptism to worship.

Not everything was perfect in the Dungarvin home. Tim's reading buddy, Linda, died suddenly. Emory, an autistic young man who never spoke, would steal Tim's books and pour his perfume down the drain. The staff turnover was huge, and it always took time to get new staff members used to Tim and to what he could and could not do. Tim discovered his cane gave him a new tool of control, and even though he was blind, he would lash out with it. We became very fearful that Tim would get himself kicked out of the home. On top of everything else, the doctors decided it was time to start weaning Tim from the medication the state hospital had put him on—a move we were sure would just increase his frustration and lashing out. Things got so bad that one New Year's Eve, Tim was to come over to see the New Year come in. This was an annual event, and we had made special plans for a good time together. I came into the Dungarvin living room and said, "Tim, are you ready to go?" "Why are you yelling at me?" Tim responded. "I'm not yelling, Tim. I just want to know if you have your meds and are ready to go," I said. "You can't tell me what to do," he shouted and raised his cane. "Tim, I think we had better cancel New Year's Eve for you this year," I responded, and I left. It was a very somber and frightened set of parents that prayed and wept together that New Year's Eve.

One day Tim's roommate Tony said to me, "Tim needs a punching bag to hit so he won't hit me. I am not Tim's punching bag." We talked to the supervisors, and within a week, Tim had a bag to hit. Tim would beat that punching bag every time things did not go right. "God wants me to be in control," he would tell me, "and I can hit the bag and it is OK." His anger could be controlled, and he was much more functional and reasonable. He continued to improve and became more and more able to deal with changing staff and situations.

One night, Tim came out to the staff person on duty about 2:00 AM and said, "I smell smoke in my wall." The staff person assumed Tim was just dreaming as she did not smell anything. About 10 minutes later, Tim came out again and said, "I hear fire inside my wall. It is burning; come and see." The staff person walked into his room to find that the entire front wall of the house was on fire from an electrical problem. The staff were able to get everyone out of the house in time, but realized that Tim's persistence had probably saved all of them. Tim made the local paper and was pretty popular for some time after that in the eyes of the Dungarvin people.

## Chapter 22

# Tim's Own Apartment

By the end of 1999, Tim was doing well in virtually every aspect of his life. We would go to the adult workshop and hear glowing reports of how well he worked. Incidents at Dungarvin were very few and far between, and the psychologists who saw Tim on a regular basis gave him high marks. It always seemed that when Tim was fully acclimated to a situation, someone would always want to change it. We were dumbfounded when Tim announced to us one evening that he was going to go into independent living—that he would actually have his own apartment. When we asked the staff at Dungarvin, we were told that the state was pushing them to put everyone in the most independent arrangement they could handle and that Tim was in fact being seriously considered to move into an independent living apartment. “What happens if he can’t handle the independent living?” we asked. “His place at Dungarvin will be gone and he’ll have no place to go!” “He’ll make it,” they responded, “Don’t worry about it.” How could we not worry when a blind, mentally retarded young man with poor muscular coordination was suddenly going to be in independent living? When we expressed our fears to Linda Rafinski, she said, “You need to get together with all of us and see what we actually are talking about.” We met with a staff of five or six people and learned that the term “independent living” is a relative term in the minds of mental health workers. What they really mean is “more independent than the person was in his last living arrangement.” We were encouraged to go to 3425 Generations Drive and meet Tim’s future apartment mate. We arrived at Tim’s future home to find Tim already there, drinking iced tea and smiling from ear to ear. We were introduced to Stacy, who would share the apartment with Tim. Stacy was in a wheel chair, wearing a diaper, and being fed by one of the staff. She had severe cerebral palsy, but was very bright. One hand was functional enough to run a keyboard, dial a telephone, or change stations on a TV remote. She was a quiet person, they told us, which was one of the reasons they thought Tim would work very well with her. Tim never did like a lot of noise so he would appreciate her quiet manner. She had a special bathroom equipped to bathe her with a hoist to move her around. There was another bedroom with its own



bath that would be Tim's.

