THE RIGHT TO BELONG

The Story of Yvonne

by Irma Penner, Fredericton, New Brunswick, Canada, 1997

Dedication

To Yvonne
You speak with your eyes.
You smile from your heart.
You have taught me much—
and enriched my life.

Lovingly,
Mom

Acknowledgements

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Nina Murray and Venessa Fox merit special recognition. Their friendship and dedication to Yvonne, and steadfast, daily support enabled me to write.

My husband Peter supported me consistently; I am indebted to him for making this book possible.

Most of all I thank Yvonne who influenced our lives and whose story, we believe, deserves to be told.

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Author's Note

"Yvonne belongs with us!" we firmly told the psychiatrist when he insisted that we place our two-year-old daughter in an institution. To us, Yvonne's sudden regression meant that she needed us more than ever. We could not abandon her; we could not reject her.

At first we struggled on our own, there were no community supports. Then, together with other parents, we advocated for appropriate supports in the community for children who were labelled "severely mentally handicapped."

We believed that Yvonne, and children like her, had a right to live at home, had a right to go to school, and had a right to participate in the life of the community. Our vision was shared and supported by some service providers and professionals, but others opposed our views and worked against us.

Yvonne's story describes both the painful experiences and the joy that she, and we as her parents, encountered as we strove for her right to belong.

Forward

Irma Penner, Yvonne's mom, kept notes! When the doctors called her daughter "retarded," she kept notes. When the Developmental Specialist wouldn't label Yvonne "autistic," Irma kept notes. When the teachers at the School for the Handicapped refused to acknowledge a mother's wisdom and knowledge of her own child, that mother kept notes... When Irma and her husband worked with other parents to get what they needed, Irma kept notes. For over 20 years, Irma Penner has kept notes about her daughter's life. She kept notes about the struggles of family and friends to help Yvonne live a good life, a life where Yvonne belongs among us, with us, alongside of us.

Irma Penner untied the string around all the boxes of all the notes. She has woven them together to tell us Yvonne's story. This is a powerful story. It is one that will benefit families, professionals, and ordinary citizens.

Yvonne's story calls on all of us, as members of communities, to welcome people with disabilities into our lives as friends, neighbours, pew-mates, classmates, and members of our families.

Yvonne's story calls on professionals to reflect about how they are with families and people with disabilities. There are tales of professionals who only want to label and exclude. There are tales of professionals who listen and stand beside families. If professionals want to know what their words and acts do to families and vulnerable people, they should read The Right To Belong. If they want to know how they can be helpful, they should read The Right To Belong. This book will help doctors and social workers, teachers, civil servants, and politicians understand what it is like to sit on the other side of the table.

Yvonne's story is also the story of her parents work with and on behalf of other families. It is about respecting families and starting where they are, not where others think they should be. It is about walking with families, challenging them, and being challenged by them. The Penners have been active advocates and supporters of families in Atlantic Canada for three decades. They have made a difference. We can all learn from them.

Yvonne's story is also about the difference that family and friends can make. Throughout Yvonne's life there are powerful instances of where both the little as well as the big acts of family and friends have made a difference. Some times, the act was one of exclusion that, beyond the hurt, strengthened the resolve of a family. Some times, the act was a thoughtful suggestion that proved the first step along a different and positive path. Some times, the act was years of support and common struggle. From Irma's notes, we begin to get a better idea of what each of us can do to be helpful. We gain insight into the little (and big) things we do which are hurtful.

Each of us has in our lives someone with a disability. That someone may be a family member never mentioned, or a school chum of our daughter's. That someone might be a neighbour's child, the one who needs someone to go trick-or-treating with. That someone might be a sister who needs a friend. Yvonne's story can help us find that person who is already in our lives.

Yvonne's story is also about how people come together in common cause. Throughout her life, Yvonne and her parents have joined in common cause with many kinds of people—Associations for Community Living, the Mennonite Central Committee, other parents who meet in church basements and over kitchen tables....Yvonne's story is about getting organized. We can all learn how to better use our own organizations to build community, and how to bring folks of like-mind and heart together to work for social change.

The Right To Belong is worth reading. It is filled with the details of life for a family. And from the details come powerful lessons and patterns. The Right To Belong The Story of Yvonne is a powerful testament to why we should all keep good notes, bear witness, hang in, stand together, and get organized.

Bruce Kappel
Kappel Consulting
Don Mills, Ontario

Chapter 1

Retardation... Autism...

“You should see Yvonne!” Exuberant with laughter, my sister-in-law Hertha pointed toward the living room and raced upstairs to get her camera. I grabbed a tea towel to soak up the suds that were running down my arms, pushed aside a kitchen chair, and made my way down the hallway to the living room.

Yvonne was standing at the walnut end table, her back toward me. I saw nothing unusual. Then, carefully balancing herself with her left hand, she turned toward me. She was black! From her face down to her pale green overalls. I looked in disbelief as she raised her right hand to her mouth and continued to eat the moist black soil that remained in the flowerpot. The bulk of the soil was heaped on the carpet with the plant lying listlessly at her feet. She looked so innocent.

My initial reaction was to scold her, but her actions were so comical. I couldn’t help myself and broke into laughter. That was August 1972; Yvonne was sixteen months old.

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Months and years later, I would recall this incident time after time and wish if only Yvonne would dig in a flowerpot again! Not only did Yvonne ignore all flowerpots, she ignored her toys and, most painful of all, she ignored us. Worse yet, she rejected us. She screamed when held or hugged. She did not want to be touched. Dressing became an ordeal. Bath time became torture.

Yvonne wanted to escape us. She crawled up the stairs each time we brought her down. Swiftly and skillfully she reached the top of the hardwood steps and turned left toward her bedroom. She raised herself using the lowered bars on the crib and cried until someone lifted her into bed. Although Yvonne was nearing seventeen months she refused to walk on her own and would not attempt to climb.

She whimpered in the safety of her crib. Her motions were quick and methodical. She sat against the footboard, leaned forward and grabbed her yellow blanket. Holding it next to her chest, she searched for the five-inch satin binding that had come loose. She held this in her left hand, positioning it in such a way as to form a “funnel” for her right index finger. While stirring rapidly in this funnel, she leaned forward and let her head crash back against the footboard. Again and again and again.

It broke my heart. What happened? Why?

Well-meaning friends assured us that Yvonne would grow out of this phase. Others supported our efforts to get medical help. Lorraine, a neighbour who worked at the Dr. Charles A. Janeway Child Health Centre in St. John's, Newfoundland, kindly suggested, "I can see that you're really worried so for your own peace of mind, why not take her to Dr. Hobeika at the Janeway?"

Because our family doctor was on vacation, I took Yvonne to Emergency and asked for Dr. Hobeika. The receptionist told me I needed a referral from the family doctor and that Dr. Hobeika was booked for the next two months. I explained my concern about Yvonne's sudden change in behaviour and her constant crying; I knew something was drastically wrong.

"Very well, I'll ask a doctor to look at her," the receptionist replied, and asked for information for their medical file.

The intern on duty wanted a urine sample. Attaching a plastic bag onto a squirming and screaming child was quite a task. The sample leaked out into the diaper. They tried again. This time they positioned the adhesive better.

Next, the doctor talked about a blood test. I felt my body become weak. I became weaker when they expected me to help them in comforting Yvonne while they drew blood! Three white-uniformed nurses held Yvonne down and I found myself leaning over the table pinning down her right arm, looking into her screaming face and saying, in a hushed voice, "They're soon finished, sweetheart, they're soon finished." Finally I heard a nurse say, "That's it."

Feeling faint, I whispered, "Watch her." I had earlier spotted a chair. Could I get to it in time? I opened my eyes. My head was resting on my knees. I raised my head enough to see a white skirt and hear a voice say, "Are you all right?" With that, everything went black again.

I have no recollection of getting back into the waiting room, but here I was with Yvonne asleep in my arms. Other children were crying, but Yvonne was sleeping. Was this real? A white figure standing at my right side interrupted my thoughts. "There is nothing wrong with her."

I shook my head and looked up into the intern's face. "I beg your pardon?"

He repeated what I thought he said the first time. "All tests are negative. There is nothing wrong with her." He left, and I sat there in disbelief. Nothing wrong with her!

I have no idea how long I sat there, or how I managed to drive our 1964 Dodge across town to the west end where we lived. However, I do remember placing Yvonne safely in her crib, and then sitting on the foot of our bed crying my heart out, "She must have a tumor, she must have a brain tumor!"

When Peter came home from work, he tried to console me. "The doctor didn't say that," he reminded me, "and no evidence suggests it. But we will keep looking for medical help." Peter was always able to analyze things rationally, probably because of his scientific training. Talking to him about my fears always helped and gave me strength.

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Yvonne was one of the first patients to see our family physician when he returned from vacation. Waiting in the examining room I placed Yvonne on the table and supported her with my hands around her waist. She raised her right hand to eye level and was looking at the back of her hand and then her palm, twisting it back and forth. She started this activity several weeks earlier. It bothered me. I had seen babies, including our first daughter, twist their hands in front of their eyes in playful discovery. Was Yvonne now rediscovering her hands?

The doctor walked in with his usual cheerful greeting. "Hi! How are you?"

Despite my concern, I found myself relaxing. His friendly and caring personality, and casual appearance in dress pants and rolled-up shirt sleeves, always put me at ease. He wore a stethoscope, the only visible indicator that he was a doctor. He stood still. His expression became serious as he looked at Yvonne whimpering and twisting her hand. He walked over to her and spoke gently. Then, directing questions to me, he asked, "Have you had a sudden change in your family situation, maybe a death in the family?"

"No," I replied, "there has been no change, but we've had a lot of company."

"Have you?" he asked thoughtfully, then quickly remarked, "Yet that shouldn't really do it." Then speaking softly, more to himself, he mused, "Let me see." He turned toward Yvonne, waved, and clapped his hands. Yvonne did not respond. He seemed puzzled. Very quietly, as though he was still speaking to himself, he said, "It's strange. It's as though she's retarded."

"Retarded!" This word hit me like a ton of bricks! Deep down, I was already telling myself that Yvonne was acting as though she were retarded, but to have a doctor confirm my worst fears was almost more than I could handle. My body temperature plummeted; my hands turned cold and clammy. I sat down. Time stood still. I was there, and yet it seemed like I wasn't. I don't know how long I sat there or what else he said. Nevertheless, I remember the doctor patiently holding a piece of paper, an appointment to see a pediatrician.

Leaving with Yvonne in my arms, I turned back and noticed the doctor looking at us. He was shaking his head, looking concerned and puzzled. Quickly though, he raised his hand and waved, forcing a smile. We both knew, however, that we had reason for concern.

That was September 1972. The following five months were most difficult times for our family. Besides dealing with Yvonne's constant head-banging and crying, we made endless trips to the Janeway in the east end of town to see the child development specialist, the hearing specialist and the neurologist. Yvonne had more blood tests, urine tests, an EEG (electroencephalogram) and X rays.

The morning I carried Yvonne into the white two-storied building to meet the child development specialist I was nervous but hopeful. Surely she would tell me what happened and prescribe a "fix." How naive I was!

After the usual procedure of giving the case history to the receptionist, I glanced around the waiting room, stepped over the Fisher-Price toys scattered on the floor, and made my way to an empty chair. Yvonne was not happy. The waiting seemed endless. Finally the receptionist announced, "Yvonne Penner." I jumped up with Yvonne in my arms and anxiously hurried in.

The child development specialist smiled and seemed friendly, but her manner was crisp and businesslike. I don't know what I expected from the specialist, but she surprised me when she did a complete medical on Yvonne. Our family doctor had already examined her.

This doctor knocked Yvonne's knees with a rubber hammer to check her reflexes; Yvonne cried. When she checked Yvonne's ears, Yvonne stiffened her body, cried and tossed her head from side to side. The doctor persisted. She pulled on Yvonne's right ear to stick the instrument into it. I tried to help by holding Yvonne's head, but she fought us both. I felt sorry for her and gave the specialist a pleading look. “Can’t you stop already?” Yvonne could take it no longer. She screamed. The examination ended.

After the medical, the child development specialist did an assortment of observations using the Denver Developmental Screening Test. Yvonne was to prove whether she could use a pincer grasp to pick up a raisin or a Rice Krispies, whether she could hold a block in each hand and bang them together, and whether she would search for the red dinky car hidden under a pillow. Yvonne did not care. She didn’t want to be here; she was so unhappy.

The specialist wrote down her observations and explained what level Yvonne was at in the various areas of gross motor skills, language, fine motor-adaptive and personal-social development. Then she got up from behind her desk and said, “I would like to speak to Dr. Brown. I’ll be right back.”

“Okay,” I replied, and waited.

After awhile Dr. Brown walked in alone and sat behind the desk. Her white hair suggested many years of experience. She looked friendly and compassionate. I watched her fold her hands and place them gently on the desk in front of her.

“We have,” she began quietly, and hesitated. “We have looked at,” she hesitated again. I told myself to be patient, perhaps she had a speech impediment.

She surprised me when she spoke in a continuous sentence. “What?” I exploded, as her words sank in.

Firmly but kindly she repeated, “We’ve looked at the results and she is perhaps more severely retarded than you might think.” Her words cut deep. Tears trickled down my cheeks. I was prepared to accept that Yvonne might be mildly retarded but not severely! My heart cried, “No! No, it can’t be!” I looked down at Yvonne on my lap but turned my head away. I didn’t want her to see my tears.

The specialist meanwhile set up another appointment. I drove home in a daze, telling myself over and over, “Next time I want Peter to take time off work and come with us.”

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Peter, Yvonne and I sat in the same office where I had heard those fateful words just a few weeks earlier. The child development specialist asked about my pregnancy, the birth and the first year of Yvonne’s development. Everything had been normal! Until sixteen months we had no indication that anything was wrong.

Granted, Yvonne cried a lot and she was not talking nor walking. However, Dr. Benjamin Spock in his book, Baby and Child Care, reassured us this was not "abnormal." We also had enough people tell us stories of late developers who turned out "perfectly normal." Therefore we were not concerned.

What did concern us was that our daughter stopped responding to us and stopped playing with her toys. At eleven months she could put the four largest pieces of the twelve nesting blocks into each other; now she would not, or could not. We explained this to the child development specialist and gave her other examples.

The specialist shook her head and stiffly stated, "Yvonne is too retarded to have ever done what you claim." Peter and I looked at each other in absolute disbelief.

Still shaken and thankful that Peter was with me, I finally found my voice. "Why?" I questioned. "Why would we say something that wasn't true? We would only be fooling ourselves."

Calmly and flatly, the child development specialist stated, "When a child reaches a certain age and parents see that the child is not developing as other children at that age, they realize something is wrong and then they come to us." With this statement, we knew we had a rocky road ahead of us. Just how rocky we had no way of knowing—fortunately.

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During this time we were in the middle of a major move. After six years of marriage we bought our first house in St. John's. We had lived in apartments in Kingston, Ottawa, Philadelphia and in a townhouse in St. John's. On November 30, 1972, when Teresa was five years old and Yvonne nineteen months, we moved to our home on Torbay Road.

Packing and moving added stress, but the excitement of being able to live in a home where we could carpet and paint rooms whatever colour we wanted helped keep my mind off the constant worry of what was happening to Yvonne. Without this diversion, I don't know how I could have survived.

Friends called often and offered to come with us to the doctor's appointment and "testify" about Yvonne's earlier development. We were glad for the support of caring friends but somehow we knew this was not enough to sway the doctor's firm opinion. After all, how much consideration had the child development specialist given to our family physician's report on Yvonne's change in behaviour? We knew there had to be another answer.

One day Bob, a friend who moved to St. John's when we did, very cautiously asked, "Do you think Yvonne could be autistic?"

"Autistic? What's that?" Peter and I asked in unison.

Bob explained, "An autistic child becomes withdrawn and doesn't want to make eye contact. The child seems deaf and engages in head-banging. Generally the child behaves very differently from the earlier 'normal' development." We listened in silence. Everything he was saying seemed to fit. "Now," Bob cautioned, "I'm not saying that's what Yvonne has, but if you're interested I can lend you my psychology book. There's a chapter on autism."

A few days later we pored over this chapter. I couldn't believe the description. It fit! Peter agreed, "Much of it fits, but she does not demand sameness nor display 'an island of intelligence' as the book suggests."

I argued with him, "She does demand sameness." I gave him several examples and then blurted out, "I think she is so upset because the fridge is in the middle of the kitchen floor." We were renovating our kitchen and moved the fridge out of its place. "As for her island of intelligence," I continued, "give her a chance. She is less than two years old."

We then went to the library and signed out everything with the word "autistic" and "autism." There wasn't much. We discovered that autism had no known cause and it was a more severe disorder than "retardation." We learned about the Society for Autism in England, and also got addresses of researchers in Australia and the United States. I wrote fifteen letters of inquiry.

We approached our third appointment with the child development specialist with renewed hope. Having found an explanation for Yvonne's change in behaviour, we wanted to look at ways to help her. The specialist, I thought, would be pleased with the homework we did.

"Do you think Yvonne could be autistic?" I asked.

"No!" she replied sharply.

My head jolted back. I was not prepared for her reaction. "Why not?" I asked. She didn't answer. Peter and I then told her about the books we read and it soon became clear that we knew more about the topic than she did. “Would you like to see the book Autistic Children by Lorna Wing?” I asked.

“Yes, I would like to have a look at it,” she said politely. This surprised us, but we were pleased. We pointed out that early in her book, Lorna Wing stated, “The only way to make a positive diagnosis is for the doctor to ask about the child’s behaviour, in minute detail, from birth up to the time of examination, because the decision depends upon the presence or absence of a special pattern of behaviour.”

We received another appointment and left her office. At home, a large manila envelope fell to my feet when I opened the white screen door. It was postmarked USA. More information on autism. I scanned the articles. WHAT? An article claimed it was the parents’ fault that children were autistic!

This couldn’t possibly be true in our case. I had searched my mind hundreds of times and questioned, “Did we do something wrong? What was it?” I couldn’t find anything. Still, with a researcher blaming the parents, the feelings of doubt and guilt came over me again.

Those feelings, however, were countered by my thoughts that Teresa was not autistic. When Teresa was an infant, we had lived in a small crowded apartment in Ottawa where she had little opportunity to develop her crawling skills. She also had little interaction with other babies or children. I had less time for her because I was typing Peter’s Ph.D. thesis.

With our second child, however, we had more physical space and I had more time! Still I agonized, what if we did something wrong? My mind went back again to our apartment on Algon Avenue in Philadelphia, the day Yvonne was born.

Chapter 2

Looking Back

Peter was lying on his stomach, his elbows pressed deep into the mattress, his chin resting in his hands with the pillow bunched snugly under his chest, totally engrossed in his Time magazine.

I was lying on my back beside him, my hands gently resting on my swollen abdomen. “I guess I better call the doctor,” I said quietly. My pregnancy was in its final stage. I was two weeks overdue, yet strangely, I wanted to hang onto and protect this child within me. At the same time, however, I wanted so much to see and hold *her*.

My mind reflected on the previous nine-and-a-half months. They were good, despite the severe nausea and indigestion during the first and last trimester. I felt so proud to be carrying our second child! I gained only twenty-four pounds but, because my usual weight was a hundred, the extra pounds were outstanding. Friends chided, “Are you sure you’re not due in February?” They knew full well I was due on April 5.

I shook myself back to the present. Peter tossed the magazine over his shoulder onto the floor and sat upright in bed. We were so happy!

My contractions came every three to five minutes; still, I was in no hurry to get to the hospital. Then, near midnight, Peter called our friends John and Judy. For the past few weeks they had a cot made up for Teresa. She was well prepared ahead of time, and accepted the rude awakening and transfer during the night.

We arrived at the Jeanne’s Hospital in northeast Philadelphia about 1:00 a.m. Back then, husbands weren’t allowed in the delivery room. “There is no point in staying around here,” the doctor told Peter. “It’ll take awhile. We’ll call you when the time gets closer.”

Peter was home less than an hour when the doctor called. “You’ve got a baby girl, born at 2:45.” He apologized for sending him home. “We hadn’t expected such a quick birth.”

