1981 Ernst Prato
An update my
Book

WHAT ABOUT ME, MOM?

Glimpses into the life of Robert, as
recalled by his mother, Hildur Morck

His brother, Fred, just 16 months Rob's senior, was preparing to spend the day with a friend. Twelve-year-old Robert sat quietly pondering the fact that he usually stayed home while his brother came and went with friends. Then slowly, painfully, he verbalized what was hurting inside: "What about me, Mom?"

"Yes, what about you, Rob?", I asked in return, trying not to betray the pain I bore for him at that moment. With those words our handicapped son had expressed the anxiety that had plagued the whole family ever since he was born at high noon on Monday, February 29, 1960. Bobby was delivered at home by our competent obstetrician, my husband lending him the needed assistance. Dr. Rozo left with the suggestion that I have a bottle of sugar water ready to give the 7-1/2 lb. baby when he would surely cry for it during the night. We proudly presented a second brother to our three school-age daughters who were just arriving home for lunch. All of us were jubilant.

No one guessed, those first four days, that the baby was born with a serious handicap. Among our friends were several nurses. One had even remarked that the baby had a crooked little finger. "But it'll straighten out as he grows older", she assured us. He was "functioning normally" as far as elimination was concerned and was an exceptionally good baby, for he slept all the time and never cried!

By the fourth day I had an adequate supply of milk but realized that he had never once cried since that first birth-cry announcing his arrival. Deeply concerned, we phoned the doctor. After examining Bobby thoroughly and forcing 2 oz. of fluid into the infant's small mouth, over his enlarged tongue, Dr. Rozo suggested we have our pediatrician look him over the next day, for he wasn't sure if the baby was simply jaundiced or had a more serious disorder. "It's possible that he could be slightly mongoloid, but I'm really not sure", was all the concerned doctor would say.

We were stunned. With the aid of a dictionary, the impact of what the doctor hinted at hit us with full force. <u>Our child retarded</u>? Not once during any of my pregnancies had we so much as entertained a notion that our baby might not be healthy and whole. We slept with heavy hearts that night, still hoping the doctor might be wrong in his suspicions and that all would be well in the end.

I was 40 when we decided to round out our family with one more boy. But first I asked my good obstetrician to check me over to make sure all would go well with me. He enthusiastically encouraged me with the words, "You have a very young uterus, Mrs. Morck; you could have six more healthy babies!"

"No thank you; one more is all we want", I responded just as enthusiastically. It was common in that Latin American environment to see many women pregnant in their 40's. But at that time in our lives we had not heard of the "risk factor" that we read so much about today. So we went ahead and planned for "baby brother".

And now, on Saturday morning, we awakened to the doctor's words still ringing in our ears: "It's possible that he could be..." We phoned Betty, our dear nurse friend who had been summoned to help us right after Bobby was born. She had come immediately to dress the baby and tend to my needs. Now we needed her again. We shared with her the doctor's concern and asked if she would accompany us to the pediatrician's office. This doctor didn't think the obstetrician's suspicions were valid. Betty checked into her nursing books and felt Bobby didn't have the obvious characteristics of a Down's Syndrome baby. We were greatly relieved.

But the baby wouldn't eat, never seemed hungry, wouldn't suck, and had to be fed by forcing milk on a spoon. He would eject it with his tongue and I would spend an hour trying to make him take an ounce of liquid.

By the end of the second week we realized he was very seriously ill and saw another pediatrician who insisted we force more fluids to prevent dehydration. Very gradually the child began to suck and gain strength.

Always a joyous experience for us to bring our babies to the Lord in holy baptism as early as possible, we sensed an urgency to bring wee little Robert Johan into the "household of faith" without delay. "You must be prepared to conduct an emergency baptism for him in case you see the need," my husband reminded me before he left on out-of-town travels when Bob was but a week old. I hoped this would not be necessary and when he was 3 weeks we took him to our church for baptism. That Sunday morning I prayed the Lord to heal him in body, mind and soul. I knew our children had been "loaned" to us for just a few short years. "Perhaps Bobby was loaned to us by the week, by the month, or by the year... perhaps he would suffer a lot in this world... perhaps it would be better if the Lord did take him back again real soon", I mused. But, oh, I loved him so; I didn't want to let him go!