The name of the staff person on duty was Pat. She explained that staff arrived at 6:00 AM to get the two started and left at 11:00 PM when they were asleep. Stacy had a button on a chain around her neck that she could punch if she needed emergency help. Tim would do his own laundry with help from staff at the laundromat in the apartment complex. He would plan meals and help cook them. Together, they would plan activities with staff help. As I talked to Stacy, I asked her if she wanted an apartment mate, and she said, "Oh, yes. It will help with the rent." She and Tim were a matched pair in that she could see, think, make good decisions, and reason through situations. Tim could move, handle objects, care for himself while staff took care of Stacy. There is not a whole lot of contact between Stacy and Tim, as both of them like quiet. Stacy will watch TV and Tim will be in his room listening to the radio, his blind tapes, or riding his exercise bike.

There is no heaven on earth. Tim's life in the apartment is about as close as he will get on this side of the grave. He loved the fact that he could have his perfumes and no one would pour them down the drain. He was ecstatic that his books never disappeared and that, when someone sent him candy or cookies, they would be there the next day. (At Dungarvin, every time Tim got something to eat, he scarfed it down on the spot—because if he did not, someone would take it when he sat it down. He got sick once eating a whole box of Whitman's Samplers he got for his birthday from one of our friends.) We gave him an old plastic picnic table and chairs we had, and he would sit outside the door of his apartment and talk to anyone who came by. Being independent meant Tim could eat anything he wanted anytime he wanted it. Eating a whole bag of potato chips and drinking a can of regular coke was OK. Within six months of his move into the apartment, Tim had gained over 30 pounds.

We expressed our concern at this turn of events, but we were told that Tim was in independent living and that a part of that was eating what he wanted as soon as he wanted it. "Even if it kills him?" I asked. "What do you do if he decides to drink Draino?" This resulted in eye rolling, but we knew that Tim's minuscule legs could not handle the weight he was putting on. Further attempts to convince the supervisors went no where so we appealed to the director and to his doctor, trotting out Tim's records and asking if they wanted to deal with Tim in a wheelchair. The powers-that-be admitted that Tim needed to lose weight and watch his eating, but the thought of restricting his access to food continues to illicit negative responses. Later I took Tim to an ethnic festival in South Bend—which is like a small county fair. We walked around the fair for a while, and Tim suddenly said "Dad, my legs won't go anymore." He stumbled and started down but I caught

him and propped him up against a police car that happened to be parked there. The policeman came running, and I explained the situation and asked if I could leave Tim there while I went and got my truck. When I came back five minutes later, Tim had three police officers who he was interrogating about where they went to church.

Over the years, we have found the leadership of homes like Dungarvin and state supervisors and workers to be caring, genuine, positive people. That does not always mean they make sense. One day, I noticed in Tim's room, there was a TV coax cable. I asked Pat if it was live, and she said it was left from an earlier resident who had passed away. I asked Tim if he would like a TV so he could listen to the local religious station or perhaps to news channels. He could not see the television, but he could hear much of what was going on. We had an old black and white TV in the basement that I knew we could use to do this. Tim thought it was a great idea so I brought it over and hooked it up. A few weeks later, Tim said, "I'm going to get a color TV. They are going to buy it out of my money." Tim had been given some money to make the move, and he had a little pay from the workshop. "Tim, you can't see the TV, and the sound is fine on this black and white set," I said. "They say it is too old and I need a new one," he answered me. When I checked, I found out that having a black and white TV was considered to be an affront to Tim, and they decided to change it. We had worked hard to stretch Tim's money by buying and assembling a bed, bureau, and storage drawers; and in one fell swoop, it was cleaned out by buying a color TV for a blind man.