Yvonne Annette Penner. Sensing that this baby would be a girl, we had chosen the name months earlier; yet Yvonne looked so much like her sister I found myself calling her “Teresa.” This time I could enjoy our baby. I shared a room with a young mother close to my age. Memories of Teresa’s birth in Kingston, Ontario, were still fresh in my mind when I was on a ward with three other mothers, but only I got a baby at feeding time. Two infants were premature and one had died. They should never have put me in that room. It was heartbreaking for the other mothers, and I was unable to fully enjoy our firstborn in that situation.

Yvonne was a healthy seven pounds, nine ounces, born Tuesday, April 20, 1971. I could hardly wait to take her home. The truth was, I really missed Teresa. I had never been away from her before.

Friday finally arrived. I dressed Yvonne and bundled her in a white lace blanket. The nurse carried Yvonne. We walked down the hall and met Peter and Teresa at the nurses' station. Holding Yvonne firmly during the elevator trip to the ground floor, the nurse told Peter, "I'll wait till you bring the car around."

After I sat, the nurse placed Yvonne in my arms. Teresa stood in the back of the car looking over the front seat. I lifted the blanket from Yvonne's face; Teresa was thrilled to see her baby sister!

It was good to be home. Peter cooked and did the laundry Friday and Saturday so I could get my rest and tend to Yvonne. Sunday I felt well enough to attend the small Mennonite church in Germantown. Everyone marvelled over Yvonne. "Only five days, she looks much older!"

I didn't look forward to Tuesday because Peter would be leaving again for job interviews, this time at the University of Toronto and Brock University in St. Catharines, Ontario. He had postponed these interviews, scheduled for the first of April, until the baby arrived.

Peter completed three years of research on a postdoctoral fellowship at the Institute for Cancer Research and hoped to get a job in Canada. The institute meanwhile, asked him to stay another year and applied for an extension to his visa. The United States government, however, didn't grant extensions as easily as before; we couldn't count on it.

Late Monday afternoon, Peter called from work. "I just had a call from the federal office. The papers for a one-year extension arrived."

"Just in time!" I exclaimed. "Our visa expires in three days."

"I have to drive downtown to get them," Peter continued. "If I don't have them they won't let me back into the States. Why don't you come along for the drive?" During this thirty-nine kilometer trip we noticed that Yvonne, at six days, enjoyed the movement of the car. However, each time we stopped for a red light or for traffic she screamed.

Later in the week, while Peter was gone, I took Yvonne for carriage rides in the warm weather and noticed the same pattern. Any break in movement she started to scream. When we came to a gravelled path, I wondered how she would react. Yvonne was quiet. What's more, she soon fell asleep! After this experience, Yvonne was not satisfied with a smooth ride. I had to bounce and rock the carriage as I pushed it along.

I felt proud of myself managing on my own with a four-year-old and a new baby. I gained confidence because I had the support of friends. Earlier, Vic and Becky insisted that I move in with them while Peter was away. Knowing it would be disruptive for everyone, I wanted to try it on my own; but if I had problems I would call them. I was at ease knowing the option was still there. I also had support from Judy and Irene who stopped in daily with their children.

I was glad when Peter arrived home. Then two weeks later, he travelled to St. John's, Newfoundland, for another interview. He returned enthusiastically. "I wish you could have come, you would have liked it!" Newfoundland sounded exciting, but I didn't want to get my hopes up in case Peter didn't get the job. Psychologically, I prepared myself to spend another year in Philadelphia.

Meanwhile, Yvonne's constant crying concerned us. Dr. Benjamin Spock, however, reassured us that some babies are just "colicky." His Baby and Child Care book was our constant source of reference. Still I worried. "I'll raise it with the pediatrician at Yvonne's first checkup," I told Peter.

I laid Yvonne gently on her back on the examining table. She was crying as usual. I expected the pediatrician to ask about it. Instead, I watched in horror as he grabbed Yvonne under the right armpit and flipped her onto her stomach as though she were a hunk of steak. Then he placed his cold stethoscope on her bare back. Yvonne screamed!

With the examination over, I took Yvonne in my arms and held her close. The doctor stated coldly, "Everything is all right. The secretary will tell you about the vitamin drops and set up the next appointment." I flashed a disbelieving look. Next appointment? But he already disappeared through the door. If he had seen my expression, he would have known I wouldn't be back.

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The job prospects in Canada didn't look good. Peter received several letters telling him they filled the positions. "If we're staying in Philadelphia," Peter said, "we'll have to move. The increased rent is more than we can afford."

With the help of friends we moved to Germantown Avenue. Our apartment was on the second floor of a newly renovated three-storied Victorian mansion. “Yvonne isn’t crying as much,” I remarked to Peter, “she must like it here. Maybe, it helps that I switched to flannel crib sheets.” Yvonne preferred to sleep on her tummy, and I noticed she scratched the bed sheet near her face with her right hand. If the sheet was polyester, she would wake up and cry. If it was flannel, she usually slept. Did the sound of the fabric wake her?

We were in our new home less than two weeks when I found myself packing for our first major trip with Yvonne. Peter planned to drive to the University of Toronto to attend the scientific meetings and said, “Why don’t you come along for a holiday? It could be a ‘dry run’ for our vacation.”

We stayed on campus. While Peter attended the meetings, Teresa and I pushed Yvonne in the carriage. We enjoyed picnic lunches in the shade under the huge trees, and made friends with a family from Asia.

The memories, however, were not all pleasant. For supper we went to a restaurant but only once. The experience was too traumatic. We couldn’t subject ourselves to that again! We had ordered our food, and Yvonne put on a screaming display that turned every head in the restaurant toward our little table by the wall. How could a two-month-old have such powerful lungs? Nothing consoled her.

Our food arrived but we couldn’t eat; our throats seemed to tighten. Peter put his fork down and, picking Yvonne up in her infant seat, said, “You finish eating. I’ll take her outside.” Teresa looked at me with huge watery eyes. We seldom went to a restaurant as we preferred our home cooking. This was to be a real treat but now I felt sorry for her. I tried to be cheerful and forced myself to eat. It wasn’t working. Finally I said, “You stay here and finish eating. I’ll stay with Yvonne and Daddy will join you.” After that, supper meals were take-out, eaten in the park or in the car.

We arrived back home in Philadelphia five days later, exhausted. We seriously thought of cancelling our summer vacation to Manitoba to attend the July 17 wedding of Peter’s brother Martin to Mary, and to visit family, friends and relatives. But family was important to both of us, and I found myself thinking back to my past.

I was born in Winnipeg. My parents and older sister Rita and brother Henry lived on a farm in Grunthal, Manitoba, an hour’s drive south of Winnipeg. Soon after my birth my mother became ill with tuberculosis and died in the sanatorium when I was two. I lived first in Kleefeld and then in Domain. At four years I was reunited with my father, sister and brother when my father remarried. We lived in Elmwood in the eastern part of Winnipeg. Shortly after I turned fourteen my father died of cancer. I continued living with my stepmother Mom Wiens (although we had our differences) and sister and brother until I was twenty years old.

The year before, I met Peter at a church youth group. Peter's family lived in Arnaud, but he was studying at the University of Manitoba in Winnipeg. In September he moved to Kingston, Ontario, as Queen's University accepted him for graduate studies. We wrote many letters that year. Then on July 30, 1966, we were married in Winnipeg at the Sargent Avenue Mennonite Church. Both families were supportive and I felt accepted by his parents, seven brothers, three sisters, five nephews and five nieces. After the wedding we left our families. Together we started a new life, a life where we experienced joy and tears, but one of love and commitment to each other, to God, to our children and to our families.

As we thought of Martin and Mary's wedding, we wanted so much to be with them and our families. We also enjoyed travelling and camping. We asked ourselves if it was fair to cancel because of Yvonne? We decided it wasn't, and we also hoped her crying would stop.

We travelled west. Stopping to pay tolls on the state turnpikes was a nuisance at the best of times, but with an infant who didn't like the starting and stopping it became a major problem. Peter became adept at coasting our Dart toward the tollbooth and tossing the exact change into the wire basket without coming to a complete stop. He also didn't stop for gas if Yvonne just fell asleep. Often this meant filling up when we still had half a tank, although Peter didn't like to because it threw off his mileage calculations. Travelling was stressful, but our solutions made it manageable.

On the second day, we arrived in Winnipeg. We attended the wedding, leaving Yvonne with Mom Wiens. Later we visited both of our families, friends and relatives. Then we headed northwest to Riding Mountain National Park for a few days of camping. The nights were cool, but we bundled Yvonne up well. She was happy in the tent. We were encouraged.

We drove north to Flin Flon. Here the highway ended and we boarded Transair to Lynn Lake in northern Manitoba. Teresa was excited about flying but Yvonne cried. Finally we landed. Our friends George and Sigrid, who earlier lived in Elkhart, Indiana, welcomed us. The north was peaceful and relaxing. There were few roads, but plenty of lakes so we explored by boat. Yvonne still had crying spells, but generally she was more relaxed.

Our vacation in Canada was tiring, but we were glad we made the trip. We wanted Teresa to visit with her grandmothers, aunts, uncles and cousins. We also wanted our families to meet Yvonne.

At the end of July, I was busy unpacking the remaining boxes and getting ourselves settled into our apartment. Peter was getting back into his research when unexpectedly he received a telegram from Newfoundland. Memorial University offered him the position of assistant professor, beginning in September. We didn't take long deciding that he should accept the position. We packed up again.

Leaving Philadelphia, we drove through New York and Boston and stopped late at night in St. Stephen, New Brunswick. Our night in the motel was a disaster. Yvonne wouldn't sleep; she cried all night. The next evening we decided to camp. We all slept!

In the morning, Teresa was excited about taking the ferry, a six-hour trip across the Cabot Strait. She handled the crossing like a natural sailor. Peter and I, however, got seasick, and we guessed Yvonne did too. We sat out on the deck. It seemed to help, but it was windy and cool. Yvonne didn't like the wind and she didn't like the rocking of the boat. She screamed! We went back inside. I expected that at four months, Yvonne might sleep through most of the crossing. However, she slept only twenty minutes of the six-hour ordeal! Peter and I alternated caring for Yvonne and taking Teresa on a tour of the boat. Finally we docked in Port aux Basques, Newfoundland.

Driving off the ferry, Teresa looked back and innocently asked, "When can we take the ferry again?" I shot her a glance. She realized this was not the best time for such a question.

Two days later we crossed the isthmus onto the Avalon Peninsula on the eastern part of the province. The rocky barrens were a strange contrast to the forests on the west coast and in central Newfoundland. This was an unusual land and we were already becoming attached to it.

We were nearing the end of our 915-kilometer trip across the province to St. John's. As we came over a rise on the Trans-Canada Highway (or the TCH, as it's known in Newfoundland), the sprawling city of St. John's lay in the valley below. I opened the city map and directed Peter; we had arranged housing before leaving

Philadelphia. Lester Street, we were there. We looked closely for number 51. We hadn't even stepped into our townhouse, yet we sighed with relief, "It's good to be home."

* * * * *

During that first year, I watched Yvonne do the usual things that infants do. She liked to sit on my lap or in her highchair, but at nine months she either was not able to, or didn't like to, sit unsupported on the floor. One day in January, Yvonne surprised us. It happened in Manitoba. We had flown to Winnipeg to be at our brother-in-law Jake Baerg's funeral, and to spend time with Peter's sister, Clara and the Penner family. During that week, we also spent time with the Wiens family. My brother Henry and his wife Verna also had two girls the same ages as ours. They had bought their girls a little toboggan, which Henry brought out, and I heard him say, "Come on, Yvonne, let me take you for a ride!" and set her on it. In his exuberance he didn't see my right hand signalling "stop" nor did he hear, "Henry, she can't—" I looked on in amazement. He pulled Yvonne out of the living room down the hallway. She stayed sitting unsupported!

We watched Yvonne and Glenda crawling and reaching for the nesting blocks. They played happily side by side. Peter took pictures. In one, Yvonne was up in a crawling position, both hands flat on the hardwood floor, intently watching Glenda playing with a toy. These pictures proved valuable in confirming a diagnosis many years later.

* * * * *

As Yvonne neared her first birthday I thought it's too bad that babies grow up so quickly. I loved the baby stages. It was fun watching what they did and how they figured things out. One morning, after giving Yvonne an orange-flavoured vitamin C, I placed the lid on the table beside the bottle and casually said, "Yvonne, you put the lid on the bottle." She reached out and using her thumb and index finger picked it up, moved it left, and lined it up over the open mouth of the bottle. I turned the bottle while she held the lid. "Good girl! You closed the bottle!" Her actions fascinated me. They were so appropriate.

Yvonne enjoyed car trips, and on weekends we often drove to the ocean. One sunny Saturday afternoon in May, with Bob and Eeva and their two girls, we explored the ghost town of LaManche on the Atlantic coast, an hour's drive south of St. John's. We were sitting on a grassy slope overlooking the ruins and the ocean. Yvonne enjoyed the outing and munched on a cracker while we discussed our summer plans. Bob and Eeva would drive to Ontario to visit relatives and we planned to drive to Quebec City where Peter would attend a biological conference. Afterwards we would vacation in the Maritimes. When we returned, we anticipated visitors from Manitoba and Alberta. "I guess it'll be September before we get together again," I remarked.

In mid-June we took the ferry but this time we had a reservation for a four-berth cabin on the night crossing. Teresa was excited about sleeping in an upper bunk. Yvonne slept in her car bed which we placed on the floor between the two lower bunks. In this way, Peter or I could reach out to her without necessarily getting up. Yvonne settled eventually and slept.

In Quebec City, we were pleased that Yvonne accepted hotel living with only periodic crying spells. We stayed out of the crowded dining room, and ate in our room, in a park or in a small restaurant. This worked well.

With the meetings over, we travelled through the Maritimes. Yvonne was always happy in the car and in the tent. She loved the outdoors and enjoyed the beach at Kejimkujik National Park in Nova Scotia. I watched Yvonne at the water's edge, happily scooping the sand and pebbles with her left hand, and pouring water from her yellow watering can with her right hand. I didn't have to worry about her putting stones into her mouth. She just played with them. From her sitting position, she even ventured a little deeper into the water, gazing down at the stones through the ripples. She laughed. We were glad Yvonne was becoming a more contented child.

Chapter 3

Sixteen Months

During July and August 1972 we welcomed family and friends from Manitoba and Alberta. Yvonne enjoyed visitors in our home and was glad to come along on trips to Signal Hill, the harbour, Cape Spear, Petty Harbour, Middle Cove, Torbay, Flatrock, Pouch Cove and Bell Island. These were our favourite places in the St. John's area.

Early in August, I noticed Yvonne started rocking her body in a forward motion while sitting on the floor playing with her toys. At times she let her forehead crash to the floor. She cried and sent her toys flying across the room. “What a temper!” I thought. Each time her forehead was about to hit, I stopped her. When I did, she cried and pushed me away. At this time she also began banging her head against the end of her crib. I was puzzled. Why did her behaviour suddenly change?

I talked to Mom Penner about my concern. In her quiet and calm way, she said, “It may be a phase she’s going through, or it could be connected with her teething.” Yvonne’s teeth were slow in coming through; at sixteen months she was only cutting her fourth tooth. Mom Penner gave me further encouragement. “Now that I think back,” she said, “my son Henry banged his head too and he stopped it after awhile.” She shrugged her shoulders, suggesting, “It may be the same in Yvonne’s case.” Having had thirteen children, Mom Penner had plenty of experience and I valued her comments. As well, Dr. Spock stated that head-banging was not uncommon. I would try not to worry.

During the ten day visit, we took Mom Penner and sister-in-law Hertha on car trips around St. John’s. We also hiked and stopped to pick wild blueberries. On this sunny hot day, Yvonne wore her yellow sunsuit. I put pants over top so she could sit on the ground and pick the berries. Her arms, however, were bare. When they touched the leaves and branches, she cried. Next time, I told myself, I’ll take a sweater along, even if the weather is warm.

Later that day, Yvonne was happy crawling outdoors in our small fenced-in backyard. In the warm weather, the back door, which opened conveniently from the living room onto the backyard, was left open to let Yvonne crawl in and out over the single step. Hertha got a nice picture of Yvonne standing and holding onto the edge of the picnic bench with both hands, but Yvonne refused to look up. She was too interested in watching an insect in the grass.

The next day, I was in the kitchen washing dishes while Hertha was in the backyard with Yvonne. Yvonne then crept into the living room and wasted no time in crawling to the end table and getting into the flowerpot. This was the day when Hertha called out to me, “You should see Yvonne!” and ran to get her camera. This was the flowerpot incident which I would recall time after time, and wish, if only she would dig in a flowerpot again!

A few days later, Mom Penner and Hertha left St. John’s. The following week, Yvonne’s head-banging and crying increased. She banged so hard that she moved the crib from the wall into the centre of the room. I worried. The stress and tension affected my back and climbing stairs became extremely painful.

Then, as if the head-banging wasn't enough, Yvonne developed a craving for plastic. One morning while I undressed her in her crib, I found the front of her plastic pants missing. I blinked my eyes and looked again hoping it was my imagination. It wasn't. The whole centre that normally covered her tummy was gone. The edges were jagged. Frantically I searched her bed between the mattress and bumper pads. I shook out her blankets. I crawled on the floor. Not a shred of plastic anywhere! A cold shiver went through my body. Did she really eat it?

I needed to prevent this from happening again. That afternoon I sewed the top and bottom of her two-piece pajamas together in the front, where they otherwise snapped into place. Thinking I solved the problem, I managed to fall asleep that night.

The next morning I saw the crib sheet bunched into a corner. I was puzzled. She's never done that before. "Oh, no!" I gasped. "The mattress is torn!" My eyes focused on the creamy cotton stuffing. I felt sick to my stomach. I searched frantically for the missing chunk of plastic but didn't find any. "What are we going to do?" I cried.

That evening Peter and I wrapped a heavy blanket over the mattress and secured it tightly. No way could Yvonne get at the plastic. Yvonne, however, outsmarted us. She then head-banged her crib over to the card table and managed to rip off a corner of the green plastic covering. Only this time, she hadn't eaten it yet.

Why did she have this sudden compulsion? How did she know the mattress and card table were covered with plastic? We made a careful search of her room. The only plastic items left were pants and a change sheet; these were now placed on a top shelf, way out of reach. The problem was solved.

We still, however, had no solution to her head-banging. One morning I couldn't open the door to Yvonne's bedroom. I cried out, "Yvonne must have head-banged her crib across the room and jammed it into the doorway!" Peter and I pushed against the door and finally freed the crib, gouging the wall in the process. That evening Peter screwed coasters to the floor and set the legs of the crib into them. The crib no longer moved.

We padded both ends of her crib with thick sponge to give her head protection. But as much as possible, we kept her out of the crib. Then, one day in the living room, Yvonne scooted over to the end wall and in a quick motion sat with her back against the wall, leaned forward, and let her head crash back. This was the beginning of her head-banging against any wall in our house. If I wasn't there to stop her, she continued in a rapid, rhythmic pattern. Of course, she cried a pitiful cry. I picked her up and hugged her, my tears spilling over onto her head. I didn't know what to do. I couldn't sit and watch her all day long. Sometimes I had no choice but to let her bang in her padded crib.

Yvonne used to love bath times, especially when Teresa bathed with her, but this changed too. Yvonne arched her back, cried and almost threw herself out of my arms when I placed her in the tub. What was happening? My sister Rita, who arrived for a visit exclaimed with concern, "Take her to a doctor!"

I sighed helplessly, and told her about my visit to the Janeway. "The intern," I said, "stated there is nothing wrong with her." With a sickening feeling in my stomach, I added, "There's nothing I can do, except wait for our family doctor to return from vacation. I have an appointment September 27." Rita left before the appointment; I promised to call her.

My friend Eeva stopped in often. She offered to babysit, do laundry or pick up groceries. She insisted that I call if I needed help. Her friendship and help meant so much! She often referred to our picnic at LaManche and smiling said, "Yvonne used to be so happy!" Her expression saddened though as she looked at Yvonne. "I can't get over what happened to her during the summer. I was shocked when I saw Yvonne's eyes," Eeva confided with concern, "they've become so sunken and sad. They were so bright and sparkling before." Eeva sensed a real significance in Yvonne's eyes. Peter and I were aware of the change too, but were more concerned about her head-banging and the sudden change in her behaviour. During this time, Yvonne had her appointment with the family doctor, and I was anxiously waiting for the appointment with the pediatrician.