Robert slowly improved in health, taking up to 3-1/2 oz. of formula every 3 or 4 hours by time he was 5 weeks, and smiling by 8 weeks. One day, at about 4 months, he developed a fever. The doctor checked his throat, handed us a prescription and started to leave. "Just a minute, doctor", I said. "What's wrong with this baby? He doesn't respond as the others did at this age."

"It's too early to tell yet if there's anything wrong. Don't compare him with other babies; each one is different." Disappearing down the hallway, our doctor left us with the suspicion that he knew the truth but didn't want to say it.

We were living in South America at the time. Bogotá, Colombia, had been our home for five years. My husband was on assignment with the Lutheran Church of Colombia. In two months we were due for a year's furlough and would live in St. Paul, Minnesota, where my husband was registered for graduate studies at the University. There in the Twin Cities we would learn the truth about our little "Bobolink", as we fondly called him.

The recommended pediatrician in St. Paul confirmed our fears after Robert had been hospitalized for tests. The diagnosis was mongolism and cretinism. Desiccated thyroid was prescribed. The doctor suggested we think in terms of institutionalizing our son. Noting our negative reaction, he added: "He'll never learn to read or write and the institutions nowadays are like high-class boarding schools." We weren't convinced.

No grass grew under our feet that year. We consulted with other pediatricians as well as specialists in the field of mental retardation, secretly hoping that by some miracle the child would normalize over the next few months or years. On one of the trips to the pediatrician for baby's innoculations, the doctor asked, "Have you told his sisters yet?" When we said, "No," he urged us to do so that very night lest some neighbor child come in and say, "I didn't know your baby brother was a mongoloid!" The girls knew their baby brother was not well, but we had postponed telling them the outcome of the tests until we ourselves had fully accepted them. Now we felt ready and with the urging of the doctor, prayed for wisdom to break the news to the girls. There were tears, but we were amazed at how accepting they were of such somber news. Agnes, then 15, remarked that she had suspected he might have something similar to this problem. She had read Dale Evans Rogers' book, ANGEL UNAWARE, several times and noted some similarities between Dale's baby and ours. Alice and Anita had also read the book and Anita, age 10, had asked one day as she stood looking at him in the crib, "What if he's an 'angel unaware'"?

Now it was also time to break the news to our parents, families and friends. Several confided later that they had already recognized the syndrome when they saw the baby but didn't wish to discuss it with us until <u>we</u> were ready for it. All were supportive and understanding. Many prayers went up for our baby. We also arranged for a special anointing service for healing according to the scriptural recommendation in James 5:13-18. The "how" and the "when" of his healing were left to the sovereign will of our Lord Jesus Christ.

At the University my husband heard someone speak on the subject of mental retardation. The speaker encouraged him to attend meetings of the local parents' association for the mentally retarded. We went to the very next meeting, driving on icy streets clear across the city, and found some 200 people gathered to hear a panel of teenagers discuss the subject of what it meant to have a retarded sibling. Also, a Boy Scout troop in full uniform marched in, taking seats up front to view slides of their recent camping trip. Before Bobby was born, we had had almost no contact with mentally retarded persons. Seeing so many at one time and in one place overwhelmed me and the tears flowed freely, not for myself but for them and for my baby. Many of the Scouts bore Down's Syndrome features and I pictured our Bobby among them 15 years down the road. A coffee hour followed. "Old timers" spotted the new parents present and invited us to share their table. They asked questions: Who were we; where had we come from; did we have a handicapped child. Here were people who had lived longer with their problem than we had. They were cheerful and helpful, giving us better practical advice than we got from the professionals. One couple mentioned the possibility of moving to Venezuela on a job assignment. Would we know if there were any schools for the retarded in Caracas? For us this was the first of many "healing" experiences. Laughter flowed more freely at our house after this encounter with "seasoned parents". We were not bitter because this had "happened to us". With four healthy children already in our home, perhaps it was time that we had our turn at caring for one of "God's special children". But I did hurt for my little son and for what his future might hold. Not wanting to cry on my husband's shoulder (he was carrying a full load of studies) nor heap more woes on the girls (they were trying to adjust to a new school and new friends), I spilled my tears under the sweet cover of darkness as I burned the trash each evening in the back yard. How thankful I was that outdoor incinerators were still permitted in that large city! The tension relieved, I could carry on again.