The system is wonderful and does great things, but trying to economize especially as an outsider is a waste of time because money saved cannot be redirected into things that would be a big help. Sometimes you have to play hardball, and sometimes you have to listen carefully. There was a time when Tim was a teenager in which someone read to him about Hindus washing in the river Ganges in India as a worship act. "It is sort of like baptism," Tim told me. "You are washing away your sins." At Dungarvin, Tim had occasionally soaked his bed while doing what Tim called a Hindu washing ceremony. The staff got mad because of the mess. Tim thought this Hindu baptism was funny, and he and I laughed about it and then talked about it. He agreed to do it in the tub to avoid getting his bed wet. At a workshop progress report meeting one time many years later, the workshop supervisor said that they were concerned about Tim's incontinence. Tim did not know what incontinence was, but when they asked him to bring another set of clothes to change into, he was glad to do it. The idea of Tim being incontinent did not make sense to me. He had always had a bladder like an elephant, and on trips it was never Tim who required a potty stop in all the years he traveled with us. As I listened to the work-

shop staff, they expressed wonder at how he could get urine all over himself. "Did you smell the liquid to make sure it is urine?" I asked. The staff person wrinkled up her nose and said, "Well, no; but I don't intend to either." "Tim," I said, "Are you doing that Hindu baptism again—at workshop?" Tim started laughing and said, "I need to do that in the tub, don't I?" We all had a good laugh on that one, but I wonder where it might have gone if I had not been listening.

At another meeting, Tim got to talking about his "Mimi." When Tim was a child, some dear friends of ours whose daughter baby-sat for us gave Tim a stuffed dog for Christmas which he named *Mimi*. Every stuffed animal after that became Mimi, and our dogs were live Mimis to Tim. As Tim rambled on about his Mimis, one of the staff people said, "I think Tim needs a dog—another live Mimi." There seemed to be mental assent around the table, so I said, "Now wait a minute. That is a major expense to Tim. He can't take the dog outside. You're adding work for staff, and Stacy may not want a yappy dog around." I was faced with seven pretty sullen looks, but Tim said, "Catholics do what the Pope says, don't they?" He was completely out of our loop and in one of his own. Two weeks later, at the grocery store, I ran into the staff person who had suggested a dog. As we talked, I said to her, "You know, if you got Tim a dog, it is going to be your responsibility—not mine. We have a dog already." As of this date, the subject has never been brought up again. Playing hardball may be the only answer sometimes.