Teresa, meanwhile, started kindergarten in September, alternating a month of mornings and afternoons. The school was six kilometers from home and I had to drive her in and pick her up because there was no bus transportation. Eeva soon told me about Dee, whose daughter Robin attended kindergarten at the same school, and that Dee was interested in car pooling. I phoned Dee that day and we took turns driving weekly.

Dee had two older children attending school; I took them as well when it was my turn. One morning Dee called and abruptly asked, "Could Yvonne have lost her hearing?"

I was puzzled. "I don't think so, but what made you wonder?"

Dee explained, "My daughter Mary was sitting beside Yvonne when you drove the kids to school yesterday. She talked to Yvonne but Yvonne didn't look at her. It was like she hadn't heard her. Mary told me, 'Mom I think Yvonne is deaf!'"

"Deaf?" I questioned, hardly believing. "We haven't noticed anything unusual but I'll check into it."

Hanging up the phone, I looked down at Yvonne. She was sitting on the floor surrounded by her toys, but she wasn't playing with them. I picked up a squeeze toy, held it behind her head and squeezed it. Her head didn't turn; her eyes didn't blink. I couldn't believe she didn't respond. I tried a few other things. I spoke loudly, then softly. I sang, hammered the coloured pegs in her wooden work bench, and banged her blocks together. She either sat still, or cried. She didn't turn her head, and she didn't reach out to take the toy.

My heart pounded wildly. I called our family doctor and told him about my friend's call and my "experiments." He said, "If she has lost her hearing, that would explain a lot of things. Bring her in. I'd like to see her again."

The doctor looked at Yvonne and spoke in his usual soft tone. He clapped his hands behind Yvonne's right ear and then the left as he had done at an earlier appointment. She didn't respond. Next he snapped his fingers; she cried. He rang a bell; Yvonne didn't respond. He used a squeeze toy; she cried.

He shook his head and looked puzzled. "Her responses are so unusual," he stated. "I want to have her hearing tested." He left the office and returned a few minutes later. "Cancel the appointment with the pediatrician," he said, "here's an appointment for a hearing test at the Auditory Clinic at the Janeway."

Two weeks later, I nervously entered the Janeway and asked the receptionist for directions to the Auditory Clinic. The large waiting room was full; I hadn't expected this. Since Yvonne was a first-time patient the receptionist needed all kinds of information: name, address, Medicare number, family doctor, and on and on. The desk was behind a high wall, so I had to stand, lean over and talk down to her. Meanwhile, Yvonne was squirming in my arms and I bounced her from one hip to the other. I was getting hot and feeling frustrated. Couldn't they have received much of this information from the family doctor? It would have made things much easier. Finally we were able to sit. I was anxious about Yvonne's condition and was in no mood for small talk with strangers. After a long wait, they called Yvonne.

The two technicians were friendly. They seemed excited about working with a baby. I gathered they usually worked with older children. Soon they found some squeeze toys, bells, blocks and hand puppets from a top shelf in a closet. I held Yvonne on my lap, while one technician used the objects to produce sounds behind Yvonne, and the other technician observed her reactions from the front. Yvonne did not respond to some sounds. At others, however, she screamed and threw her arms in the air; she fought to get off my lap. Nevertheless, there was one definite, positive response. She turned her head immediately toward the sound of a cellophane candy wrapper. The technicians were puzzled. They wanted to see Yvonne again.

Yvonne had two more appointments. After the last visit, the technicians said they would report to our family doctor in a few days. I should call him Friday. I called Friday and for seven days after that. Finally, the doctor's receptionist responded, "Yes, Mrs. Penner, the report is in, it just arrived." Then she asked, "Can you hold? The doctor wants to talk with you."

I was not surprised when the doctor told me, "The report says the technicians are basically baffled." My hope sank. A hearing problem would have been an explanation for Yvonne's behaviour. The doctor sensed my dejection. He encouraged me, however, by saying, "I would like Yvonne to see a child development specialist. I've arranged an appointment for nine o'clock on November 20." This appointment was in less than two weeks. It seemed like a long time to wait but for seeing a specialist, this was swift. With each passing day, I increasingly hoped that the specialist would have the answer to what happened to Yvonne and how we could help her.

The day of the appointment came at last, but this was the day my hope was shattered. Yvonne was labelled "severely retarded!" This was a cruel blow. It might have been easier had the doctor set another appointment without Yvonne, and discussed it with just Peter and me. I drove home in shock. That first week after the devastating news, I spent many hours sobbing at the dining room table after Peter left for work and I drove Teresa to school. Yet I had to pull myself together, I had work ahead of me, we would soon be moving to our own house. Our new location had many advantages: Teresa's new school was within walking distance, there were several churches in the area, and the Janeway was only two kilometers from our home.

Before Christmas, Yvonne had her appointment for the EEG. As usual, patients crowded the waiting room. Yvonne was crying. I was trying to comfort her. Other children also cried and still others were banging on toys. How I hated the waiting room! Finally the nurse called us into the examining room. She wanted to weigh Yvonne. She tried to lay her on the baby scale but Yvonne stiffened her body and screamed. The nurse glared at me, as if to say, "Can't you get her to shut up?" I didn't need that. Dealing with Yvonne's crying was stressful in itself. I expected the nurse to be more understanding, patient and helpful. I needed her on my side, not against me.

The nurse called for help and eventually she and her assistant managed to weigh Yvonne and glue some electrodes on her head for the EEG. No one explained what was happening. I expressed my concern about the electrodes. The nurse simply stated, "We're checking for any abnormal electrical activities in the brain; it won't hurt her." The way Yvonne was crying, I wasn't sure. Nevertheless, I had to trust the nurse. After awhile, Yvonne calmed down. Later, I wondered if they gave her a sedative. No one told me. At the time, I was just relieved when it was over, and I'm sure the nurse was as well.

This was a new experience for me. I didn't know what was involved in doing an EEG. I also didn't know what I should be asking. I sensed that the nurse was working in her specialized field and it wasn't important for her to inform or educate a parent.

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Christmas! A break from medical appointments. A time for relaxing and visiting with friends. Christmas, however, was not a happy experience for Yvonne. She was not interested in the tree, and she cried at the sound of tearing wrapping paper. I soon put Yvonne in her crib. It wasn't fair for Teresa not to enjoy gift-opening because her sister was so unhappy.

Yvonne cried that whole week. Reluctantly we drove to the pharmacy to buy the medication Syrup of Phenergan. The child development specialist gave us the prescription, but we had resisted using drugs to sedate her. We now asked the pharmacist about the drug and any side effects. He looked at Yvonne who was crying and struggling in Peter's arms. He recognized our reluctance but assured us the medication was harmless. “I would give it to my own daughter,” he said, “if she needed it.” This made us feel better; I asked him to fill the prescription.

Giving medication to Yvonne was a struggle. She clenched her teeth and turned her head from side to side; she pushed at us with both arms and kicked her legs. We managed to get some medicine into her two or three times a day. However, she never got the prescribed amount as she managed to let it run out of the side of her mouth. Several days later, the crying stopped and she cheered up.

The first two weeks of January were encouraging. Although Yvonne still slept little at night and not at all during the day, she started taking an interest in her surroundings. She was particularly interested in looking at the creamy-beige wallpaper with the curly wrought-iron design in the hallway of our new home. Yvonne kneeled in her bed, holding the lowered rail of the crib and leaned forward, peering through the open doorway on her right. She still preferred to spend much of the day in the safety of her crib.

I tried to get Yvonne interested in things outside her crib. I lifted her out and placed her on the floor near her toy box. Occasionally she stood, held onto the box, bent over, took a few toys out and tossed them on the floor. At other times she looked at a toy or put it in her mouth. I sat on the floor beside her and put the coloured plastic rings on the ringtoss or built a tower with the blocks. I knocked the blocks down and watched for a reaction. Sometimes she turned toward the fallen blocks, but she never smiled.

Sitting beside her on the floor, I made up little songs always using her name. She seemed to relax when I quietly sang, “Sunshine, moonshine/ love-shine, Yvonne-shine/ Mommy love the little girl/ little girl Yvonne.” Over and over I sounded like a broken record. Something in it soothed her. I reached out and touched her shoulder. Then gently I laid my hand around her waist. I held my breath. Would she scream and dart away?

She was silent! She didn’t crawl away! I didn’t dare move my hand nor change the pressure of my touch. After awhile she cried but it was a different cry. It was as if she was experiencing some nostalgia. It seemed painful to her. Quick, I told myself, think of a different song, something bouncy. To the tune of Jingle Bells, I sang, “Sugar-plum, sugar-plum, sugar-plum Yvonne…” It worked. She stopped crying. She sighed and relaxed.

It was like a magical moment. I wanted so much to hug her. I was afraid, however, she might cry and scream. I was afraid of losing what I had just achieved. Very gently, I placed my other hand around her waist from behind and slowly slipped her onto my knees in my kneeling position. I held my breath. She remained quiet. She didn't fight me!

Very quietly I sang, "I love you, I love you/ I love you, I love you/ I love you 'Von, Yvonne/ I love you 'Von, Yvonne!" Yvonne stayed sitting on my lap for over twenty minutes. Later, when she was in her crib, I called Peter at work. I couldn't wait until evening to share the news with him.

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Early in the new year, we had another medical appointment with a neurologist at the Janeway. He had already examined Yvonne's EEG and found nothing abnormal. We were at a loss. There seemed to be no medical reason for her change, and we were getting no advice on how to help Yvonne. Yet it was important for us to obtain as much help as we could. Privately Peter and I talked about getting a referral to a doctor who had experience in working with autistic children. We agreed to be cautious since we had read about other parents who spent their life and life-savings globe-trotting in search of medical help yet it got them nowhere. We wouldn't do that. We owed it to Yvonne, however, to get a second opinion from a doctor knowledgeable in autism. We would then accept that decision. I now asked the neurologist for such a referral.

He was quiet for a moment, and seemed to be deep in thought. "I know of a doctor in Montreal," he said. "However, a referral will need to come from the child development specialist."

"Would you ask her?" I asked enthusiastically.

"Yes, I can speak to her," he said calmly.

A few days later, I phoned the child development specialist. "Yes," she said, "I had a call from the neurologist."

"Will you make a referral?" I asked hopefully. She said she would. Because Peter and I agreed to ask for only one out-of-province referral, it was important that it be an appropriate one. "I just want to make sure," I said, "that this doctor has experience in working with children who are autistic."

She remarked, "Yvonne certainly seems to have some of the characteristics associated with autism, but Yvonne is retarded and has been all along and it is hard for you parents to accept that." I was seething! How could she say that? Yvonne was not always like this. We knew Yvonne had a problem and we were trying to get help.

My mind flashed back to a scene that I had witnessed as a teenager when a young boy was rejected by his parents because of his mental disability. The mother, rushing into the living room in a state of frustration, had shouted to her husband sitting on the sofa, "Look what your son just did!" Her husband snapped back, "He's not my son, he's your son!" The boy, who had been standing in the doorway and heard what they said, grabbed a metal tray and crashed it over his sister's head. The scene that followed was utter chaos.

Much later, I learned that these parents loved their son and they had refused doctors' advice to place him in an institution. Yet the parents were not given any help in the home. Worse still the school system rejected their son. The lack of community support resulted in frustration which created enormous stress. This incident had a powerful impact on me. I vowed that, if I ever had a child with a disability, I would accept and include that child right from the beginning.

I was now exasperated with the child development specialist. With my blood almost at the boiling point, I fired away, "We realize Yvonne is retarded, but we feel she is retarded because she is autistic!" Before she could interrupt me, I grabbed Lorna Wing's book which was lying on the desk by the telephone and read to her: "Most autistic children are below average in intelligence and many are severely retarded because the handicaps which underlie autism produce serious learning problems. And a delay in diagnosis also means that the child has developed many secondary behaviour problems which might have been avoided if the handicaps had been understood from birth.'"

"That is why," I emphasized, "having a consultation with a doctor experienced in this field is so important to us." When I finished, I felt my body shaking. She was silent. Would she withdraw the referral to Montreal? Still, I had to say what I just said. I broke the silence and bluntly asked if she was still going to make the referral.

Stiffly she replied, "Yes, and I will mention what you just said."

Still fuming over her earlier comment, I pressed on believing I had a right to request even more help. "Is there anyone in St. John's who knows something about autism who we could see in the meantime? It could be months before we get an appointment in Montreal."

"There is a psychiatrist at the Child Psychiatry Unit at the Janeway," she said. "I can check with him."

To my surprise, she called back with an appointment in two weeks to see a neurologist in Montreal.

In preparation for the appointment, Peter and I recalled everything we could about Yvonne's development. From birth to sixteen months she was active and slept little. She responded with smiles and laughter, played appropriately with toys, such as putting nesting blocks into each other and responded appropriately to words: bath, ball, juice, teddy, soother, sleep, foot, vitamins, no, Mommy, Daddy, Teresa, and her own name. She learned by imitation, such as following my example to put her toys back into the toy box. She walked while holding on to furniture at thirteen months. But she never pointed nor raised her arms to be picked up.

We also listed her behaviours from sixteen months to her present twenty-two months: head-banging, twisting her wrist or objects in front of her face, a blank and faraway look in her eyes, wanting to be by herself, fearful of a bath, not responding when she was called, crawling over toys (or people sitting on the floor) yet taking no notice, unhappy in stores and at friends' homes, obsessed with chewing plastic and string, and fearful to stand without support.

We noted recent improvements: she started enjoying rough play; she stood at the end of her crib smiling and raising her elbows, indicating she wanted to be picked up; occasionally she slept through the night. When we finished, I had a full page of single-spaced typed notes. It was important our information be accurate, and it was important that Peter and I agree on the facts.

I was not keen on shouldering the responsibility for Yvonne on my own, but I had no choice. Peter couldn't take time off from work, and for Teresa it was better to be home and attend school. Teresa was very understanding of the difficulties concerning Yvonne, but she was feeling the stress too. She needed stability as she was still adjusting to a new school, new teachers and new friends. I had to go on my own and I had to be strong. Still, it was frightening when I thought of the plane trip and being in a large unfamiliar city on my own. Then I thought of John and Judy who moved from Philadelphia to Montreal. This was a spark of hope! I called that night to ask if Yvonne and I could spend a few days with them.

Judy sounded excited. "Of course! I'll pick you up at the airport and take you to your appointment."

I sighed with relief. Being with friends would help reduce the tension. I booked a flight to leave St. John's on February 6 in the morning and return Friday evening February 9.

Chapter 4

The Montreal Nightmare

Judy's bright smile was heartwarming even from a distance. Her young children waited patiently beside her as Yvonne and I made our way toward them in the busy airport. For a while, I could forget why I was in Montreal. We laughed as we shared memories of good times in Philadelphia, but all too quickly we were jarred to the present.

"We're here," Judy said, stopping in front of the neurologist's office.

"I have no idea how long it'll be, I'll take a cab when we're finished."

Yvonne and I entered the building. The receptionist immediately ushered us into the neurologist's private office. The doctor introduced himself and soon talked about admitting Yvonne to the Montreal Neurological Hospital for a few weeks. I stared at him. "Hospital? For a few weeks!" As this possibility sank in, I declared, "I don't want her admitted to a hospital!"

The neurologist explained, "We'd like to do some tests."

"Can't I just bring her in for the tests?" I asked matter-of-factly. His stern expression made me apprehensive. "What kind of tests?" I added.

"We want to do some blood and urine tests and X rays."

I exploded, "Yvonne has just been through all of that! Have the reports not been forwarded to you?"

"Yes," he said, "but we want to do our own tests. We would also like to do a pneumoencephalogram."

"What's that?" I asked. He talked about an injection in the spine and blowing air between the skull and the brain and taking an X ray. It sounded scary. "What are the risks?"

"Risks," he retorted. "What are risks? You take risks every time you walk across the street."

We were not getting off to a good start. I didn't like his attitude. I asked him, specifically, "Would these tests determine whether Yvonne is, or is not, autistic? Because that is why I came to Montreal."

"What makes you think she is autistic?" he snapped. I was floored. Surely the child development specialist informed him, especially after my recent conversation with her! What was going on here?

Firmly, I stated, "We think Yvonne is autistic because of her sudden change in behaviour." I opened my purse and handed him the page of typed notes on Yvonne's twenty-two months of development. I emphasized, "We're encouraged by the recent improvements. Yvonne is allowing us to touch her again. She's enjoying her bath time. She lets me put her on the potty and she uses it. Occasionally, she breaks into a bright smile. We even saw her dimple which we haven't seen for five months!"

We launched into a lengthy discussion on autism. At times, it became heated. "I can see," he muttered under his breath, "why the doctor in St. John's called you 'difficult' parents."

I was astonished. I didn't know we were difficult parents; we just wanted answers!

Exasperated I said, "I didn't come here to argue. I came here to meet someone knowledgeable in autism who could tell us whether our daughter is, or is not, autistic. I also came here for advice on how to help her."

The neurologist leaned back in his chair with his pencil in his mouth, and just looked at me. I was puzzled. What was he thinking? What was he going to say?

Nodding his head slowly, he commented, "I can see you are quite knowledgeable on the subject of autism." His comment was not sarcastic, nor was it intended as a compliment. His expression and tone merely suggested he was aware that I knew my facts and he just had to figure out how to deal with me accordingly.

He brought our conversation back to Yvonne's hospitalization. "If you want Yvonne to see a psychologist and psychiatrist, experienced with autistic children, you'll have to admit her to the hospital. That's the only way Yvonne will get to see them."

My choices seemed clear; hospitalize Yvonne, or, go home. My mind raced. I wasn't prepared for her to be in a hospital. I didn't want to subject Yvonne to those tests again. Yet, the neurologist's firm statement, "that's the only way Yvonne will see a psychologist and psychiatrist," rang in my ears, so I asked, "What is the minimum time she'll need to be hospitalized?"

"Minimum time ten days."

"I need to think about it," I said. "This is so different from what I expected. I need to talk to my husband about it tonight." Yvonne was on my lap resting the whole time. I had given her Syrup of Phenergan for the morning flight and she was still drowsy. I lifted her against my shoulder and stood to leave. "I will call you in the morning."

I approached the receptionist about getting a cab. She told me one should be parked in front of the building. It was. I got into the back of the dark vehicle and gave the driver the address. He could have driven to Quebec City and I wouldn't have noticed, I was so distraught. My mind kept repeating, "Hospital! Ten days! Hospital! Ten days!" The cab stopped. I sighed with relief to be safe in Judy's home. As I sank into a chair in the living room, I spotted a playpen that Judy had prepared as a bed for Yvonne. I broke down and cried, "He wants to hospitalize Yvonne for at least ten days."

As I agonized over my decision, John and Judy listened. "You're welcome to stay as long as necessary," they assured me kindly.

"What would you do," I asked, "if you were in my situation?" Both said they would agree to the hospitalization on the chance that someone might find some answers. I kept checking the clock, anxiously waiting for Peter to call.

Finally the phone rang. I was so glad to hear Peter's voice. We talked a long time; I had so much to tell him. He knew I was under a lot of stress. I asked him for his advice. He affirmed what John and Judy said. "I'll leave the decision up to you, however, and I'll accept it either way. It might help you to decide," he advised, "if you ask the doctor what the diagnosis might be if all the tests are negative."

"I already asked him," I replied, "but I didn't get a clear answer. I'll ask him again in the morning." That night I didn't get much sleep.

At 8:40 a.m. I called the neurologist. He returned my call two hours later and coldly demanded, “What have you decided?”

“It depends on the answers to a few questions. What do you expect the diagnosis to be if the results are negative?”

“We spent over an hour talking about it yesterday,” he stated sharply, “I’m not going into it again. I’m seeing a patient. Do you want her hospitalized or not?”

I persisted, “I have another concern. I want to confirm that Yvonne will see the psychologist and psychiatrist.”

“Yes,” he replied, “they will see her next week. You can speak with my secretary about admission to the hospital,” and he slammed the receiver down.