I was invited to a "Mother's Club". About 30 mothers came. The leader of the group suggested we go around the circle giving our name and telling something of our problem. She started across the room from me. There was time to listen to only six. After hearing their story I wondered what I was doing there. Compared to theirs, I had no problem at all! Each one told of serious difficulties with her child, and several added that their husbands refused to accept the fact that their child was mentally handicapped. And if they did admit it, they blamed their wives for the misfortune! I breathed a prayer of thanks to God for a supportive husband who never once insinuated that I carried the blame for Bobby's condition. Doctors called him "an accident of nature". My husband called him "our son"!

I was grateful for a positive encounter with one mother there who had had more experience than I in caring for a Down's Syndrome child in the home: "He can learn just like the other children do, but he needs more time and lots of love and patience. If he is naughty, give him a little spank when he needs it." She also said she used the reward system to teach him new words. He liked gum and would be offered a piece only after he'd sit on his mother's lap and name the objects in the room that she pointed at, repeating them after her several times, if necessary, to perfect his pronunciation.

A whole new world had opened up to us - the world of the mentally handicapped. Before Bobby we almost never saw them. Now we saw them everywhere.

We met another missionary couple home on furlough from Madagascar. They also had a handicapped child. Our Mission Board recommended that we place our children in a "home" as it would be difficult to carry out our responsibilities on the foreign field with a handicapped child to care for. Together we visited a large state institution. It seemed to be clean and with a happy atmosphere, but neither of us could conceive of our child in such a place. We were advised to contact the County Welfare Services regarding placement and discovered that only resident taxpayers were permitted to place their child in any institution - public or private. We were resident taxpayers of another country and, as a result, happy that we couldn't leave our child behind in an institution as suggested by our Board. For us, this was God's way of saying, "Take him with you; he's my answer to your prayer for a little brother".

We returned to South America convinced that the parent encounters were a good thing for mutual help and encouragement. Robert was 18 months by now. We had read everything we could lay our hands on to inform ourselves about mental retardation in general and what specifically could be done to help the individual child develop to his full potential. We learned that infant stimulation was very important, so there was no time to lose. Colombian doctors prescribed vitamins and gave him special exercises to strengthen his leg muscles. He walked without help for the first time at 3 years and 2 months, fourteen months after he had first pulled himself up to a standing position in his crib. The family was seated in the livingroom on a Sunday afternoon when Bobby suddenly stood up and walked across the floor. We all applauded. He liked the attention so walked across the room again, and again, gaining a round of applause with each length. When, after several sessions, we stopped the applauding, he sat down on the floor and clapped for himself. From then on he was steady on his feet. We had many stairs, both inside and outside the house, but I don't recall that he ever tumbled his ever tumbling down any of them. Until he walked, he spent much time in a large play pen in the kitchen where he could observe constant activity.

A friend said she had noticed a school for handicapped children in Bogotá. We went in search of it and met the directress - a charming Colombian psychologist. But her little private school for 25 children in a city of 3,000,000 could in no way meet the existing needs. She was thrilled when we offered to help get an association started for parents and other interested individuals.

Our first Board of Directors consisted mainly of professional people - doctors, psychiatrists, educators, a lawyer, a business man and a few parents. I started a Mother's Club as the "working arm" of the Association. We were 12 the first time. Each one "told her story". When we came to the last one, she paced the floor and blurted out: "My problem is <u>me</u>; I find it so hard to accept the fact that my little daughter is not a normal child." And she wept. Some of the "veteran" mothers tried to comfort her by assuring her that with time she, too, would be able to cope with the problem. That was the first time most of them had talked of their problem outside the home, "and we've been talking ever since", they told me years later.