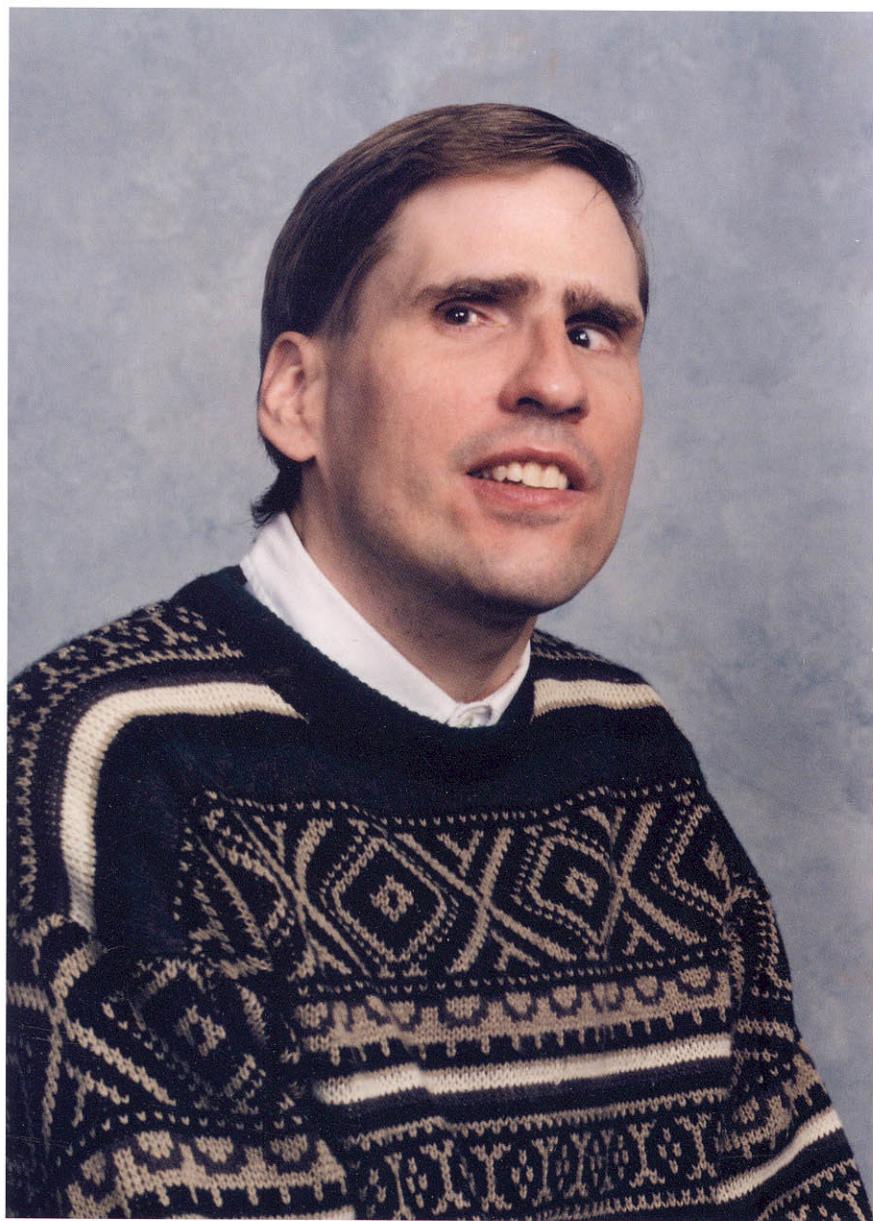
## Chapter 23

## Lessons

And so Tim has been my son and my teacher. He has shown me how much good can come out of bad. He has shown me that a handicapped child is a thing of love. He has given me the talent to reach out to those that others feel uncomfortable reaching out to or even being around. I have learned to be patient in some matters and to be pushy in others. I have seen that those who are found to be faced with an affliction need the help of others to get where they need to be in order to receive the most help. Tim has taught me forgiveness and how much a wife and husband can mean to each other if they bear the burdens together. I have also seen how little the Church understands the needs of someone like Tim, but how effective Christians can be once they understand the problem. Jesus dealt with those who had afflictions. He went where others would not go. Those who wear the name "Christian" need to see a "field ripe unto the harvest" in families that are battling these problems. I have learned to love in spite of pain and to comprehend how God's love sustains and supports to work all things "together for good to them that love God."

The final chapter or chapters of this book remain to be written. We are at an age ourselves where we have many more days behind us than are in front of us. What will happen to Tim when we are no longer alive is a concern to us. Tim is proud of his independence, and we have learned that the system moves slowly, but it does move. We hope that family and friends would keep track of the situation, but never interfere with Tim's independence or allow him to become a burden to them. Tim's life has been filled with good things and happiness. He has never complained about his circumstances in life and has always maintained a relationship with God. He has succeeded in his employment and has had good friends who care about him. What more can a parent hope for in a child? The lessons he has taught us have been enormous and not always pleasant, but they have been lessons that have brought great blessings to us. One of those lessons and blessings has been to talk to and share with people who also have a disadvantaged child. If you would like to talk to us or write to us about your situation and how to deal with things you are facing, we would encourage you to do so.





## **Tim As an Adult**

This story is true and is presented with the hope that, if you or someone you love is wrestling with a similar problem, there may be something in our story that will help. Those who have walked a path before can lead us better if we find ourselves forced to walk that same path. —John Clayton