I was shaking. My vision blurred. I would have to deal with him for ten days! What would he be like toward Yvonne? My first impulse was to forget the whole thing and fly home. But if I called the airline and rebooked my ticket for an earlier flight home what would I say to the child development specialist and to our friends about the findings in Montreal? Oh, they’d hear about the neurologist, but what about any help for Yvonne? Would we ever get another referral? And more importantly, could I live with my decision to run away because of a doctor’s attitude?

I admitted Yvonne to the Montreal Neurological Hospital, that afternoon. The nurses were excited. “The baby’s here! The baby’s here!” They were ready for Yvonne since the day before. They placed Yvonne in a crib with high iron bars. She was wearing a white harness with long straps tied to the bars of the crib. I felt sorry for her. She couldn’t roll over, she couldn’t sit, she couldn’t stand up. I talked to a nurse about it. She explained this was hospital policy and harnesses were used on children up to six years; it was for their safety. I was, however, given permission to remove it while I was with her.

Yvonne was in a twelve-bed ward that included boys and girls up to sixteen years. The noise and commotion were upsetting for her. It wasn’t long, however, before the head nurse realized this and decided to move Yvonne into a “private” room—the weigh station. They moved some equipment aside to make room for the crib. The nurses were wonderful. I appreciated their understanding. One of them even said, “There’s another family here from Newfoundland. They arrived yesterday.”

Suddenly I didn't feel so alone; I had something in common with someone. I'll wait till tomorrow, I told myself; this being Yvonne's first day in the hospital, I need to stay by her side.

I changed Yvonne's diapers and gave her supper. The neurologist and three other doctors stopped in to see her. Then I got her settled for the night. It pained me to put the harness on her but I knew if I didn't, the nurses would. I just put my coat on to leave when another doctor arrived. He apologized for being so late, but he had several emergencies. He needed to do a few tests on Yvonne which were part of the hospital admission procedure. He flicked on the light switch and Yvonne woke up. She cried of course! It was 9:00 p.m. before I got her settled again.

I took a cab to John and Judy's. Peter called in the evening; he was glad I decided to stay.

The following morning I took the bus. John accompanied me to the hospital pointing out various landmarks along the way. We walked several long blocks to catch the connecting bus. With John's help, I was confident I would remember the route. The trip took just over an hour. I arrived at 10:15. Yvonne was sitting in the middle of the crib, wearing a loosened harness and smiling. I was relieved to find her happy. She was playing with her honeybee tambourine and brightly coloured wooden beads. A nurse obviously put them into her crib. I was glad. At least Yvonne had something which was familiar to her.

A nurse told me Yvonne had a good night's sleep. She also told me that the psychologist had observed Yvonne. This was sooner than I expected. I was pleased. In the afternoon the psychologist met with me, and again observed Yvonne. The chief neurologist also observed Yvonne, and they took a skull and chest X ray.

In addition, I met Richard, his parents and grandmother, and although we were total strangers, we soon became friends as we talked about Newfoundland, Richard and Yvonne. The first full day in the hospital was a busy one. I left at 8:00 after Yvonne fell asleep. On the bus trip, I realized this was Thursday evening; I would have to reschedule my flight to the following Friday.

The next morning I arrived at 10:15, and again the psychologist had already observed Yvonne. The chief neurologist now examined Yvonne. How I wished he was Yvonne's doctor! He was friendly and gentle. When he placed his long slender fingers on Yvonne's head, I sensed he could almost get a computer reading. He must have read my thoughts because he said, “These hands have felt thousands of heads.” I believed him; I also trusted him. He took time to explain things.

He shook his head and stated, “You definitely have a serious problem. I don’t think it is a clear-cut case of infantile autism, although she does have many autistic patterns. Yvonne’s behaviour and irritability are different from autistic children I have seen. If however, it turns out we diagnose her as autistic, then it would be severe autism.”

Severe! Memories of an earlier appointment came to mind and as I tried to suppress tears the other neurologist walked in. Both now spoke about some retardation having been present all along because Yvonne was late in crawling, sitting and standing, and she never spoke.

I was confused. Other children developed late, but they weren’t retarded. However, these doctors had so much experience. Maybe they were right. Even so, it didn’t explain the sudden change in Yvonne’s behaviour! Or did they not believe our account?

The chief neurologist talked about an organic problem. He encouraged me to agree to the pneumoencephalogram. He explained that sometimes the brain remains small and therefore the head also remains small.

“Do you think this is Yvonne’s problem?” I asked.

He said he didn’t know but went on to say if this was his child, he would want to know what the problem was. Of course we wanted to know what the problem was. The pneumoencephalogram, however, still scared me. I felt sick. It was a big decision. “I’ll need to speak with Peter,” I stated.

The next day, Saturday, was a quiet day at the hospital. No tests, no observations. I took Yvonne out of the crib. She was happy to sit on my lap. She also enjoyed walking down the corridor holding onto both of my hands. She crawled on the floor. At first she enjoyed it. Soon, however, she spun around and around and cried as if she were looking for something. I suspected she was homesick and looking for something familiar.

In the afternoon, after Yvonne fell asleep, I tiptoed out of her room, closed the door and sat in the lounge just outside her room. I took my note pad from my purse and recorded the day’s events; I was keeping a diary. Also, I visited with Richard’s parents and some children on the ward.

Richard's father had chest pains. Everyone was concerned about him because he already had one heart attack. He was under a great deal of stress worrying about Richard. When he improved later in the day, we were all relieved. Yvonne fell asleep early; I left at 7:00. I had an easy day with Yvonne, but the serious medical problems of Richard and his father moved me. In the evening, I had a long conversation with Peter. He had talked to some of his colleagues at the university about the pneumoencephalogram. No one spoke against it.

I arrived at the hospital Sunday morning to find Yvonne lying on a contraption in her crib. As I came closer I saw she was wearing her pajama top but not her bottoms, with the harness securely tied to the crib bars. Her back was resting on a blue net fastened over a large metal container. The nurses were collecting a twenty-four-hour urine sample.

What would happen if they collected more than just urine? Would they keep repeating the twenty-four-hour cycle? I felt sorry for Yvonne; I would have to watch her closely and intercept. With all the best intentions and precautions nature still prevailed. I called for help. I then gave Yvonne a bath while the nurses salvaged some urine and set up a fresh net over a clean container. I sighed with relief when the nurse said she only needed to be on it overnight.

The next day Yvonne was scheduled to have her hearing checked by a husband and wife team who specialized in testing young children. The psychologist, who took a keen interest in Yvonne, asked if she could come along to this appointment. I was glad; she was caring and understanding, and I needed that kind of support.

The two doctors were friendly and spoke casually. Yvonne crawled on the floor and they let her explore their equipment. They explained they would watch Yvonne's reaction when they switched on one of their instruments. We should continue talking in normal tones. Then we heard a soft, but high pitched sound. Yvonne immediately turned her head toward it. The doctors packed up their equipment and declared, "We would be wasting your time and our time if we continued. A child with any hearing problem would not have heard that sound."

I was disappointed, because a hearing problem would have offered an explanation. On the other hand, I was relieved because it established she had good hearing.

We barely returned to Yvonne's room when the neurologist strode in. "Well, what have you decided?" he asked briskly.

Still feeling apprehensive but having no basis to deny him permission, I reluctantly consented. “You can do the pneumoencephalogram if you think it’s necessary.”

“Fine,” he responded quickly, “we’ll do it tomorrow.” I sensed both relief, and urgency in his voice. Urgency, in case I would change my mind. Then, with some sensitivity, he added, “Thursday a psychiatrist will see Yvonne and give you advice on how to handle and stimulate her.”

I spent a positively horrible and sleepless night. I was sick with worry. Morning finally came. The trip to the hospital seemed to take forever. Yvonne was still in her room. Soon I learned she couldn’t have the pneumoencephalogram because they didn’t tell the nurses to withhold breakfast.

“They’ll do it tomorrow,” a nurse told me. I felt weak. Another twenty-four hours of anxiety!

Meanwhile, Richard’s parents got devastating news. Their son had a malignant brain tumor. He was scheduled for surgery. I worried for Yvonne and for Richard and his parents. I was losing sleep and I couldn’t eat. Yet I knew I had to force myself to eat something to keep up my strength. Small amounts of bread, milk and cheese were all I could tolerate. I also had chest pain. Heartburn, I thought. I chewed antacids. They helped a bit.

Wednesday morning I took an earlier bus to the hospital. Yvonne was already upstairs for the pneumoencephalogram. At 10:30 they brought her back to her room. The backs of both hands were covered with large bandages. A tube in her nose was taped to her forehead. I saw bloodstains on the sheet. She was hooked up to oxygen. Fear gripped me. All this for doing an X ray! Slowly, it dawned on me that I hadn’t asked what the precise procedure would be and nobody had volunteered the information.

I stayed at Yvonne’s side and watched her closely, not daring to glance away. I couldn’t let myself daydream nor cry. I had to be strong for Yvonne. At noon, Yvonne’s eyes opened a crack. Slowly, she lifted her left hand to her face and twisted it back and forth.

“You’re all right!” I exclaimed with relief. Leaning over I kissed her, “You’re all right, sweetheart! You’re all right!” I was so worried that something might happen to worsen her condition. This was a good sign! Yet several months ago her hand twisting had worried me!

That afternoon I again rescheduled my airline flight. Since Yvonne wouldn't be well enough to travel Friday, we would fly home Sunday morning. All day I waited anxiously for news about the X ray. At 7:00 I spotted an intern leaving the nurses' station. I ran after him and nervously asked, "Do you have any results from the X ray?"

He looked puzzled, "Haven't you been told?" His tone sent a shiver up and down my spine.

"What's wrong?" I asked with alarm.

"Nothing is wrong. It's just that it didn't work." I looked at him blankly. My heart pounded. "They didn't hit the right spot. They tried two or three times. There was some bleeding."

"Didn't work? Bleeding! Why did no one tell me?"

Later that evening I told John and Judy. John looked concerned and asked, "Did he say what kind of bleeding? Was it internal?"

My stomach somersaulted. I couldn't wait until morning. I had to call the neurologist immediately.

I reached him at home. A baby was crying in the background. The neurologist simply stated, "It is not uncommon for a pneumoencephalogram not to work fifteen to twenty percent of the time." Then he asked, "What do you want to do?"

I was flabbergasted. "This is the first time," I accused him, "you're telling me that it's not uncommon for it not to work! Now you ask me what I want to do. I don't know. What do you suggest?"

He replied, "We couldn't do it tomorrow."

"No, I wouldn't want you to!" I responded instantly.

"We would need to wait about ten days," he said. Wait ten days! I was in shock. I couldn't reply. Then I heard, almost as an afterthought, "We didn't really expect to find anything so there's no point in trying again."

I remained speechless. Why was it so important to do it in the first place? Not once was there a suggestion that it might not work! Was this true? Or was there some sort of cover-up? I would never know.

The city was hit with a major snowfall that night. It was 11:00 a.m. before I arrived at the hospital Thursday morning. "The psychiatrist," said the nurse, "has already observed Yvonne."

Surprised I asked, "Where is she?"

"She left."

"Left?" I asked disbelieving. "She's coming back—"

The nurse shook her head. "No. She said she was finished."

"But I wanted to talk to her, I need to meet with her." The nurse gave me a phone number.

After many attempts I finally reached the psychiatrist. "I observed Yvonne a good long while," she said flatly. "I'll see her again in twelve months."

I couldn't believe my ears. "I'm from out-of-town! I'd like to talk to you about how to help Yvonne, and get some literature." We talked at length. She said it wasn't necessary to meet with me.

My head was spinning and I was getting angry. "I came to Montreal to meet a specialist in this field. They put Yvonne through a lot of tests, some unnecessary, and I am not leaving until I get to see you!" My statement carried such determination that the psychiatrist reluctantly scheduled an appointment at 11:00 the next morning. I was stunned. I come to Montreal to meet a doctor knowledgeable in autism and this is what I get? A psychiatrist sees Yvonne while she's immobilized from an anesthetic, and then I fight to meet with this doctor!

Yvonne slept most of the day. She was still drowsy from the previous day's experience. Leaving the hospital that evening, I found the walk through the snow very tiring. I had to breathe shallowly, to avoid a piercing pain in my chest. Warmly dressed for the winter weather, I still shivered as I sat in the warmth of the bus.

Judy always had a delicious hot meal waiting for me, but I found it increasingly difficult to eat. My stomach felt raw. I was worried about Yvonne, and frustrated by my experiences. Still I had to hang in there. I couldn't afford to get sick. Yvonne needed me.

Friday morning I arrived at the hospital at the usual time. I soon left to meet with the psychiatrist. With hopes of still getting some help, I hurried down the street to her office. The office was in one of the older houses. Ordinarily I would have taken time to look at the delicate woodwork, but I was too eager to meet with the psychiatrist.

I found her office and turned the white porcelain doorknob. The door opened quietly. I was awestruck. The room was huge with a high ceiling. The psychiatrist's desk, straight ahead in the centre of the room, was about twenty feet from the doorway. Beyond the desk, light streamed in through a bay window. Furniture and office equipment lined the walls. On my left, I spotted a dark brown leather couch. A real psychiatrist's couch, just like in a movie.

The psychiatrist stood up. She was of average build with shoulder-length dark hair. She smiled and gestured for me to sit in the chair in front of her desk. Without any small talk, she went straight to the point and told me, "Yvonne doesn't have autistic patterns, she has general retardation."

I became upset. First, the psychiatrist didn't see Yvonne until the end of the ten day stay, and when she did, it was while Yvonne was still recovering from the pneumoencephalogram. None of this was fair. I couldn't help being on the defensive. "How could you come to that conclusion after one observation especially when Yvonne was in a knocked-out condition?" To further emphasize my point, I sarcastically asked, "Did you observe Yvonne while she was sitting, crawling and standing?"

"Yes," she said, in a tone that wasn't convincing.

"You did! Did you realize that Yvonne had a pneumoencephalogram done the previous day and she was supposed to stay flat on her back for two days?"

The psychiatrist was visibly shaken. She either did have Yvonne up, which I doubted because Yvonne was drowsy all day, or she lied to me. I couldn't understand it. Why wasn't I getting an honest answer?

I knew I didn't have much time. I still wanted help so I quickly told her about the things Yvonne used to do but didn't do anymore. I told her we had read a lot on autism, and found Lorna Wing's book very helpful. Expecting her to confirm its helpfulness, I simply expressed, "You're probably familiar with the book."

She genuinely surprised me when she said, "No." How can a doctor in her position, I thought to myself, not keep up with current literature on the subject? The psychiatrist interrupted my thoughts and said, "Yvonne doesn't behave like a two-year-old autistic child."

"How does a two-year-old autistic child behave?" I asked, in all innocence.

"Yvonne doesn't have the motor activities," she replied.

I asked her to explain what she meant. "Yvonne doesn't walk or talk," she said. "She doesn't hold or handle things like an autistic child."

Thinking she would give me examples from her experiences, I asked specifically, "How does an autistic child handle things?"

"Yvonne does not behave like an autistic child!" the psychiatrist exploded. "You are getting me all worked up and nervous. I can see why the neurologist was so upset." I sat back in my chair, astonished. A parent upsetting a psychiatrist and a neurologist? It boggled my mind that I was upsetting them; I was only asking questions to help our child. Obviously the professionals had no idea of the worry, anguish and frustration that I as a parent was dealing with to help our daughter. However, I kept these thoughts to myself.

The psychiatrist regained her composure and said, "The psychologist observed Yvonne and I have used her reports. It's all in her books."

At this stage, I couldn't help myself and simply stated, "That's what I call a very unbiased opinion." I then asked her, "How many autistic children have you seen?"

"Oh, five or six," she replied.

I raised my eyebrows. "So you couldn't have seen too many two-year-olds?" She was silent. "Surely other doctors are diagnosing young children."

"Oh yes," she acknowledged with confidence. "I can refer you to five other psychiatrists who have diagnosed many autistic children."

I sighed a sigh of resignation, realizing I wasn't going to get any help. "That is what I wanted when I came to Montreal." Still, I asked the psychiatrist how I should be handling Yvonne.

She replied, "You answered that yourself earlier by having contact with her. That is all that can be done for her at this age." I didn't argue. Surely there has to be another doctor somewhere who can help us. Then, thinking she might have literature on autism which we hadn't read, I asked her.

"Literature!" she scoffed, "You can't go by literature." Then after a brief reflection, she added, "I can, however, give you Dr. Rimland's address and you can write to him."

“You mean Dr. Rimland in California who is working on the vitamin theory?” I asked.

“Yes,” she replied, “that’s about all I can help you with.”

I made one last attempt. “Well, what about the parents of autistic children that you have seen? Don’t you have literature for them?”

Her reply was a curt, “No.”

Realizing any further discussion was pointless, I gathered my coat in my arm, shook my head slowly and, not wanting to sound defeated, calmly expressed my disappointment. “I came to Montreal hoping to get advice on how to help Yvonne.”

The psychiatrist walked to the door with me and held it open. I nodded a quiet goodbye. A look of relief crossed her face. She closed the door behind me. I thought back to her earlier outburst and I couldn’t help but wonder—could she now be stretched out on the leather couch?

Slowly I walked back to the hospital. I was almost in shock. Of all the professionals, wasn’t it the psychiatrist who was supposed to have understanding and be considerate and helpful? Why was I having such negative experiences with the medical professionals? Why were they so antagonistic? Why couldn’t we work together? Why couldn’t I get help for Yvonne?

My frustration and anger toward all medical professionals slowly subsided when I thought of the psychologist, the husband-wife team of hearing specialists, the chief neurologist and the nurses. They were different. They were caring and they wanted to help. This, I realized, was my answer! I would focus my attention on the people who have positive attitudes because I needed their support. I would have to avoid dealing with professionals who have negative attitudes. But what do you do, I asked myself, when you’re referred to someone like that?

I couldn’t help thinking, these are the professionals, they are the experts. They of all people should have some solutions. I reasoned I’d have to disregard negative attitudes but I could keep pressing the professionals for a solution to the problem. If they were unable to help, I could insist they make a referral to someone else. Having found a plausible solution, I was no longer upset at the professionals and I returned to Yvonne with a brighter outlook.

Later in the day, I met with the neurologist and his two assistants. He told me, "All the tests are negative. From our experience, we all agree that Yvonne has definite autistic characteristics but they are secondary to mental retardation."

Somehow I was expecting to hear this. I didn't argue but calmly stated, "I still question the mental retardation diagnosis, because no one can tell us why Yvonne changed."

The neurologist replied, "I'm not surprised you aren't convinced but, convinced or not, you definitely have a serious problem and you're going to have to face it."

I acknowledged, "Yes, I know we have a serious problem. We're looking for ways to help Yvonne." Knowing that back in St. John's the child development specialist was making an appointment with a psychiatrist at the Janeway, and surely no psychiatrist could equal the one in Montreal, I was confident of getting help. With this assurance, I boldly told the neurologist, "I'll be taking Yvonne back to the doctor in St. John's." Then, wanting to make sure he would send his report without too much delay, I observed out loud, "You will be sending your report to her?"

"Yes." His tone suggested he would send it immediately. Was he anxious to close this case? He then explained that one of his assistants would sign the hospital release papers for Yvonne on Saturday afternoon; he wished me a good trip back to St. John's. I went back to Yvonne and got her ready for the night. Her final night at the hospital.

When I arrived at John and Judy's, they had arranged a babysitter for their children and were taking me out to a movie. "You need to relax," they said, "and take your mind off the past ten days." This was extremely thoughtful of them. Nevertheless, I didn't have my heart in it. Later, when I tried to recall some scenes I couldn't.

Saturday. I had mixed feelings as I packed Yvonne's belongings. I should have been excited to leave the hospital, but as I said goodbye to the children on the ward my heart ached for them. Many seemed worse than Yvonne, and several would be there for some time yet. And Richard was still waiting for surgery; his parents promised to call when they arrived back in St. John's. Before leaving, I also stopped at the nurses' station to thank them.

Stepping outside, Yvonne got her first breath of fresh air in ten days. I stood on the sidewalk in front of the hospital holding her in my arms. I wasn't ready to step into a waiting cab. As the cool air entered my lungs, I looked at Yvonne and sighed with relief, “It’s true, you’re out of there. You’re safe!” I hugged her tightly. It was all like a nightmare and the nightmare was finally over.