When the group outgrew my livingroom, after about the third meeting, we were granted the use of the medical center just two blocks away. At each meeting we had more mothers looking for answers. A United States Peace Corps Volunteer offered his services. He set the wheels in motion to organize us as a society and got some classes started with volunteer help at one of the local churches. We held teas and bazaars to raise money for operating expenses. The men decided to get into the act, too, so the Association for the Mentally Retarded, which had been inactive for most of the two years since it was organized, got off to a fresh start. Our first goal was to educate the public through the media and through seminars, urging them to do something positive for the handicapped instead of pitying them and/or letting them vegetate in a back room somewhere. The doctors on the Board organized a seminar during Holy Week at the Military Hospital, inviting university students majoring in early childhood education to learn from special educators how to teach the mentally retarded. More than 100 attended the lectures. From them 3 were chosen to be the first teachers of a pilot school we intended to start within months. The director was to be a teacher from Spain with experience in special education. There would also be teacher assistants. An old school building was rented and a pilot school got off the ground with 50 pupils from every level, ages 5 to 50. This became the center for observation by university and medical students in the ensuing years. A second school for "educables" was started within months. Today, 16 years later, there are at least 30 special education schools in that city, now over 5,000,000, some of them within the public school system and others privately operated.

Robert was five when we finally got the pilot school operating under the parents' association. He attended it very briefly until we could place him in a bilingual kindergarten for "normal" Colombian children who came to learn English. A private school, it was fully equipped with fine teaching aids and educational toys. Two dedicated teachers were in charge of the class of some 30 children. Bobby went off to school each morning and didn't complain of having to stand on the crowded school bus. He had the edge on the other children for he understood English and Spanish equally well. They didn't know he had a problem and enjoyed playing with him, for a ball bounces the same in every language. However, from September to the following May, Robert didn't say one word in school. He understood his teachers and did what he was asked to do in desk work and other activities, but never talked. One day in May he spoke. They told me later that they wanted to put out the flag in his honor! His vocal forms, however, amounted to only a word here and there.

One day a psychologist friend remarked to us, "Your child won't talk until you limit him to one language." By now we were making plans for our next furlough year and had decided to spend it in Alberta where all three daughters were now studying. My husband requested a 3-year leave-of-absence in addition to the year's furlough so that Bob would have more opportunity to absorb his mother tongue. And we also wanted to spend more time together as a family.

We settled into a house just two blocks from a local grade school where Fred would be entering Grade 3. Wouldn't it be great if his little brother could start Grade One in the same school? The Guidance Counsellor who assessed Robert encouraged us to give it a try. Perhaps we were overconfident, but until now Robert had been completely accepted in every situation - in the family, in the church, among our friends and in school. His brother and sisters loved him and at no time appeared embarrassed to be identified with him.

We went to the school with our request: May Robert enter Grade One as a "special" student so he can hear English from the lips of "normal" children?

The answer was no. The teacher was alone with almost 30 pupils eager to learn what school was all about. We understood. Without a teacher aide how could she possibly give extra time to an obviously handicapped child when there might be several children with learning disabilities amongst the thirty "normal" children?

We then took the next best step and placed Bob in the only Opportunity Class offered in Camrose at that time, funded by the County but held in one of the Separate Schools. His home-room teacher was not at all receptive to the idea. She felt he belonged in the Burgess School for the Mentally Retarded. However, another teacher came to the room to teach reading and she was enthusiastic about Bob's progress and encouraged us to leave him there. We lived 1.2 miles from the school. Bussing service was provided only to those living 1.5 miles from the school, no exceptions made. I had to drive So I drove Bobby to and from school each day. Ever since he learned to walk, Bobby has had problems with his feet. He has not been able to walk more than a block or two before his feet start to hurt mercilessly. Podiatrists said his feet were atrophying and that surgery would be painful and not necessarily successful. So he has learned the painful lesson of not being able to go for long walks with his friends even though at times he seems to be able to exercise mind over matter and play a game of floor hockey with his friends, usually as goalie.