Chapter 5

The Psychiatrist

It was so good to be home. I embraced Peter and Teresa with tears of joy and relief. Sinking into a chair in our living room, I sighed, “If it wasn’t for John and Judy, I don’t know what I would have done. I don’t know how other parents can survive something like this if they don’t have support from friends!”

We had so much to talk about, but I was overcome with fatigue. I needed to lie down. Knowing that Peter was with Yvonne, I could relax. Several hours later I awoke, shivering and sweating simultaneously. I tried to get up but could hardly move. My chest hurt too much. My body, it seemed, went into an abrupt shut down. Ten days of worry, negative experiences and full responsibility finally caught up with me. Peter phoned our family doctor; I was supposed to rest, take aspirin and come to the office in the morning.

Having slept little, I was ready early and got the first appointment of the day. The doctor informed me I had pleurisy and a slight lung infection. This explained the pain. I thought back to the psychiatrist’s outburst in Montreal, that I was upsetting her and the neurologist; if the doctors only knew how the experiences affected my health. I found myself wondering how such experiences affected other parents. I was certain if the doctors’ attitudes were more positive, it would reduce the stress and anguish.

For the time being, I had to take care of my own health before I could help Yvonne. I slept most of the first day, and fortunately so did Yvonne. Peter and Teresa helped in the evening, allowing me to rest as much as possible. By Wednesday, I felt completely well and could resume the usual activities and spend time with Yvonne.

Later in the week, at the supper table, Yvonne screamed and refused to eat. We couldn’t calm her. In desperation we gave her Syrup of Phenergan and put her into her crib. About an hour later she cheered up and ate her supper, but only if I fed her. This was different. Mealtimes used to be happy times and she used to like to put food into her own mouth.

The following week I had a doctor's appointment to check on my condition. I couldn't get anyone to stay with Yvonne so I took her with me. Before leaving, I gave her Syrup of Phenergan as a precaution. It didn't help. She screamed the whole while, both in the waiting area and in the examining room.

Returning to the car, Yvonne was fine. I debated if I should stop at the mall since I needed a few items. Yvonne seemed settled; I would give it a try.

I carried Yvonne into the mall and put her into a shopping cart at the entrance between K-Mart and Sobeys and steered the cart into the K-Mart. Suddenly Yvonne put on a screaming display. People stared. I tried talking to her. I held her. It didn't help. I put her back into the cart, ignored her screams, and headed for the household section. No Sunbeam bags! Quickly I made my way toward Sobeys. I had to lift Yvonne out of the K-Mart cart into the Sobeys cart. "What a nuisance!" I muttered.

Yvonne calmed a little, although she was still crying. I got the milk and a few bags of sugar but I decided to forget the other items and turned the cart toward the checkouts. We had to wait in line. Yvonne screamed an ear-piercing scream. All cash registers fell silent, and every head turned in our direction. A rush of clerks in white uniforms, from the meat counter on my right and the produce counter on my left, converged on the front of the store. They stopped abruptly, their eyes piercing through me.

My heart was pounding. I wanted to run. My mind, however, told me to stay in control. I picked Yvonne up, hugged her and tried to comfort her, but she only tore at my hair and screamed louder. I set her back into the cart. A little grandmother flashed a look that clearly said, "I'd wallop that child and put her in her place!" The only way I could keep my sanity was to pretend I didn't hear Yvonne's screaming. My quizzical look at the long faces suggested, Do you have a problem? Do you hear something? I don't hear anything.

I paid for my groceries and, carrying them in my right arm, with Yvonne struggling in my left, walked out to the parking lot. I couldn't afford to break down. I drove home across town in a daze. Yvonne was fast asleep when I pulled into our driveway. I left her sleeping. I went inside, but came out often to check on her. Soon

I needed to drive to Vanier Elementary to pick up Teresa for her first dental appointment. Eeva would arrive any minute to babysit Yvonne.

In the evening when Yvonne and Teresa were in bed, I let my pent-up emotions explode. “I will never, never take Yvonne shopping again!” Peter just listened. He knew I had to get my feelings of frustration and hurt out of my system. He knew he needed to be patient until I was finished. Emphatically I continued, “From now on, if I can’t get a babysitter, I’ll go shopping in the evenings when you’re home.” My statement carried such conviction that Peter didn’t discuss other options at this time. He simply agreed I could shop in the evening, and he would be glad to stay home with Yvonne.

If Peter hadn’t agreed or if he had argued, I would have fallen to pieces. His understanding and support and his acknowledgement that it would be good for me to get out on my own gave me renewed strength.

My resolve never to take Yvonne shopping was short-lived. A recent article on autism stressed the importance of involving the autistic child in normal activities and normal environments even if the child rejected the situation, because that was the only way the child would learn to accept people, places and activities. The key, however, was to involve the child slowly and build up the time of exposure and involvement gradually.

This approach seemed to make perfect sense to us. We would try the technique with shopping. Peter and I planned our strategy. Our target: K-Mart. The date: every Saturday morning. The time: two minutes at first, adding a minute or two each Saturday, and both Peter and I would take Yvonne. Teresa would come along unless she went to a friend’s house.

At the beginning, Yvonne cried and people stared. It didn’t matter. The outing was only a few minutes and this was a “teaching program.” We stuck to our time limit and made no purchases. Generally we steered the cart to the toy section, hoping Yvonne would take some interest. I carried a tumbler of juice in my purse and gave Yvonne a drink. This kept her quiet for a while. I placed my purse in her lap in the shopping cart and let her chew on the plastic strap. This too helped keep her quiet. Gradually we increased the time and Yvonne accepted the Saturday routine. After a few months she even enjoyed these outings and with time I took her shopping on my own.

Meanwhile, the child development specialist received the reports from Montreal and asked to meet with us. “The diagnosis,” she said, “is definite autistic characteristics, secondary to mental retardation.” I nodded with awareness, and she continued, “I’d like to observe Yvonne next week and suggest a home-teaching program.” Noticing my smile, she added, “Yvonne has an appointment on April 30 with the psychiatrist at the Psychiatry Unit at the Janeway.” Finally we were getting positive action.

The following week, the child development specialist observed Yvonne and suggested various activities to promote Yvonne’s gross motor, fine motor, language and social development. Most of her suggestions weren’t new. Still, she offered several ideas: sand play, tactile experiences, large crayons, and a mirror at low crawling level.

The giant crayons were easier for Yvonne to handle than the regular ones, and I helped her to scribble on paper. We bought a door mirror, positioned it down to the baseboard and encouraged Yvonne to look at herself. She cried however, and refused to look up. Was she afraid? “Yvonne!” I exclaimed, “Mirrors are fun.” Turning on the Fisher-Price radio which played “Here We Go ’Round the Mulberry Bush,” I held her and talked to her in front of the mirror briefly every day. Gradually I increased the time. Months later, she finally smiled at her reflection.

Peter made a sandbox which we put downstairs in the unfinished basement, but Teresa got more enjoyment from the sandbox than did Yvonne. We tried every suggestion, as we wanted to give Yvonne every chance.

The day of our appointment with the psychiatrist arrived. Peter took time off work, and the three of us sat in the waiting room nervously wondering what this doctor would be like. A nurse approached us and smiled, “May I take Yvonne? The doctor wants to meet with you first. I’ll bring Yvonne to his office later.” I was apprehensive. The nurse was a total stranger. Could she handle Yvonne? I forced a smile and placed Yvonne into her outstretched arms.

Soon the receptionist directed us to the psychiatrist’s office. “Come in. Come in,” he welcomed us cheerfully, as we stood by his open door. He was tall and heavy-set with black wavy hair and a short curly beard. He was wearing a white lab coat. His office was small and crowded, a sharp contrast to the office in Montreal. Bookshelves lined the two end walls. The other walls each had a desk piled high with papers and books. A couch at one end faced into the cluttered room.

The psychiatrist opened the meeting with a questioning statement, “So, you think your daughter is autistic.” Again we went over the events, beginning with my pregnancy, which was normal, to the early months when Yvonne cried a lot, through to sixteen months. At sixteen months Yvonne changed.

He listened. He also interjected. His comments suggested he had carefully studied the reports from the child development specialist and the doctors in Montreal. “I don’t think she is autistic,” he said and smirked. I didn’t appreciate his attitude. This was nothing to smirk about, this was serious. He hadn’t even met Yvonne, yet he was telling us she was not autistic.

The psychiatrist explained how autistic children demanded sameness and that everything needed to be in its place. “We’re aware of that,” I said.

“All right,” he said, “we’ll have Yvonne come in, and if she is truly autistic,” he pulled open a drawer from his cluttered desk, “she will see there’s something wrong and she will close this drawer.” The determined expression on his face showed he was serious. We were dumbfounded. This was the ultimate test? Yvonne had never been in his room before, yet in this clutter she was supposed to know what was out of order. Not to mention that Yvonne had never closed a desk drawer in her life. Now the diagnosis would depend on whether or not she closed this drawer.

The nurse brought Yvonne in and put her down on the floor. Yvonne crawled toward us. She stopped at the desk with the open drawer. She turned to a sitting position, faced us and screamed. I picked her up and held her tightly, trying to comfort her. The psychiatrist closed the drawer and nodded his head, indicating he was correct. We, on the other hand, interpreted it differently.

The psychiatrist now told us about Exon House, an institution in St. John’s for retarded children. He advised us to place Yvonne there. He would make the referral. Shocked and wide-eyed with disbelief, Peter and I shook our heads. I finally found my voice. “No! We don’t want her in an institution. She belongs with us. We’re asking for advice on how to help her.”

When he realized how emphatic we were about keeping Yvonne at home, he pronounced, “Well, you can probably do it while she is young. In a few years, however, when her retardation becomes more obvious, you will have to put her into an institution.” He added accusingly, “You also have your older daughter to consider and it’s not fair for her.” We were aghast. Before either of us could reply, the psychiatrist continued, “The stress of having a retarded child usually leads to a family breakup. If you want to survive as a family, you will institutionalize her.”

“How can you say that?” I fired back. “You haven’t seen Teresa’s interaction with Yvonne. She loves her. It would be devastating for all of us if Yvonne wasn’t with us.”

Looking sternly at the psychiatrist Peter retorted, “What do you mean ‘If we want our family to survive?’ Placing Yvonne into Exon House would in itself tear our family apart.”

I was angry and upset. Yet my conviction and determination gave me strength. I recalled my frustrations with the doctors in Montreal and my subsequent resolution. Boldly I put my plan to the test. “We do need help,” I acknowledged, “we don’t know how to stop Yvonne’s head-banging.” With growing confidence, I continued, “If you can’t help us, then I am asking that you refer us to someone who can.”

This approach obviously worked, because he immediately said, “I can stop Yvonne’s head-banging.” I thought to myself, maybe we’ll get some help after all.

The psychiatrist now talked about hospitalizing Yvonne in the psychiatry unit, for two weeks, starting the next day. I flinched. I wasn’t ready for another experience in a hospital; nor was Yvonne. Still, I was curious about his intentions. So I asked him. He talked about Yvonne being in a crib, wearing a harness with long straps, tied to the crib bars.

“No,” I interrupted, “Yvonne went through that for safety reasons in Montreal, and it didn’t stop her head-banging. I won’t put her through that again; there has to be another way.”

He retorted, “Obviously there is a problem in her environment.”

If he was blaming our home life, I wanted to know what it was. Having nothing to hide, I pleaded, “Come to our home, and help us figure out the problem or what we’re doing wrong.”

When he realized I was sincere, he suggested I bring Yvonne to his unit on a daily outpatient basis. To us it was clear he wouldn’t leave his own turf. “We can start the observation immediately,” he said.

I took my pocket calendar out of my purse. “I just enrolled Yvonne in a six-week tiny-tot swim program Tuesday and Thursday mornings.” After some discussion, we agreed that for the next two weeks, I would bring Yvonne to the psychiatry unit every morning except Tuesdays and Thursdays, and every afternoon after her nap.

After a week of observation, during which the technicians mainly held Yvonne in their arms or let her chew on toys, the psychiatrist called me at home. He tried to persuade me to admit Yvonne as an inpatient. “I don’t see any benefit to Yvonne to spend nights at the hospital,” I said. “Besides, since the Montreal experience, Yvonne has lost some earlier gains. She is crying more, she won’t eat by herself, and she prefers to spend more time in her crib head-banging. Furthermore, we are now teaching Yvonne to accept environments in the community which she finds upsetting. We’re making good progress, and I’m afraid we might lose what we’ve just achieved.” Still he pressured me.

I became emphatic. “We won’t agree to admit Yvonne in the hospital, unless it’s essential for medical reasons!” The psychiatrist wasn’t pleased. I hung up and told Peter about the call.

“We should write a letter to the psychiatrist,” he insisted, “explaining why we won’t allow him to hospitalize Yvonne for observation purposes.”

“I think my conversation should be sufficient,” I replied.

“I think he needs to have our decision and our reasons for the decision on record,” Peter stated firmly. Together we worked on the wording of a full-page, single-spaced typed letter. We kept a copy.

This was our second letter in a week. We just mailed a lengthy letter to all doctors involved with Yvonne, in which we expressed the concern that they virtually ignored our questions about Yvonne’s change in behaviour. “Furthermore, it appears that only our family doctor believes our account of Yvonne’s early development. We’re accused of being difficult parents unwilling to accept an unfavourable diagnosis, but autism can be an even more serious disorder than retardation,” and we quoted some references.

We also wrote that we had no preference for a diagnosis, we just thought they didn’t consider all the facts. Most importantly, we wanted to know how we should treat or handle Yvonne to her greatest advantage, and we expressed concern about losing valuable time. We outlined the progress that Yvonne made from applying what we had read. We acknowledged that the child development specialist recently suggested a structured home program, the first assistance we received. We hoped the psychiatrist at the Janeway would be helpful as well. Our letter ended with a quotation from Dr. Lorna Wing: “It requires considerable courage for parents to make their own decision as to whom to trust and whose advice to follow. They usually have to make a decision on the grounds of their own common sense and experience with children.”

The psychiatrist no longer talked about admitting Yvonne to the psychiatry unit. At the end of the two-week observation period, the psychiatrist asked to meet with Peter and me. Seated in his office, he said, “For someone to be diagnosed as autistic, the individual would have to have all the characteristics described in Dr. Creak’s Nine Points.”

To the best of our understanding Dr. Creak was a researcher whose points identified various aspects of human development: a child’s awareness of his or her personal identity and the child’s use of personal pronouns; interaction with other people; behaviours related to changes in the environment; excessive anxiety, ritualistic or bizarre postures; and communication. Dr. Creak described each point in language that required interpretation. The psychiatrist clarified these statements. Peter and I needed time to think about them. The psychiatrist said, “You can work on this at home but independent of each other.” He set up an appointment in two weeks time to conclude our discussion.

Peter drove me home and went back to work. Eeva was with Yvonne at our house; she was so helpful! I talked to her daily about the developments concerning Yvonne. After countless doctor’s appointments and tests, we still didn’t know why Yvonne had changed. I was frustrated. I put my faith in doctors, believing they were the experts, believing they had the answer, believing they could help.

When Eeva left, I sat at the dining room table mulling over the past eight months, hardly believing that the doctors hadn’t found the reason. I stared blindly at Teresa’s kindergarten art taped to the wood panelled wall. Then a revelation struck me, that the doctors didn’t know the reason for Yvonne’s change. What’s more they might never know. I now sensed that what happened had to be God’s will. I experienced a strange feeling of peace which convinced me. The diagnosis didn’t matter anymore. What did matter was to help Yvonne the best we could, the way she was. Maybe someday God would show us the reason.

In the evening, I shared my experience and thoughts with Peter. He disagreed with my conclusion that illness and tragedy occur because it is God’s will. I, however, received strength and a renewed commitment to my faith, and that's all that mattered then.

Later though, I struggled with that belief and often questioned pastors and ministers in search of an answer. Through these discussions it became clear this was not a black and white issue. I finally came to understand that God does not will illness, tragedy, disaster or evil, but these things happen. How we accept them and deal with them depends on us. If we maintain our faith, we will be strengthened and find peace through the trials which we face. I could accept this; I no longer needed to question.

During this time Peter remarked, "Retardation can occur in one of twenty births. We already have twenty-three nieces and nephews in the Penner family." Then he confided, "I've often thought, that if retardation had to happen in the Penner family, I'd rather it be in ours. I'm glad it didn't happen to my brother Art." Peter's brother Arthur and Henrietta had a son, born six months after Yvonne.

Relieved, I also shared my feelings. I often thought of my brother Henry and Verna who had a daughter born two months after Yvonne. I was thankful it hadn't happened to them and I too would rather it happened to us. Sometimes I felt guilty thinking that way, I didn't know if it was fair to Peter. After Peter and I shared our feelings, we were drawn closer together and this strengthened our commitment to Yvonne.

We had our follow-up appointment with the psychiatrist to discuss Creak's Nine Points. Although Peter and I had different examples for each point, our general assessment was the same. We agreed that Yvonne very definitely displayed only five of the nine characteristics. According to this assessment, Yvonne was not autistic.

The psychiatrist suggested, "If Yvonne has done what you claim she has done, then she must have a regressive condition." To my surprise he admitted, "However, I do not know what that would be." His statement reinforced my belief that the doctors didn't know why Yvonne changed. It no longer mattered to me. What did matter was whether he could help.

He talked about our next appointment. Since we were leaving on a four-week vacation, the appointment was set for August 6. As we walked toward the door, I said, "It would be very helpful if we could meet with other parents in a similar situation. Do you know of any parents with an autistic child in the St. John's area?"

"Yes," he said flatly.

My hope rose. With enthusiasm I asked, “Could you put us in touch with them?”

He shattered my hope, however, when he simply stated, “No.”

“Why not?” I implored.

“Because I do not want you to become ‘professional parents,’” he stated stiffly.

I was puzzled and let down. At the time, I didn’t know what he meant by “professional parents.” All I knew was he could have helped but he refused. Peter and I already debated if the sessions with the psychiatrist were of any value. This added to our doubts.

Ironically, that evening our friends Walter and Patricia told us about their acquaintances who knew a family with a daughter, several years older than Yvonne, who was autistic. They put us in touch with this family. Our first contact was by phone. I was encouraged by their daughter’s progress. Much of the progress, however, was due to the parents’ efforts. They too had stories of their struggles in obtaining help for their daughter. The mother invited us to their home. “We’d appreciate any help you can give us,” I said, “and maybe somehow we can support each other.”

“We finally have someone to talk to,” I remarked to Peter, “who has experienced what we’re experiencing!” I couldn’t understand why a doctor wouldn’t put parents in touch with other parents in a similar situation. This family gave us hope.

With a brighter outlook and no more medical appointments until late summer, I could concentrate on preparing for our vacation. This summer we planned to drive to Saskatoon where Peter would attend a conference. Afterwards we would drive to Vancouver Island. Hearing about our plans, a friend expressed concern. “You won’t get a holiday if you take Yvonne with you.”

I reflected on her statement. Even if we wanted a holiday on our own, where would we leave Yvonne? We couldn’t expect friends to assume such a responsibility. We had no options. Yet if an option was available, would we accept it? Yvonne enjoyed car trips and tenting. Should we be selfish and deny her that enjoyment?

On the first day of our trip Yvonne threw her head against the back seat of the car to head-bang repeatedly. She cried pitifully. Later she scurried to the wall of the tent and bounced her head against the canvas. She whimpered. I was disillusioned. Later, while visiting at Mom Penner’s in Manitoba, we noticed that Yvonne no longer banged her head. When had she stopped? Could it really be that her last attempt was that first night in the tent back in Newfoundland? We were elated. Tenting had cured her head-banging!

On our return trip Peter turned to me late one night and haltingly, whispered in my left ear, "Do you know what one of our aunts said to me?"

"No, what?" I asked, sensing it was significant.

"She said," he stopped momentarily, "'maybe God will be merciful and take Yvonne from us.'"