One very cold day in winter while Bobby was attending Opportunity Class, I forgot to watch the time and discovered I was a half-hour late in fetching him. When I arrived there, my little son was the only person in sight, but he was keeping warm by going up and down the slide. That was the only time in the year that Bob waited for me. Usually, I waited for him - and for some of his friends who begged a ride home. One of his Opportunity Class friends these was quite talkative and volunteered: "Bobby is our favourite; we all help him." I picked up on that statement and, rather than waiting for him out in the car, decided to see what was happening in the school room. There they were, various friends handing him his lunch box, bringing

him

him his coat, boots and mittens, and proceeding to help him into them! How would he ever learn to tie his own shoe laces with such a congenial bunch of caterers around him both before and after school? But how could I quench such a beautiful concern in his friends by asking them not to help him? This, coupled with the unwelcome attitude one of his teachers had towards him, and the need of bus service for this handicapped child, made us take a long look again at his schooling situation. Come September, then, he was enrolled at the Burgess School for the Retarded and made a happy adjustment with the 15 to 20 other pupils, ages 6 to 18, and with one of the teachers who believed more in the philosophy of keeping them happy with games and crafts than in the fact that her pupils could happily learn to read and write if given the right orientation. To compensate for this, I'd have a snack waiting for Bobby when he got off the bus at 3:15 each afternoon and then we'd sit down and read for an hour. Slow but steady progress was made as we reviewed the pre-primers and moved on into the First Grade readers.

His second year at the Burgess School brought him an enthusiastic new teacher who initiated many exciting activities. A grand Christmas program was presented to families and friends of the students. Bobby was asked to read the story of Jesus' birth as recorded in St. Luke's Gospel, but in a very simplified form worked out by his teacher. The following Christmas he read it again in a not-so-simplified version, showing definite reading progress. Our hearts swelled with pride as he carefully sounded out the words of that beautiful old story.

Those were very fulfilling years for Bobby, but now our leave of absence was terminating. He had forgotten all the Spanish he knew four years earlier and was now talking in English phrases. He was 10-1/2 when we again returned to the bilingual situation in Colombia. With this move came a slight name change. Up to this point he had been nicknamed Bobby or Bob. But he had both an uncle Bob and a cousin Bob, a fact that sometimes caused confusion as to whom we were referring. Also, "Robby" sounded better in Spanish than did "Bobby", so we posed the question and let our son decide. "I want to be called Robert", he said ("Roberto" in Spanish). We honored his wish. Of course, the diminutives inevitably followed, but he didn't object to being called either Rob or Robby.

We arrived in Bogotá in July. His brother was ready to go into Grade 7 at a large English-language private school in that city. There were 4 kindergarten units and at least that many first-grade units. Again we thought: "It would be good if Rob could go to the same school as his brother".

We knew of at least 5 English-language families in the city with mentally handicapped children, so we approached the head of the kindergarten department at the American "Nueva Granada School" to inquire whether she would be willing to take the two smaller children into the regular kindergarten classrooms. She responded enthusiastically because she had worked in a situation of that kind in the United States. But she could convince neither the Director of the school nor the 4 kindergarten teachers that this was a workable scheme. "We have enough problems in this school without deliberately taking on more", was the official answer we got. We then asked if they would start a special classroom for all five slow-learners. Again the answer was "<u>no</u>". "This is a school for academically advanced students", they reminded us.

So we went to "The English School". The headmistress admitted the two six-year-olds. The mother of a 9-year-old Down's Syndrome boy chose to tutor him herself. We set up a classroom for Rob and a 7-year-old girl in our home and obtained a university student to tutor them. Both Rob and Joan made good progress during the months she was with us. Joan then returned to the United States with her family, and our tutor returned to her university studies. Before setting up the class in our home, however, we did approach the Sherwood School where Rob had taken his kindergarten but now the headmistress felt that it would be more difficult to fit him into a regular classroom situation because of his size.

The following five years found Rob in a series of Spanish-speaking schools for the handicapped, on a part-time basis, to encourage his social development, while I tutored him in English for an hour or two a day, armed with good resource material from both the United States and Canada.

We also availed ourselves of good educational games, Scrabble being our favorite. It taught Robert to spell as well as to add, as he learned to keep score. He still enjoys an occasional game of Scrabble and often wins.