My mind and body went numb. I stared ahead into the darkness, seeing nothing. I couldn't cry. I wasn't even angry. I was simply stunned. After the initial shock wore off, I felt sad that the aunt didn't understand. "How could she say that?" I asked aloud. "We love Yvonne. Sure, Yvonne needs extra care but that doesn't matter to us. We love her for who she is. Please, Lord," I prayed, as tears trickled down my cheeks, "don't take her from us." I reached for Peter's hand and clutched it tightly. Then, questioning but not expecting an answer, I said, "Had the aunt not seen that Yvonne's retardation didn't matter to us?"

I lay awake a long time, totally overwhelmed. I recalled past events. First we had the experience with the medical profession, and now this experience within our own family. It was so unexpected. I then recalled an earlier comment by another relative who had nodded toward Yvonne and whispered, "Do you want this kept quiet?"

Disgusted by her attitude, I shot back, "Do I want what kept quiet?" She didn't pursue it any further.

Recalling this incident I silently acknowledged we had a lot of work to do. "Lord," I prayed, "help us to show others that Yvonne's disability doesn't matter and have people accept her the way she is."

* * * * *

Our appointments with the psychiatrist resumed in August and carried on into the fall. He talked to us about retardation in general. He informed us that we could expect to see a gradual but slow improvement in all areas of development. We found this encouraging.

"What about her talking?" Peter asked.

"Oh, I have no doubt that she will talk," he replied. Relieved, my body relaxed. But only for a moment because he continued, "If, however, she has not learned to talk by five years then she won't talk."

My muscles tightened and my mind raced—we have three years to teach her to speak. We can't waste any time. I asked the psychiatrist, "Where can we get help to teach her?"

To my amazement he said, "There is a speech therapist in town. I can speak to the child development specialist about making a referral." This was a positive session. We left the meeting feeling we were making progress.

Arriving at our next appointment, the psychiatrist introduced us to his three psychiatry students, all in white lab coats. "I have asked them to sit in on the session," he stated, "because I thought it would be a valuable experience for them." Looking at Peter, I raised my eyebrows. He shrugged his shoulders. I felt uneasy. I sensed that Peter did as well, but what could we do? The psychiatrist hadn't asked if it was all right with us. Apparently this was part of his teaching procedure.

The three students sat on the couch behind Peter and me. The psychiatrist, also wearing a white lab coat, faced us like a lecturer. He informed Peter and me that he gave his students some background on Yvonne and he would carry on from there.

I asked myself, is this ethical? Shouldn't he have obtained our permission first? While I pondered this thought, I heard him say, "Today we will deal with the emotional aspects of having a retarded child." He then instructed us not to "bottle up" our emotions. "Let me give you an example," he said. "If you're in a grocery store and you suddenly have the need to cry, don't hold back. Cry. There is nothing wrong with crying in public." I chewed my lower lip and told myself this is contrary to our upbringing; I will never, never let that happen.

During this session, the psychiatrist said something about Yvonne which brought tears to my eyes. I fought hard to blink them away and succeeded, but not before the psychiatrist noticed. Swiftly he announced to his students, "If you had seen what I just saw, you would understand what I'm talking about." He turned to Peter and instructed, "Put your arm around her. She needs you." Peter didn't and I was thankful. To us the psychiatrist clearly wanted an emotional display, but he would not get it from either of us.

In another session, we asked the psychiatrist about support services. He sat back in his chair, curled his lower lip, shook his head and simply stated, “There are none. If you want services, you’ll have to move to England.”

“England?” Peter and I exclaimed in unison.

“Yes. That’s where the services are.”

Astonished, I blurted out, “This is where Peter’s job is and Teresa’s school and our families all live in Canada.”

He sighed, “Well, if you insist on staying in Canada, you’ll have to move to Saskatoon.”

“Saskatoon?” we said, surprised.

“Yes, they have the best services in Canada.” His voice had a note of authority.

Peter and I looked at each other. Ordinarily Peter left the talking to me, but this time he said what we both were thinking. “If they have services in England and Saskatoon, then why can’t we have services where we live? We can’t be the only family who needs services.” We didn’t accept the psychiatrist’s advice and gave him our straightforward reason. No doubt we reinforced our reputation for being difficult parents.

We had another appointment with the psychiatrist. Why did we continue? Perhaps it was because the community regarded a man in his position highly, and we shouldn’t turn down assistance from someone of his calibre. Regardless, we wanted to do our part as parents.

In this session, the psychiatrist talked about our feelings toward Yvonne. “It might be easy to love and hug Yvonne while she is young; but when she gets older and her retardation becomes more obvious, it will be very difficult. There will be times,” he emphasized, “when you will wish her dead.” Shocked, I wondered if I heard him correctly. He obviously saw my expression because he repeated, “Yes, there will be times when you will wish her dead but that’s normal. There is nothing wrong with that.”

I felt the blood drain from my face. This man is supposed to help us? Does he use this approach with other parents? Peter and I eventually left his room in stunned silence. I cancelled future appointments and we never saw the psychiatrist again.

Chapter 6

Happy Times, Sad Times

We felt so alone. Who could we turn to? Often I talked to the mother of the girl with autism, but somehow this wasn't enough. Were we the only ones dealing with such problems?

My friend Eeva encouraged me to get involved in other activities. "It'll be good for you," she said. "You need time for yourself too." She often invited us to dinner parties. She also persuaded me to join the Women's Association at the university. Eeva was right. Taking time for myself helped. I even enrolled in a twelve-week night course on interior decoration. Peter and I became members of the Horticultural Society, and we joined a weekly badminton club.

Being involved in various activities broadened my interaction with adults and took my mind off the difficulties concerning Yvonne. I became more energetic and enthusiastic. I enjoyed playing with Yvonne and working on the home-teaching program which the child development specialist outlined. I also worked on tongue and lip exercises which a speech therapist suggested. Both specialists arranged appointments to reassess Yvonne in six months.

Meanwhile, I observed that Yvonne made considerable progress. Occasionally she played appropriately with her toys. She turned the knob on the Fisher-Price radio, pulled the bumblebee by the string, and placed rings on a peg. I kept a diary on her development and behaviour. For several days each month, Yvonne was the happiest and most lovable child. Her boisterous laughter was contagious. Her radiant smile and sparkling eyes were most captivating. During these happy times she allowed me to teach her new skills and she learned them more quickly. She even attempted things on her own.

One day, before her third birthday, she stood up on her knees. I watched as she inched forward with one knee and then the other. Then, dropping onto her hands, she let out a nervous laugh. I laughed with her. "Yvonne, you're walking!" I exclaimed and hugged her. "Good for you! We love you so much!" Her eyes brightened. She crawled off my lap and got up on her knees again. Cautiously but still smiling, she moved forward a little farther. She tried it over and over, laughing at her accomplishment. She taught herself to walk on her knees. My hope soared. “Someday you’ll walk on your feet.”

A former neighbour, Maria, came for a visit while Yvonne was happy. “I can hardly see anything wrong with Yvonne. She’ll probably snap out of it.”

“That’s interesting,” I said, “several people have recently said that. Yet we have to face reality. Peter and I don’t expect it’ll happen.”

Yvonne’s happy times were short-lived. For several weeks she went through a difficult time; she cried and was not interested in anything. She preferred to be by herself, in the crib. At night she couldn’t sleep. At these times I sat up with her, hugged her tightly, and sang softly in her ear. Singing seemed to soothe her. She became quiet. But one cold and snowy night I was unable to calm Yvonne. It was already 3:00. I was exhausted and exasperated. I didn’t know how to help her, and I couldn’t stand her crying any longer. I needed to get away.

I laid Yvonne down, walked out of her bedroom, and closed the door. Tiptoeing into our bedroom I gathered my clothes and got dressed. In the darkness I groped for my coat, scarf and mittens. I assured myself if Yvonne cried too loudly, Peter would wake and tend to her. I had to get out. Some time ago I had discovered that a walk by myself enabled me to meditate, giving me renewed strength to cope with the situation. Never before though, had I considered a walk in the middle of the night.

Turning the doorknob, I stopped. Silence! I waited and waited. Had Yvonne really fallen asleep? Holding my breath, I quietly undressed. If she wakes, I vowed, I’ll be out like a shot! Yvonne remained asleep. So did Peter, unaware of my night’s frustration and intention.

Eventually Yvonne came through the difficult time; joyously I said, “Welcome back, Yvonne. Welcome back!”

I approached Yvonne’s next appointment with the child development specialist enthusiastically. Socially, Yvonne had improved a great deal. She smiled a lot and made good eye contact. She liked to be held and wanted to be with us. The assessment, however, didn’t reflect this improvement. Yvonne was also using the potty regularly, but didn’t get credit for this achievement because the chart did not list this skill. According to the chart, Yvonne made no significant gains in the past six months. Annoyed I declared, “I don’t think this is fair for Yvonne!”

“You’re right,” the specialist acknowledged. “Yvonne has improved socially, but the chart does not adequately reflect it.”

I pursued the subject a little further. “I also don’t think it’s fair to test Yvonne in a strange environment with unfamiliar toys. I think you should come to our home where Yvonne is familiar with things around her. I think you would get a different assessment.”

“Yes,” she agreed, “testing children in their familiar environment would be better; it takes time, however, and there aren’t enough of us to do that.” At least she recognized that a home assessment would be better. Eventually it might happen.

I noticed that Yvonne liked being with other children. Teresa’s friend Renate and her younger sister Krista came over frequently. Yvonne smiled and wanted to be with them. “Look, here comes Yvonne!” Renate giggled, when Yvonne crawled after them. “Boy, can she travel!” They laughed and Yvonne laughed with them. Renate and Krista often played the Bontempi electric chord organ in our living room because they knew Yvonne loved music. Yvonne stood at the organ, smiled, hummed, and nodded her head to the tune. I was glad they included Yvonne.

Sometimes, however, Yvonne got in their way. Once I heard an anxious cry. “Oh, no! Where’s the Barbie shoe? Where’s the belt? There’s only one stocking!” I raced into the room and dug my finger into Yvonne’s mouth. Nothing! We searched the room; we couldn’t find the articles. A few days later, the missing items passed through Yvonne’s system. Frightened and concerned, I had to come up with a solution. I talked with the girls and we agreed that when they played with tiny items, they would play in Teresa’s room with the door closed, and I would keep Yvonne with me. At other times, the door would be open and they could include Yvonne. This arrangement worked well, giving the girls time to themselves which they also needed.

Realizing that Yvonne enjoyed being with other children and that it could help her development, I contacted the YWCA preschool where Teresa had attended three years earlier. I explained that Yvonne was slower than other children her age, and she needed to be watched closely as she still put objects into her mouth and could swallow them. However, I thought it would benefit her to interact with other children.

The preschool program was full, but with my offer to help they accepted Yvonne Thursday mornings. I helped with the other children but if they needed me for Yvonne, I was there. After several weeks the coordinator suggested, "Yvonne might come to depend on you being here. It would be better for her if she didn't. Why not leave her and we'll see how we make out." I was speechless. They could manage without my help? She read my thoughts and said, "If we run into problems, we'll call you."

I drove home and sat by the phone. It didn't ring. I checked the clock. I picked up the receiver; of course the line wasn't dead. I went from one room to another. I didn't know what to do. This was my first morning of freedom and I felt lost. At noon I arrived at the preschool filled with apprehension, yet everything had gone well. Eventually I learned to relax and use my time wisely.

Each time I arrived to pick Yvonne up, the staff eagerly told me what Yvonne did. Some days Yvonne cried, but they managed to console her; other days she stayed beside the children and watched them play. Sometimes she attempted to play with a toy by herself. Most significantly, she stayed seated and enjoyed the story time. The staff enjoyed having Yvonne; they were excited about any progress she made!

I noticed a boy, about a year older than Yvonne, who also appeared slower than the other children. This day his mother arrived as I was helping Yvonne and we began chatting. "At birth," she said, "they labelled my son 'mongoloid' and the doctors said he wouldn't amount to anything." I was astonished and briefly told her about our experiences. "Oh!" she replied smiling. "Yvonne is such a sweet child. It's hard to believe she wasn't always this way." By this time her son and Yvonne, dressed in warm clothing, became impatient with us. The mother swiftly said, "My name is Ginna. Why don't we get together?" She gave me her address; she lived just two kilometers from our home. But each time Ginna and I arranged to meet, one of us had to cancel, either because of illness or unexpected appointments. With summer approaching we decided to wait until the fall.

July arrived. This year we decided to stay in Newfoundland as we were expecting visitors. My sister Rita came, this time with Mom Wiens. During their visit we drove to Placentia on the southern shore of the Avalon Peninsula. We entered the interpretation centre on Castle Hill and viewed the exhibits. I paused to read the inscriptions posted on the wall. Yvonne was standing beside me, holding onto my hand. Suddenly her hand released mine. She was standing on her own!

Looking into her eyes, I slowly extended my hand toward her. "Come, Yvonne. Come to me," I coaxed, with whispered enthusiasm. If I kept looking at her, maybe she'd take a step. Ignoring everyone around me, I became exuberant. "Come, Yvonne. You can do it. Yes you can!"

She smiled, breathed heavily, twirled her fingers in her mouth and took a step. I held my breath and backed up another step, my eyes never leaving hers. She took another step! I backed up. She took yet another step! I reached out and hugged her. "Yvonne, you're walking! You can do it. Yes you can." Looking up I saw Rita, Mom Wiens, Peter and Teresa smiling. Strangers strolled by and smiled. This was an historic day. Yvonne walked on Castle Hill.

When we got to the parking lot, Teresa excitedly said, "Let's see if Yvonne will walk again!" I was concerned about pressuring Yvonne but relented to Teresa's pleading. Teresa held Yvonne's hand, then staying close beside her, let go. Yvonne kept walking. Her walk was strange, her legs were spread far apart and her body teetered side to side, but she smiled broadly, thrilled by her achievement.

We too were thrilled to see Yvonne walking! She was three years and three months. Four days later, however, Yvonne caught a cold and wouldn't walk. It was a week before she tried. Then she slipped and fell on a neighbour's hardwood floor and was badly frightened. It was three months before she gained enough confidence to try again. After that, nothing interfered with her desire to walk. She walked with a wide awkward gait. Eventually though, it developed into a long stride.

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In the fall, Ginna and I finally got together. Although twenty years older than I, Ginna had energy that could shame many a younger parent. She had a wonderful sense of humor, a raspy laugh, and a voice which boomed with confidence and authority. Her older children had already left home. "My son has Down Syndrome," she explained. "It's a recent and kinder label than they gave him at birth. She then told me how doctors, friends and some family members encouraged her to put her son into Exon House.

"That happened to you too?" I asked with surprise.

"It's values, my dear," she stated. "People with retardation aren't valued for the human beings they are. People with retardation will never be doctors, lawyers or teachers, and society would rather lock them up and forget them." I began to understand why we too had experienced such negative attitudes and we were not alone in our struggle to have our daughter accepted.

Ginna told me the joy her son had brought and about the things he could do. “To think,” she scoffed, “doctors told me he would never be able to do that; well, I’ve shown them!” With a defiant laugh, she continued, “And I’ll keep showing them!” Ginna’s determination and her confidence that she was right in what she was doing boosted my spirits immeasurably. I found someone else I could count on.

She told me about the National Institute on Mental Retardation (NIMR) in Toronto and gave me some recent booklets. This literature spoke of people with mental retardation in a positive way and emphasized that “a retarded child is just another member of the family.”

How different from the literature we got from the child development specialist. Articles from that bibliography list, dated mainly in the 1950’s, some in the 1940’s, called “retarded” people “subnormal, subhuman, mentally defective, deviant, sick, inmates, patients and the best place for them is an institution.” Such literature was disgusting. It was a waste of our time. We were appalled that even in the late 1960’s negative attitudes still prevailed. We disregarded any advice that was contrary to what we believed about the value of all people. We welcomed the books from NIMR. These articles addressed the importance of supporting families and providing resources within the community. Community resources were exactly what we wanted, and now we had books to back us up.

Ginna also told me about the St. John’s Association for the Mentally Retarded (AMR). I knew nothing about it and went to the next general meeting with her. Here she introduced me to Helen, an older parent, who delighted in welcoming newcomers. Helen wanted to know everything about Yvonne. Suddenly she said, “I want to introduce you to Mr. Dicks. He knows all about autistic children.”

Mr. Dicks was the Supervisor of Institutional Schools. He wore a suit and tie, and his jet black hair was slicked back with every hair in place. His smile complemented his suave image. He extended his hand, and in a soft voice welcomed me to the meeting. “We have a class for autistic children,” he informed me. “We have two teachers and a part-time helper for three children aged seven to fifteen years.”

I explained, “We’re no longer sure if Yvonne is autistic; she’s overcoming some of the earlier characteristics. Besides, isn’t she too young for the class?”

“Don’t worry,” he assured me. “The younger we get them, the better.” He encouraged me to call the senior teacher the following day and arrange an appointment to see the program. I was overwhelmed. In one evening, I learned about other parents, an association, and even met an official from the Department of Education and all were helpful.

A week following this meeting and a meeting with the teacher, I drove Yvonne to the Class for Autistic Children located in the basement of a church. She attended Tuesday mornings for one-and-a-half hours. The two teachers talked about working in cooperation with us. They even asked what was important to us. "I'm trying to toilet train Yvonne," I said. "Could you work on that too?"

"Sure," she replied, "how do you do it at home? We should use the same approach."

I added, "I'd also like Yvonne to keep her fingers out of her mouth and get her to use her hands appropriately."

"We can work on that," the teacher smiled. "We'll build up the time gradually so she can come the full week without being tired."

"Oh, don't worry," I laughed, "when she's home, her days are full. Sometimes I wish she would get tired!"

Shortly before Christmas Yvonne had her six-month appointment with the child development specialist. The specialist was pleased that Yvonne showed further improvement in her social behaviour. I informed her that Yvonne was attending the YWCA preschool and for the past month she was in the Class for Autistic Children. She asked many questions about the class. I was stunned. Didn't she know what was available in the community? Unexpectedly she asked, "Will you be going to further meetings of the St. John's Association?"

"Yes," I replied, not knowing why she asked.

Quite abruptly, she said, "I will see Yvonne again in six months; we will then talk about getting her into the Vera Perlin Preschool." I was puzzled. Why couldn't Yvonne stay at the Class for Autistic Children?

Soon the realization sank in. The specialist was clearly displeased that Yvonne was in the Class for Autistic Children whereas Vera Perlin was a preschool for "retarded" children. Her attitude disgusted me, but I said nothing. I would, however, find out everything I could about the program at Vera Perlin so I would be well informed.

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Since Yvonne began walking, she was a grown-up little girl. It was time to move her out of the crib. Peter built her a bed, low enough so she could get in and out on her own. Later, we could raise the bed with legs. We put the new bed opposite the crib so she could get used to it gradually. During the day, I changed her on the big bed and sat with her reading stories. A few weeks later, just before Yvonne's fourth birthday while I sang her favourite songs, she crawled off my lap and lay down. She stayed in her new bed and drifted off to sleep. I found Peter and motioned for him to look at Yvonne. We were amazed how quickly she accepted the new bed.

Soon we took down the crib and replaced it with Teresa's long play table. Yvonne was pleased. She stood at the table and played with her toys. She showed interest in things all around her. Often she reached up to take items off her dresser or the dining room table or the kitchen counter. We were delighted at Yvonne's new interests, but they also created tense moments.

One afternoon I heard a strange tapping sound from the kitchen; it sounded like metal. I went to investigate and saw Yvonne holding a sharp bread knife. She was waving it in the air like a music conductor. I froze. Then, without saying a word so I wouldn't startle her, I approached her cautiously. I reached out, gently placed my hand over hers, took the knife, and softly reprimanded her, "Yvonne, this is a knife. A sharp knife." I put the knife into the drawer and my knees gave way. Sinking to the floor, I reached out and hugged Yvonne. Thoughts of what might have happened flashed through my mind.

That night we established a rule: no one was to leave a sharp knife on the counter. Either it was washed and put in the drawer, or placed behind the taps of the kitchen sink. Yvonne, however, soon discovered when we were forgetful of our own rule, but not once did she suffer an injury. Often when Yvonne held a table knife, I was intrigued how she balanced it on her right index finger and played a rhythm with the blade on the counter.