Never having been physically robust, Rob has nevertheless seldom missed school because of illness. A congenital heart condition showed up at age 10 and this has curtailed his participation in sports. In spite of his feet hurting, he enjoyed playing soccer, badminton and basketball in our back yard with Fred and his friends. However, his heart went into failure, at age 13, and all manner of exercise was prohibited, even a walk to the neighborhood grocery. When he had a cardiac catherization at age 11 to determine the true nature of his problem, the cardiologist termed his condition inoperable and said that the prognosis allowed him 3 to 5 years. No medication was given until his heart went into "failure" two years later. He was put on digitalis and a diuretic and checked regularly to see if any improvement would occur. Cardiograms showed considerable improvement and he was permitted to participate in limited exercise and sports to a point that he himself could determine and tolerate.

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Since a 3-month furlough in Canada was coming up for us during the summer of 1976 and we hadn't seen the cardiologist for over a year, I made an appointment with him and told him I'd need another prognosis. Rob had outlived the first one prognosis by several years. We were now seeing the head doctor of the heart clinic, a kind, elderly heart specialist. When I showed surprise at his suggestion that Rob could live many more years with the modern medicines at his disposal, Dr. Fernández teased: "Mrs. Morck, haven't you lived long enough to observe that many doctors die before their patients do?"

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Thanking him for his encouragement, I mentioned that we'd soon be going to Canada for three months. To this he responded that we would be wise not to bring Rob back to Bogotá because of several stress factors there which were a deterrant to better health for him. These included he pointed out, the almost 9,000 feet altitude, the high pollution rate in the city, the coping with two languages and the fact that he missed his sisters and brother.

Fred, who had left for Canada a year earlier, had not only been a good brother and best friend to Rob, but he had always been his "special guardian". One day when Fred was just 2-1/2, Rob moved like lightening in his walker, heading for the open doorway. The girls had left the door ajar in their haste to leave for school that morning. Fred ran for the door, slamming it shut just in time to save Bob from tumbling down the stairs. He stood with his back to the door and looking at his little brother said, "No, Bobby, no!"

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Some years later, here in Camrose, Fred, then 9, asked to take Bob to a Saturday matinee. I feared he'd be a handful for him because Bob didn't like loud noises and even a rollicking Santa Claus frightened him. "What would you do with him if the MGM roaring lion comes on the screen?" I asked.

"Oh Mom, I can handle him better than you can", he replied.

[illegible] Bobby [illegible] a movie

~~So I agreed to let the two of them go.~~ When I asked Fred how things went for them, he said, "Fine, except at the intermission when the lights came on. One of the kids turned around and pointing at Bob said, 'Hey, look at that monkey!' I wanted to get up and punch him but if I did that I knew the manager would make me leave, and I wanted to see the rest of the movie, so I kept quiet."

A year or so later Fred was walking alone down the street and some boys rode by on their bikes. "Hey, there goes that retarded kid", one of them called to the others.

"They couldn't tell the difference between Bob and me", laughed Fred as he told us about it later.

About the time Fred was 20 and well into his post-high school studies, we were discussing Rob's limitations one day. "He isn't exactly the brother we had hoped you'd have," I commented. "Don't say that, Mother," responded Fred; "he's the answer to your prayer and he's been a good brother to me."

Fred and his sisters have all had a part in Rob's upbringing. They taught him to hold his silverware properly and feed himself in an acceptable manner, held his hand as he tried so hard to walk, gave him the cuddling and loving that I didn't always have time to give, and even loved him from a distance when they left home to continue their studies in Canada. Nursemaids were employed from time to time as needed. A variety of visitors came and went. So Rob had many "resource people" around to help shape his life. It seemed we never had to invite for his birthday for there were always extra people at our table. When his birthday actually fell on February 29th, friends would phone to ask if they could come to the party. Even now his birthday is Rob's most exciting day of the year.

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We tried not to burden his siblings with too many "Bobby-sitting" responsibilities. This was not a problem in South America where servants were needed and still a financial possibility. But in Canada he had built-in sitters as long as his sisters were still studying in Camrose. As the boys grew older and the girls left home, it was his brother who took over the job of "sitting". This naturally cut into his plans for the day or evening - unless he intended to study at home. We know that Fred often gave up his own plans in order not to leave Rob home alone when the boys were in their late teens, or he would include Rob in his plans to spend the evening with friends. Happily, Rob is now able and content to stay alone, sometimes many hours in a stretch, rather than accompany us to a function he's not at all interested in. He takes telephone messages for us and knows that he's to call a sibling or a neighbor if he runs into any problem. He doesn't sleep alone in the house all night, however. We believe fire or sudden illness could cause him to panic, thus bringing harm to himself.

When we took the cardiologist's advice in 1976 to have Rob stay in Canada, it was decided that we would establish our residence in Camrose where Rob had earlier spent 4 happy years. His sisters were all married now and two were living here. His brother had come up a year earlier and was studying also in Camrose. Rob returned to the Burgess School and had the same teacher he had had 6 years earlier! He was elated, and so were we. We had high esteem for those "angels sent from heaven" who so patiently worked and played with the mentally handicapped, not only at that little school, but often in their free time as well.

In the fall of 1977 his teacher said that Rob had begged her one day: "Mrs. Omoth, please help me grow up! I want to be a scientist but I have to grow up first. Oh, please help me grow up!"

In March the following year Rob said to his Mom: "I've been thinking".

"Yes? What have you been thinking?", I asked.

"I want to be a mechanic."

"Great! Why don't you talk to your shop teacher about it," I suggested.

The next day the boys had shop at the school. Rob came home and said, "I changed my mind".

"What did you change your mind about?", I queried.

"I'm not going to be a mechanic".

"Oh? Why not?"

"Because the teacher said it's too hard."

After those two years of "growing pains" at the Burgess School and Rob had turned 18, he became eligible for full-time work experience at the Horizons Unlimited in nearby Wetaskiwin where he and other handicapped were bussed from Camrose each day. Rob enjoyed the daily rides and the people he mingled with. But at one point after having sanded furniture by hand for several days, he blurted out: "I'm tired of going to the workshop in Wetaskiwin. Why did you send me there, huh?"

"Why, all the kids who finish Burgess School go there, don't they?" I suggested.

"No, they don't", he shot back.

"Who doesn't?", I questioned. He named a friend who had recently quit simply because he didn't feel like going. And, of course, we both knew that there were others who had gone off to centers of training in other parts of the province.

Rob has now transferred to the newly-opened Centra Cam Workshop here in Camrose. He still gets bored with sanding but is bright-eyed and cheerful when he can come home from work and announce, "I painted today", or "I mended some books today". used the jigsaw today There have even been times when he is enthusiastic about the sanding he does, especially if he's been commended for a job well done. Those are the days when he seems to feel it's all worthwhile.

Robert learned to print the alphabet at age 6. At age 16 he learned cursive writing and, though ambidextrous, writes exclusively with his left hand. He draws quite well and has made many special-occasion cards for family members, showing good taste when coloring them, as well as including his own personalized greeting. Arithmetic has been difficult for him and he is still unable to understand the value of money even though he usually gives the correct change up to a dollar when selling snacks at the workshop canteen, using the "plus system".

Besides watching sports on television, Rob spends much of his free time poring over books and working hidden-word puzzles. Perhaps his favorite reading material is the Bible. Some years ago he purchased Kenneth Taylor's THE CHILDREN'S BIBLE and read it from cover to cover between May and November. Friends recently gave him a copy of the New International Version and he is now halfway through it. (Comprehension is best in the narrative material.) delete

Our family has had the custom of reading together a portion of Scripture each day, followed by spontaneous prayers, and as each child learned to read, he would "take his turn" in this little devotional time. When Rob asked if he could also take a turn, we readily agreed and encouraged him to "sound out the words". He became proficient at pronouncing even the longest of names, like Nebuchadnezzar. Bedtime stories were also a part of our family life and this may have created the appetite for reading that all our children have.