We established another rule: we put all twist-ties into a box in the kitchen drawer or threw them into the garbage. One day, after taking bread out of the plastic bag, the phone rang. When I returned, I couldn't find the twist-tie. Instinctively my finger searched in Yvonne's mouth. Had she swallowed it? Or did I automatically put the tie into the drawer? Frantically I called the doctor. Calmly he said, "We don't want to pump her stomach if we don't have to. Keep an eye on her. If she throws up, take her to the hospital; if she doesn't, she'll be all right." I was tense for the next twenty-four hours. She didn't throw up.

Around this time Yvonne's eating behaviours deteriorated. When I gave her a cracker or cookie, she immediately crushed it into powder. In a swift motion she enclosed the cracker in her fist, rapidly rubbed her fingers in her palm, and then put the fine crumbs into her mouth. She also stopped chewing her food. She swallowed it whole, often choking on chunks that weren't cut finely enough. How could I get her to chew again?

I was convinced a solution could be found. On sleepless night I visualized Yvonne sitting in her high chair eating bread and cheese—gluey foods. Yvonne needed something crunchy but not harsh. Apples! Apples were crisp and would soften in the mouth.

The following morning I cut an apple into thin slices and removed the peel. I held a slice between Yvonne's teeth; she bit off a chunk. She swallowed it whole and almost choked. I sighed, "Yvonne, how can I get you to chew?" Pondering this question, I put my own jaws into motion. "Okay, Yvonne," I shouted enthusiastically, "this time I've got it!" I tried forcing a slice of apple between her back teeth. She wouldn't open her mouth. Putting the apple down, I held her chin and forehead and instructed, "Open!" Her mouth opened and before she could close it, I pushed the apple between her back teeth. Now she wouldn't bite down! I placed one hand under her chin and the other on top of her head, pressed down and exclaimed, "Bite!" She did. With physical assistance I repeated the procedure, over and over. Finally Yvonne opened her mouth on her own and I could keep the up-and-down movement going by pushing the apple in after each bite. It worked. Yvonne was chewing.

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I visited the Vera Perlin Preschool. They had three classrooms: one with equipment to develop gross motor skills, another with a piano and musical instruments, and the third with tables and chairs, toys, books and paints to develop fine motor skills. Each child received some amount of one-on-one attention. The staff were friendly and seemed dedicated. I was pleased with the program. Still, I was uneasy because the children displayed odd behaviours, such as hand-flapping and face-slapping; Yvonne might model these behaviours.

I raised this concern with the child development specialist when she talked about Yvonne attending this preschool. The specialist, however, said, "This is the most appropriate placement for her; I will make the referral. Yvonne has been in the Class for Autistic Children illegally because a child has to be five years of age.

Yvonne is still only four." That September I enrolled Yvonne at the Vera Perlin Preschool, which was operated by the St. John's AMR. She attended every morning. I became a member of this organization and helped in their fund-raising.

I also got more involved with Teresa's school. Teresa walked to school every day and I noticed the traffic problems. One child was hit and died; something had to be done. At a PTA meeting, a Safety Committee was established to address the pedestrian safety needs around the school. I volunteered, along with nine other parents, to be on this committee. My role was to obtain a copy of the Highway Traffic Act, pick out regulations which were applicable, and summarize them in a letter to be sent to all parents and staff.

The Safety Committee met with City Council regarding crosswalks and safety patrols. The chairman wrote a letter to the minister of Justice, with copies to the news media, outlining the problems and listing recommendations. This was my first experience with the political system and much to my surprise, this approach brought results.

Meanwhile, I was often on the phone with Ginna. She always had new information about retardation and support services. Now she told me about the Portage Project. "I used the approach they suggested to teach my son to button his jacket, and it works. It really works!" The kit included a booklet called the Checklist which covered six areas of development: infant stimulation, socialization, language, self-help, cognitive and gross motor skills. Each section was colour-coded and listed a variety of behaviours from birth to six years. A box of cards matching the six areas of development, each numbered to match the activity, outlined several ways to teach the behaviours. It was excellent. I later ordered my own kit and had great fun teaching Yvonne.

Ginna also told me about the Early Childhood Education courses taught through the University Extension Service. She took courses the previous year and highly recommended them. I then took two courses every semester for three years. The courses dealt with child development in general and more specifically with how children learn. They dealt with behaviour management and positive reinforcement. They taught the importance of observing a child, and how to observe the child. Some courses were directed specifically toward children with special needs.

I also learned through Ginna about the Direct Home Services Program (DHSP), a new program provided by the Department of Social Services, for mentally handicapped children from birth to six years.

I called. The receptionist was friendly but informed me, “Our workers’ caseloads are full. However, we can send someone to your home to do an initial assessment. Then we’ll see when we can fit you in.”

On February 3 the doorbell rang. “Hi! I’m Dr. Jennings from the Direct Home Services Program.” Dr. Jennings was a psychologist. He carried a briefcase and strode into the living room with an air of authority. “I’ll do an assessment using the Alpern-Boll Developmental Profile,” he explained. “I won’t test Yvonne; I’ll just ask you if Yvonne can or cannot do the tasks.” I was surprised and relieved; he trusted me! And Yvonne was spared the stress. He had pages and pages of checklists. When he completed the assessment, he said, “Yvonne qualifies to be in this program.”

The following week, Dr. Jennings returned to do a more thorough assessment using the Portage Project Checklist. He then asked, “Which skills are most important to you for Yvonne to learn?”

“That’s easy,” I said. “I’d like Yvonne to hold a glass, drink without spilling and set it down. A tumbler always slips through Yvonne’s hands and drops to the floor, unless I have my hand under it. I’d also like her to hold a spoon and scoop up her own food. It seems she has no strength in her hand, yet at times she has a solid grasp. I’m puzzled.”

Dr. Jennings opened his briefcase and removed a target sheet. “We’ll start with drinking,” he said. He wrote out detailed instructions on how to teach it. He noted the reinforcers: juice and praise. I was to teach Yvonne daily, five trials, and record all attempts, clearly identifying the successes. “I’ll review the target sheet next week and, depending on the result, we’ll either break the task into a smaller step or we’ll advance to the next learning step.”

During each weekly visit, Dr. Jennings also brought books such as Families, Living with Children, Beginning with the Handicapped and Child Behaviour Modification. Each week we discussed what I read. This was valuable. Soon I asked if I could write out my own target sheets under his supervision.

I was thrilled to see Yvonne learn. She drank by herself and set the glass down on the table. She ate by herself, drank from a straw, bent down and picked up items from the floor, and walked up the stairs. She did so many new things. I discovered I had to be persistent and very enthusiastic in my teaching approach. Teaching a single skill could take days, weeks or sometimes months. The longer it took for her to learn, though, the greater my reward when she finally succeeded.

I tried to teach Yvonne to flick on a light switch but I had no success. I was baffled until I realized she might not understand the relevance of the switch. I darkened the room, then flicked the light switch on. Still she didn't make the connection. "I need a small light bulb right next to a wall switch," I told Peter. "I'm convinced if she sees the light come on when she flicks the switch, she'll understand!" Then I added, "I've not had any success in teaching Yvonne to turn a doorknob. Maybe the door is too big. With that, I got an idea and explained it to Peter.

Together we designed a large activity board and mounted it on Yvonne's bedroom wall. It contained a miniature door with hinges and a regular doorknob. The door had a sliding latch and a chain lock. Next to it, we installed a miniature cupboard door with a regular handle and a magnetic catch. On top of the activity board I hung a tiny curtain on a rod. When Yvonne pulled it open, she saw a mirror and her name underneath. Peter installed a push-button doorbell, and next to a twelve-volt bulb, a regular light switch.

Every day I took Yvonne to this activity board. With great enthusiasm I announced, "Ring the doorbell." I demonstrated by pushing the button. "Open the door." I helped her and she found a puppet behind the opened door. "Put the light on." I guided Yvonne's thumb to the switch and assisted with an upward motion. And always I watched her eyes.

One day, three months later, her eyes brightened. I knew she understood. "Yvonne, that's right! Yvonne put the light on!" I hugged her, picked her up and carried her to the light switch by her bedroom door. "Yvonne, put the light on," I instructed. She did! Then I carried her to the kitchen, to the bathroom, to the living room; the light switch was the same in every room. In each room she flicked the switch. Her face glowed; she understood the function. This was a major achievement for her!

This incident made me realize how important it was for us to make modifications to help Yvonne understand. I also realized the importance to her that we explain the relevance of what we were teaching.

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Since Yvonne could attend preschool, we decided to attend church. In her younger years, we tried churches of various denominations in search of one where they would accept Yvonne. The nursery workers, however, always called for help. I found it too stressful to keep Yvonne quiet in a crowded nursery; staying at home was easier. Then, for a while, Peter and I alternated enabling Teresa to attend Sunday School regularly. This, however, was unsatisfactory because we couldn't participate as a family. Eventually we quit attending.

Now we attended a Baptist church and Yvonne adjusted well. One Sunday I participated in a workshop on Early Childhood Education; Peter still took Teresa and Yvonne to church. In the evening they greeted me with excitement. "Guess what happened this morning."

"Tell me!" I demanded impatiently, realizing it was significant.

Peter and Teresa smiled and blurted out, "Yvonne talked!" I stared at them. Was I dreaming or had I heard them correctly? Peter went on, "When I went downstairs to get Yvonne, Jean told me Yvonne stood by the door and said, 'I want Mommy.' Disbelieving, I looked at them blankly. In the past, Yvonne had spoken syllables like "eee-eee, a bwa-bwa, bwee-bee" and on rare occasions she said, "ma ma," "I," and "good" but never a phrase. There must be a mistake.

I called Jean and skeptically said, "Peter was just telling me you told him that Yvonne said, 'I want Mommy.'"

"Yes," she said, and then added, "Yvonne doesn't talk much, does she?"

"Yvonne doesn't talk at all."

"Well, that's what I thought you told me," Jean said. "This morning Yvonne was upset; she walked to the door and cried. I just asked her, 'What's wrong Yvonne?' That's when she said very plainly, 'I want Mommy.' A little girl standing beside her heard her too." When I hung up the receiver, tears of joy surfaced. Yvonne really talked! How I wished I'd heard her! Yet, if it happened once, it could happen again; our hopes soared!

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Sometime later, I encountered a very different experience in the church. I sensed at times the new pastor avoided Yvonne and me during the traditional handshake when leaving the morning service. I felt let down and mentioned it to Peter. "No," he assured me, "there is always a rush of people, and he doesn't shake everybody's hand. I wouldn't read anything into it." Maybe Peter was right, but still I had an uneasy feeling.

The following Sunday, with Yvonne in front and Peter behind me, I extended my hand, smiled and made eye contact with the pastor. He glanced at me and, avoiding my extended hand, looked at Peter, then cheerfully said, "Good morning, Dr. Penner!" My suspicions were confirmed and I was steaming inside. He ignored Yvonne and rejected me. Yet he accepted Peter because of his profession.

"I told you so," I said to Peter when we got to the car. For Teresa and Yvonne's sake I said no more, and sat in stony silence during the six-kilometer trip home. Inwardly, however, I was in turmoil. I would not attend where Yvonne and I were not welcome. Yet the people were accepting and supportive. And Yvonne had a right to go to church. If the church can't accept her, how can I expect the community to accept her?

By the time we arrived home I decided that if the pastor had a problem accepting Yvonne, this was something he would need to overcome. Perhaps we could even help him. We would continue to attend and maybe in time he might learn to accept Yvonne and shake her hand.

Attending church was stressful, but I was determined to have Yvonne participate. Yvonne had outgrown the nursery; therefore, she was in Sunday School with my support or she sat with us through the service. During the service, I watched Yvonne's facial expressions and was ready to place my hand over her mouth if she let out a cry. Sitting in a back pew near the door, we could leave quickly and easily if necessary. In the foyer I would explain to Yvonne, "You have to be quiet, like the other people." When she was quiet, we'd go back in.

Yvonne, however, was swift and at times caught me off guard. Disregarding my instructions, she stood up and made a loud sound, or cried. I was usually tense and got little out of the messages. Yet if we didn't include Yvonne and teach her, how could she possibly learn appropriate behaviours? For us it was important that Yvonne be part of our family and the church family.

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Ginna called, "I just got some mail from Ontario about a Pilot Parent program. My dear, it sounds marvelous! It's precisely what we need here."

Pilot Parents were parents of sons or daughters with a mental handicap who could provide moral support and information about services to new parents of a handicapped child or to a new family moving into the community. “How do we go about getting it set up here?” I asked excitedly.

“It’s quite simple,” she said, “we’ll bring this to the next meeting of the St. John’s Association; and you, my dear, can tell them about the problems you had. Then you emphasize that had there been a Pilot Parent program, you could have gotten information much earlier.”

Sweat formed in my palms, “I haven’t spoken in public before. I can’t do it.” Ginna persisted. I acknowledged she had, in essence, been my Pilot Parent and without her I would still be very much alone. I owed it to other parents. Nervously and reluctantly I agreed.

As planned, the Pilot Parent program was on the agenda at the next St. John’s AMR meeting. At the end of the meeting several parents, including Ginna and myself, volunteered to form a Pilot Parent committee.

This committee met twice a month and received guidance from resource people from NIMR. Five months later the committee produced a blue and white brochure containing the inscription: “Pilot Parents for the Mentally Handicapped” and proclaiming, “When you feel alone with your problems, maybe we can help.” It described the program and included the names of five parents with their phone numbers. We distributed these brochures throughout the city in doctors’ offices, libraries, hospitals, churches, preschools and any appropriate public building. We wanted people to know there was a support group for parents.

Parents whose children were in the Direct Home Services Program met regularly. Sharing experiences and information was valuable. We learned that some families were on a waiting list because of insufficient child management workers. The parent group, with the director of the DHSP, developed a plan to support the need for additional workers.

Ginna and I found ourselves elected to represent the parents. We prepared a two-page questionnaire for every parent in the program and those on the waiting list. We met with doctors, including the child development specialist, and worked together on a brief. We noted cost comparisons between home support and support for children in the Exon House institution. Home support costs were dramatically less. We mailed this brief to the minister of Social Services. Eventually Social Services approved funding for additional staff. Our efforts had paid off.

During one of the DHSP parent support meetings, I met a mother whose daughter was similar to Yvonne. I offered to lend her a book I found encouraging. It was about a young girl with autism. The doctors had given up on her, but her parents hadn't. Their unfailing efforts eventually brought miraculous results. The girl progressed, she learned to talk, and later she even got a job. It was a story which gave me much hope.

Several weeks later, I asked the mother what she thought of the book. The muscles in her face tightened and she unzipped her purse, removing the book. "Here," she snapped, and threw it at me. Shouting and shaking, she continued, "I get sick and tired of reading books like that. It's fine for them to talk about their daughter but that will never happen to mine!" I was shocked by her outburst.

Later, after I reflected on what she said, I recognized truth in her statement. I began to realize that many parents might work just as hard but never see a miraculous breakthrough. This could lead to feelings of bitterness or even failure.

I thought of Yvonne and how we rejoiced at each small achievement. Yet no stories supported parents for their efforts, no matter what the outcome. It was then I decided that I would write a book someday to encourage these parents. Their efforts are as valuable as those of parents who achieve remarkable outcomes.

I kept all my notes and letters and placed them in a large cardboard box. Tucked safely in our bedroom closet, this became my greatest treasure.

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Yvonne made certain developmental gains while she attended the Vera Perlin Preschool, but she was missing out socially. She needed to be with children who weren't handicapped. I mentioned this to Dr. Jennings and he asked, "What would you want for her?"

"Well," I reflected, "Yvonne just turned five. I think a year in a regular preschool would be beneficial. The older group, however, attends only two mornings a week. Maybe she could attend the Class for Autistic Children the other mornings."

He looked thoughtful, then nodded. "It sounds like a good combination for her. I would suggest you inform the child development specialist and I'll support these two placements."

Dr. Jennings' support carried a lot of weight. Late in July, I received a letter from Mr. Dicks at the Department of Education. "We are pleased to accept Yvonne at the Class for Autistic Children for the school year 1976-77, provided an appropriate program can be worked out for her." I wasn't concerned about the qualifying clause in his letter since Dr. Jennings had assured me he would be involved to provide a transition from the home program to the school.

Enrollment at the preschool was straightforward. Ginna told me a former teacher from the YWCA preschool started her own, Happy Times Preschool. Ginna's son attended the previous year and she raved about Mrs. Lono, her staff and the program.

I called Mrs. Lono to register Yvonne. She remembered Yvonne and was glad to accept her. I was relieved; the program was nearly full and Mrs. Lono accepted only one handicapped child for every nine non-handicapped children. This was for the benefit of all children. Mrs. Lono had a real gift of relating to all children and when a child asked why someone couldn't talk or do something, she explained it simply and casually. Her approach was always positive. She treated all children with equal warmth, understanding and love. She and her staff provided a fun and caring environment.

With Yvonne's school program settled, I had five mornings a week to myself. By the second week, however, I was spending my time and energy dealing with problems at the School for the Handicapped (previously called the Class for Autistic Children). The teachers seemed to feel threatened by Dr. Jennings' involvement. The atmosphere was tense, and establishing cooperation between home and school was difficult. The previous year, the senior teacher greeted us with a bright smile. This year, however, she didn't smile. The junior teacher took close direction from her superior, and she too became unfriendly.

Once, during a meeting with the teachers, Yvonne was kneeling on the floor and the senior teacher extended her hand and instructed, "Get up, Yvonne. Get up!" Yvonne didn't move. Consistency in language was crucial. I therefore politely told the teacher that Yvonne understood the word "stand" up. The teacher ignored my comment and commanded, "Get up, Yvonne. Get up!" Still Yvonne didn't move. In a swift motion, the teacher withdrew her hand, tossed her soft light curls into the air and announced, "All right then," and walked away.

I went to Yvonne, held out my hand and said, "Stand up, Yvonne. Stand up." She stood up immediately. The teacher's attitude disappointed me. After all, she earlier stressed the importance of consistency in communication and cooperation between home and school. I was further frustrated because the school did not set up an individualized structured program. At home, I continued to write out teaching programs and worked diligently with Yvonne. I learned that enthusiastic praise, sometimes to the point of over dramatization, was a key to Yvonne's learning. Yet the teachers used a cold, demanding approach.

Our friends recognized our frustration and suggested, "Why not pull Yvonne out of the program? You're doing more for her at home, and your health is suffering." It was true. The stress was affecting my lower back and limiting my activities. Nevertheless, we wouldn't withdraw Yvonne from the program. A principle was at stake. We believed that although Yvonne didn't have a legal right, she had a moral right to be in school.

Furthermore, Mr. Dicks had stated, "These teachers are professional and highly qualified to teach autistic children." If this were so, then we should expect to get services equal to or greater than what I as a parent could offer Yvonne. We requested further meetings with the Department of Education to address the problems and to find solutions. Mr. Dicks used a silky-smooth approach toward us and the teachers. Unfortunately, he did not resolve the problem.

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By late November, we looked forward to Christmas for a break from the problems at the school. Christmas in the past, however, was not a happy occasion for Yvonne. During Dr. Jennings' visit, I explained how Yvonne screamed when we opened the gifts; I asked him for advice. He suggested, "Prepare her for Christmas."

"How?"

"You know what to do," he stated confidently. Clearly he challenged me to think. His confidence put me under pressure. I brainstormed. Did Yvonne enjoy anything about Christmas? What did she find most difficult? Why?

In mid-December, I got an idea. I made a game of opening presents. First, I wrapped up some of Yvonne's toys as she watched. Then I exclaimed, "Yvonne! It's time to open presents!" Tearing the paper with great exuberance I revealed her favourite toy. "Look, Yvonne!" I shouted excitedly. "Here's your bumblebee tambourine." Recognizing her toy, she smiled broadly. We played this game every day. By the time Christmas came, the opening of gifts was no longer an anxious or overwhelming experience. It turned out to be our happiest Christmas.

January arrived. The school still had not improved. We met with the other parents and learned that they too were frustrated. They were afraid, however, of saying anything for fear of losing what they had. Peter and I saw it differently. We were convinced we would never get improvements unless we demanded them.