In thinking over the past 21 years, we all agree that Robert has been a real asset in our home, enriching our lives in unique ways. One of his sisters recently commented, "He's added an extra dimension of love to my life." # He was only about 4 when he kissed my hand just after it had spanked him for some misdeed. I was ashamed at my impatience with him for he has always been sensitive and thoughtful even though at times he could be destructive and get into all kinds of mischief. Like the rest of us, he was born with a selfish and stubborn nature that needs to be replaced by a positive and unselfish attitude. He also tends to be lazy, especially when it's time to do the dishes, dust the furniture or take a bath. When reminded too often, he becomes irritated. But he is able to say, "I'm sorry", and looks for our approval with a hug or a kiss. He is a meticulous dish washer and just as meticulous when he dusts the furniture, very carefully removing nic-nacs and objects before dusting under them, and just as carefully returning them to their place. His Daddy likes to tell this one about Rob's thoughtfulness:

> (my wife) Hildur had been gone for a month, having taken Alice and Anita to Canada for high school. When it was time to leave for the airport to pick her up we looked all over for Rob and finally found him in the back yard, picking flowers. Busy with the day's work, I had not even thought of buying a welcome-home orchid for my wife, let alone suggest to Rob that he might pick some flowers for his mother. When she had cleared customs and stepped into the lobby, Rob, now 5 years old, handed her his neat little bouquet and beamed: "For you, Mommy!"

Eating out is a pleasurable experience for Rob. He likes reading the menus to pick whatever his appetite demands and then placing his order. He has many favorite foods and eats with dexterity, using both his knife and fork as the Europeans generally do. We think he may have figured this system out over the years as being the neatest way to get the food to his mouth from his plate. Now that he is earning his own spending money, he often invites the family out to dinner. His generosity delights us!

Robert also provides us with many laughs. Shortly before his 20th birthday, he said to his Mother: "Soon I'll be 20, and then I'll be a man! I feel so good!"

"Oh, what does it feel like to be a man?", I questioned. Rob thought a moment and replied: "Comfortable".

On the way to church recently, his Mom was applying lotion to her hands. Rob sniffed the air and said, "I smell lotion". His Dad quipped, "You smell the ocean?" Quick as a flash Rob spelled back: "No! l-o-t-i-o-n, lotion!"

The best home for Rob, we feel, is with his family where he has the understanding and loving support of parents, siblings, friends and relatives. What better advocates could he have than those who have known and loved him since he was born? When the Alberta government required legal guardianship for dependent adults, we applied for and were granted his guardianship while his brother happily became his alternate guardian.

We are fortunate in Camrose to have a small but active association for the mentally handicapped that has supported recreation programs for both children and adults. Members of the Association, teachers and former teachers of the handicapped, as well as friends in the community, have over the years organized and supervised indoor and outdoor sports and games, bowling, special interest events and field trips. More recently adult education classes have been offered to those who would like to improve their academic skills. Although the recreation programming exclusively for the handicapped is frowned on by some of those advocating integration, Robert is happy to interact with his peers who have many of the same strengths and weaknesses as he has. He also counts among his dearest friends those dedicated and cheerful people who direct the recreation programs and thus add a bit of sparkle to the lives of the handicapped.

Church membership has also provided Rob with a warm environment in which to develop. He won't miss church services if he can help it and participates joyfully in the liturgy and singing of hymns. He is able to follow the bulletin to locate the prayers and hymns without our help. He began receiving holy communion at age 13 and more recently asked if he could be an usher in our large church here. He feels needed while serving in this way. He was especially pleased when one of the pastors asked him to help distribute the bread at holy communion. Observing him move from person to person with the communion wafers and saying to each one, "the Body of Christ", as he places a wafer in each cupped hand, we realize that here Rob is neither lesser nor greater than the others who serve us with the Sacrament. Rob feels secure and happy in his church and feels loved by the people. They accept him as he is and he accepts them as they are. In this fellowship he has found a source of belonging and self-worth.

As we consider Rob's future, and that of his peers, the question, "What About me, Mom?", continues to demand an answer. Their very limited capabilities, both mental and physical, severely restrict their scope of possibilities for challenging jobs in today's work force. But perhaps society has pressed us into believing the false notion that one can only be fulfilled in life if he is intelligent, highly trained in a skill, and has a glowing personality. What is it to "succeed" in life? Is it not to be faithful in the little things that daily add up to a life-time of living? Did not He who gave His life for all of mankind teach us, through His example, to be servants of one another and to faithfully use the talents He has given each of us? Did He not also say: "Well done, good and faithful servant; you have been faithful over a little, I will set you over much; enter into the joy of your master"? (Matthew 25:23)

Is not <u>this</u> the answer to Rob's question, "What about me, Mom?"