We explained our strategy. "First we need to identify the problems. Then we'll request specific action as a group." I told them about our experience: "At a meeting with the teachers, I asked about Yvonne's program. The senior teacher said they had a written-out program. Yet when I asked if I could look at it, she said, 'No, it's all in the book,' and she pointed to a binder on a top shelf."

Another parent echoed the same complaint, and added, "Our daughter is still not in school for the full day. The teachers claim she is not ready, yet when I asked, 'How do you know when she's ready?' the teacher said, 'Oh, we'll know.'" By the end of the meeting, all parents agreed to make an individual request to observe in the classroom.

Mr. Dicks gave the parents permission to observe the class. Later, the parents met to compare notes. The problems were even greater than anticipated. The parents did not see a structured program nor any documentation. The teachers used neither social nor nonsocial reinforcements. The parents noticed inconsistency with communication. The teachers were doing things for the children that they could do for themselves. Most painful, parents saw their child lose acquired skills.

After my observation, I realized why Yvonne was spilling her juice. The teacher told her to lay the glass down, and by helping her awkwardly, Yvonne managed to do just that. I was heartbroken. I had taught Yvonne to drink and set her glass down independently.

Peter and I wrote to Mr. Dicks outlining my observation, our concerns and several recommendations. He immediately requested a meeting which included the teachers. Tension filled the air but following this meeting, Yvonne had some structure to her day and the teachers smiled occasionally.

In April, the teachers talked about next year's schooling. They recommended that Yvonne be transferred to Pine Grove School. We knew nothing about Pine Grove except that it was called the "school for the retarded," with over one hundred students. Peter and I had doubts, but we agreed to the teachers' request to visit this school.

After our visit, we wrote a letter to the Department of Education. “Yvonne should remain at the School for the Handicapped because the individual instruction that is available at this school is more suited to her needs than is the classroom situation at Pine Grove with six to eight children per teacher. It is essential that she be taught on an individual basis using a structured and positive reinforcement program. She is very capable of learning under these conditions.” We also noted, “Mrs. Lono is most willing to work out an arrangement by which Yvonne could attend the Happy Times Preschool for another year for two or three mornings a week. The School for the Handicapped, together with Happy Times Preschool, offers Yvonne the best possibility to develop to her fullest potential.”

Mr. Dicks replied, “The decision you have made regarding her attending the School for the Handicapped in September is acceptable to us. This program has been in operation for six years and has received enormous support from the university and many other professional individuals over the years. Both teachers are well-qualified teachers in this province and we have a high degree of confidence in their capabilities.” With those credentials, we could expect a good program.

In a follow-up letter, Mr. Dicks stated, “Before we will be in a position to discuss specifics of a program for Yvonne, we are requesting that a reassessment of Yvonne take place through the child development specialist. May we suggest that you contact the doctor to arrange this assessment at your convenience.”

I argued, “The specialist’s assessment has little or no bearing on setting up a school program. The teachers can assess Yvonne using the Portage Project Checklist.” Nevertheless for three weeks I tried, unsuccessfully to reach the specialist for an appointment. Finally I called Mr. Dicks. “I’ve been unable to reach the specialist. I’d like a meeting with you and the teachers.”

As usual, he tried a stalling approach. “I didn’t realize you would have these problems; hang in there a little longer.”

“I’m not happy,” I stated forthrightly. Perhaps this struck a sympathetic chord because he offered to call the specialist himself. Much to my surprise, he called back that same morning. “The child development specialist wasn’t available, but I spoke to her partner. You were right, they only do assessments. The programming is something the school has to do.”

I was annoyed. Yvonne meanwhile lost valuable weeks of program time because of the teachers' tactics. Now I nailed him down for an appointment to discuss a program plan.

The child development specialist called me late that afternoon after hearing about the problems at the school. She arranged to assess Yvonne in two days time. She was genuinely concerned and wanted to help. During this assessment, she talked about the school and said, "Under the circumstances, would Pine Grove not be more beneficial to Yvonne?"

I simply said, "The School for the Handicapped exists so children can learn on a one-to-one basis, which is what Yvonne needs."

The specialist then talked about the original diagnosis. "How do you feel now," she asked, "do you think Yvonne is more retarded than autistic, or more autistic than retarded, or fifty-fifty?"

I replied, "I really don't know; perhaps fifty-fifty."

"The Division of Special Services," she said, "likes to place children in programs according to their handicap, either retarded or autistic." Had her question been a trap? I was relieved I said fifty-fifty. Had I said "more retarded," Yvonne would surely be placed into Pine Grove. Had I said "more autistic," I would be labelled an obstinate parent. It occurred to me that in the future, I would need to assess questions very carefully before giving an answer.

The teachers at the School for the Handicapped requested my signature for a copy of the child development specialist's assessment. Their request made me realize that teachers, social workers and public health officials all had written information about Yvonne, but we parents had nothing. This had to change. I called the specialist about getting a copy of her assessment, but she explained, "Medical information is confidential."

I challenged her. "People in the three service sectors have copies; service providers often move and files get misplaced. To me it makes sense for parents to have a complete record of information on their own child. As parents we are constantly asked about Yvonne's development, yet we have nothing to refer to. It's all from memory."

The specialist soon mailed us a copy of the assessment with a supportive note: "I appreciate that you have always wished to have full details of any investigations on your daughter and for this reason have decided that these wishes should be followed now." I wrote back, thanking her for her support. From then on, I received all copies of her assessments. Furthermore, when Yvonne saw other specialists, I requested copies of their reports. We always got them. Once however, I had to be very assertive.

A special education coordinator requested our permission for a psychologist to do an observation and assessment on Yvonne. I agreed, provided we got a copy of the report. She told me, however, we could not. After a lengthy discussion, I firmly stated, "Then I will not sign the authorization form consenting to the observation." When the coordinator realized I was serious, she reluctantly agreed we would. Then, to avoid any misunderstanding, under my signature I wrote, "I give permission on the condition we receive a copy of the report."

The remaining few weeks of school dragged on. We welcomed mid-June with great relief. We took Yvonne and Teresa out of their schools a few days early, since we needed seven days to drive to Calgary, Alberta, where Peter had registered for the annual scientific meetings. We noted two significant developments on this trip. Yvonne wore panties and had excellent daytime bladder control. She understood when we said, "We'll go to the bathroom when we stop for gas or for a picnic." She held on. We were so proud of her and she knew it. Also, we were able to put the car radio on at times. In the past, Yvonne was greatly disturbed by the radio. Now she accepted it because she eagerly waited to hear her favourite song, Glen Campbell's Rhinestone Cowboy.

Vacations were fun. Though physically tiring, we were mentally energized.

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Teresa looked forward to accompanying her sister to school in September. Yvonne was six years old, of legal school age. When Teresa realized Yvonne wouldn't be going to Vanier Elementary, she was very disappointed. "Why not?" she asked. "Yvonne needs education as much as anyone, if not more!" Teresa was ten years old and ordinarily not outspoken. We were proud of her attitude.

The School for the Handicapped remained in the basement of a church. The previous spring, the parent group requested that the class move into a regular school where the children could have contact with non-handicapped children. We suggested Vanier Elementary or MacDonald Drive Elementary because these schools were nearest to the homes of the two younger children. The Department of Education promised to look into it, but nothing was done.

The parents continued their efforts throughout September. Finally in October, Mr. Dicks told the parents, "The class will move into a regular school; the move will take place by the first of December." Holloway School, an older school downtown, was not what we hoped for, but it was a step in the right direction. As December neared, I asked about the move. I was annoyed to hear that the necessary arrangements were not made. "When will the class move?" I persisted.

Mr. Dicks finally promised the move would take place during the Christmas holidays. Again I realized that changes occur only when people are pressured.

Meanwhile, our demands for more structure in the program paid off. The teachers worked on specific tasks and used positive reinforcement. I had weekly consultations with the teachers and Yvonne was making progress. Realizing we could effect changes, we also recognized the importance of acknowledging improvements. In a letter to the Department of Education, we stated, "We are pleased with the program as it presently exists for Yvonne, and we now hope it will be made available for all children attending this school." We made this statement to give support to the other families. They requested but still didn't have a structured program for their children.

As promised, the School for the Handicapped moved to Holloway School after Christmas. On the first day, the teachers became upset because Yvonne cried and screamed for the first one-and-a-half hours. I suggested it was the change in environment. "It's too bad a few visits weren't arranged ahead of time, as we had suggested," I said. "It might have alleviated the stress for Yvonne."

At a meeting in February, the teachers told me, "Yvonne isn't well. She's not been happy since Christmas."

Surprised, I said, "She's happy at home and she's happy at the preschool. Could she still be adjusting to the new school?" Shortly afterwards, Yvonne cried every morning. I noticed when I said, "Yvonne, today you go to preschool, see kids, see Mrs. Lono," she stopped crying. I then understood and said, "Yvonne, you need to know when you go to Happy Times Preschool and when you go to Holloway School. Mommy will make you a calendar."

Using a large scrapbook, I drew two-inch squares. In the blocks under Monday and Friday, I used a red marker and drew three stick people with the words: Mrs. Lono, preschool. In the Tuesday, Wednesday and Thursday blocks, I used a black marker and drew a car to signify a taxi which picked Yvonne up for Holloway

School. In the Saturday blocks, I wrote the word Home. In the blocks in the Sunday column I drew a book using a green marker and pencilled the word church beneath it. At the end of each day, I took Yvonne to the calendar, which hung on her bedroom wall, and crossed off the day. Then I explained what she would do the next day. "After you sleep, you go to...." I wasn't sure if she understood but I was convinced, if I kept it up, eventually she would.

The pattern in Yvonne's behaviour, persisted. She was happy when I drove her to Happy Times Preschool, but she often cried when the taxi arrived to take her to Holloway School. We were more distressed when Yvonne began to hit her forehead and chin with her clenched left hand, and rubbed her finger until it bled. She arrived home with bruises on her ears and hips. She no longer had a bowel movement on the toilet. Instead, she filled her nighttime diaper and developed a rash. What was upsetting Yvonne?

I asked the teachers, but they couldn't figure out the problem. I was discouraged. I noticed that the teachers themselves were often upset. Soon I wondered if the teachers felt under pressure because other staff and students were observing them. Until now, the teachers were isolated and safe; they were their own bosses. No one knew what was going on.

The tension affected my lower back. During the day, I lay on the living room floor trying to relieve the pain. I also worried about Peter; his ulcer was bleeding again. After much pleading, he made an appointment with the doctor. He warned me the doctor would advise surgery. Naively I said, "Can't they just give you a transfusion like the other time?"

Peter called me from the hospital. "The doctor sent me to Emergency and I've been admitted. I'm waiting for a surgeon." I mustered every control to suppress my stomach from reacting violently to this news. I couldn't speak. Peter was in the hospital for a week before the surgery. I couldn't eat; I couldn't sleep. I felt so guilty. If I hadn't insisted, he wouldn't be going through this. His family history flashed through my mind. His brother Cornie had surgery for an ulcer when I was eight months pregnant with Teresa, but he died in the hospital. The Penner family experienced five deaths, averaging one every two years, in the last ten years. For two years now, there were no deaths. Why did I insist he go to the doctor? He had bleeding episodes before and his ulcer had healed.

Friends from the university and the church provided child care and brought cooked meals. I was extremely grateful. The prepared food was a blessing because cooking a meal was even harder on my stomach than eating it. On the morning of Peter's surgery, a friend, Karen, stayed with me at the hospital. The previous evening, she invited the girls and me for supper; it was Yvonne's birthday and she had baked a cake for her. The support from friends pulled me through a difficult time.

Besides my worries about Peter, I continued to deal with the problems at the school. Just that week Yvonne arrived home with an injured hand but without an explanation. I called the teacher the following day. She told me, "We gave Yvonne extra attention because of her birthday, but another student got jealous." I found it hard to understand that two teachers couldn't manage three students. The teacher broke into my thoughts and added, "An older student sometimes pulls Yvonne's hair—"

This was the first I heard of it. "No wonder," I blurted, "Yvonne has been so unhappy."

The teacher continued, "When we notice it, we take Yvonne's hand and assist her in pulling the other student's hair."

This was the last straw! My blood pressure soared. "We do not want Yvonne to learn aggressive behaviour," I stated vehemently. "It's bad enough that she's hitting herself, but to teach her to strike back is wrong. We won't tolerate that!"

That day, I drafted a letter to the supervisor of institutional schools. I went to the hospital to get Peter's opinion, and mailed the letter. "We are withdrawing Yvonne from the School for the Handicapped at Holloway School, effective immediately." I stated our reasons and expressed concern for Yvonne's physical and psychological well-being.

I was relieved to have Yvonne safely at home, though I had less time for myself. Time was precious, it was already the end of April, and we were still working on plans to spend a sabbatical year in Edmonton, Alberta, beginning in September. We hadn't yet completed housing arrangements and school registration for Teresa and Yvonne. We also needed to rent out our home.

By the time July 20 arrived, we were ready to leave St. John's. Peter's surgery went extremely well and he recovered quickly. We rented our furnished house to a couple. I needed to pack only a few boxes which we mailed to Alberta. A family in Edmonton was renting their furnished house to us, as they themselves were going on sabbatical.

Our Plymouth wagon was packed with our usual camping gear and food. We jammed in the Bontempi electric chord organ, which Yvonne thoroughly enjoyed, and my treasured box of notes and letters since I planned to write during our year in Alberta.

Chapter 7

A Year in Alberta

We left Newfoundland and followed the Canadian route to Niagara Falls, crossed over into New York, and drove south and west through seventeen states before heading north to Edmonton.

Yvonne as usual was excited about driving and tenting. She often hummed a soft, high-pitched musical tone. Yvonne also sang "Da't, da't," and laughed heartily. Usually this happened following a picnic stop. Soon it occurred to me she was saying, "Tent!" Yvonne was eager for us to drive so we could set up the tent! Once, Peter and I discussed if we should spend the night in a motel because our tent was muddy and wet and our bedding soaked from a steady rain. Unexpectedly, from the back seat of the car, Yvonne sang out, "Da't!" She had listened to and understood what we said!

"Yvonne," I said, "First we have to find a laundromat to wash and dry the sheets. Then we'll see if the rain quits."

We drove and drove until the sky cleared. Setting up the still-wet tent, Yvonne smiled and breathed heavily. Again she sang, "Da't!" She was delighted to camp!

On another day I was making supper at the campsite and Yvonne was resting in the tent. Teresa excitedly called out, "Mom! Yvonne said 'Ou,' she wants to come out." Yvonne was verbalizing more on this trip than ever before. I was careful, however, not to repeat what she said. I learned from bitter experience that she clammed up, sometimes for weeks, if I repeated her sounds. I had spoken to the speech therapist about it, asking what I should do. The therapist advised to encourage her. So I simply said, "Yvonne, I like to hear you talk. Talk more." Often she then repeated her sound; she knew we were pleased.

On vacations, we always learned to make adaptations to accommodate Yvonne. She couldn't reach the top of the picnic table, even if she sat on a pillow. "How about," I said to Peter, "if we used a tray? But how could we secure it?" Peter bought C-clamps to attach the metal tray under the edge of the picnic table. It worked perfectly. Yvonne could reach her food and eat by herself.

Teresa came up with a brilliant suggestion to a problem in the shower. Yvonne was dreadfully afraid of a harsh spray and a change in water temperature. "Take a plastic basin into the shower," Teresa said casually, "and wash her that way." It worked. Eventually Yvonne overcame her anxiety. Much later, she even enjoyed a shower if the spray was gentle.

Yvonne was also fearful of waves when we walked the saltwater beach. Peter and I turned it into a game, exclaiming, "Here comes the wave!" and lifted her up and laughed. We did it repeatedly until she too eventually laughed.

Yvonne learned to walk greater distances without tiring. In Disneyland, she managed a six-and-a-half hour outing. Earlier, Yvonne surprised us by walking five kilometers in the Carlsbad Caverns in New Mexico. In the cave, Yvonne unexpectedly thrilled a few young boys. She sang a high-pitched, soft musical, "Ah, ah."

As the sound echoed through the cave a boy called out excitedly, "Listen! That's a bat!"

His friend replied, "Yeah! Wow!"

We chuckled. "Yvonne, you made their day!"

Yvonne also left her mark with a gambler in Las Vegas. We stopped at Circus-Circus while driving through Nevada and tried the slot machines. Leaving the air-conditioned darkened room with clanging slot machines and flashing coloured lights, Yvonne, wearing pink with blue trim shorts and haltertop, dashed forward with an excited laugh. A fellow at a nearby table exclaimed, "There goes a winner."

I looked back and smiled, "She certainly is."

Soon our vacation was just a pleasant memory. We travelled 16,400 kilometers, spent thirty-four nights camping, and saw magnificent scenery. Relaxed but also exhilarated, we were ready to get back to a routine.

We arrived in Edmonton late in August. We met the Wilsons before they left, and completed details for renting their house. They lived in a small two-storied house in a quiet neighbourhood. The upstairs had two bedrooms, as did the basement.

The Wilsons introduced us to a few neighbours. They pointed out McKernan Elementary-Junior High School within sight of the home, where we registered Teresa for Grade 6. They also pointed out the University of Alberta, within easy walking distance for Peter.

Yvonne's schooling, however, was still not settled. Nevertheless, we were excited as we anticipated new experiences which lay before us. We also looked forward to spending birthdays, long weekends and special holidays with our families. Peter's brother Jake and his wife Bea with Daryl and Valerie lived on a farm in Hays. My sister Rita and her husband Kornie with Kenneth and Sharon were on the ranch in Fort Macleod, and my brother Henry and his wife Verna with Wendy, Glenda and Heather lived in Calgary. This was the first time we lived close to family.

On September 5 Teresa went to school and Peter went to work. Yvonne, however, remained at home until her school placement was confirmed September 18. Again, we noticed discrepancies in services for children who were labelled handicapped. People in the service system didn't understand how important it was for Yvonne to start school on the first day. Yvonne knew that Teresa left for school and she was upset because she had to stay home.

Ironically, I addressed the school placement for Yvonne much earlier than for Teresa. The year before, I wrote to the Alberta Society for Autistic Children, to Father Kenneth Kearns School Educational Developmental Program, to Elves Memorial Child Development Centre, and to the Handicapped Children's Services with the Department of Social Services.

Yet it wasn't until June, a month before we left St. John's, that we received a letter suggesting Elves Memorial Child Development Centre as the most appropriate for Yvonne. However, placement at this school depended on availability of space. "If arrangements can be made," the letter stated, "to move a few of the older children presently at Elves to a more appropriate facility, there may be room for younger children."

The school made these arrangements in September, and they finally accepted Yvonne. A few days before Yvonne started school, Peter and I took Yvonne to meet the staff and see the building. The school was several kilometers from our home. The low brick building, to our surprise, looked brand new. Each classroom had large windows down to the floor with a view to the outside. The door of each classroom opened into the centre of the building which contained an assortment of equipment for gross motor development. Light streamed in through the overhead glass panels. To one side, we saw a glassed-in swimming pool for the very young children.

The staff were friendly and they eagerly welcomed Yvonne. We couldn't imagine a better environment for her. The teachers said, "Yvonne needs tactile experiences to develop the use of her hands; the best classroom would be with children who are visually impaired." We worried how this might affect Yvonne, but were willing to try this class.

Meanwhile we were getting to know our neighbours and the people from the local Mennonite church. They instantly made us feel at home. We received dinner invitations from several church members and several encouraged us to attend Sunday School. I hesitated, then said, "We'd like to include Yvonne."

The friend responded, "We have a young teacher who has worked with a handicapped child. She's looking forward to having Yvonne in her class." We were delighted, and I volunteered to provide the support that Yvonne would need.

The following four weeks Yvonne attended Sunday School with my help. I wanted her to stay sitting and listen quietly. I helped her hold a crayon when the other children coloured. Another mother did the same with her four-year-old daughter in the same class. The fifth Sunday, however, we were absent. This was the Thanksgiving weekend and we were in Fort Macleod. The celebration was extra special as our niece Sharon was christened and the whole family, including Mom Wiens from Winnipeg, was present for the occasion.

We returned to Edmonton late Monday evening. I had just jumped into bed when the phone rang. I sprang up to catch it before the second ring. "Irma, I'm sorry to call you so late." It was the voice of the Sunday School superintendent. "I tried all day, but no one was home."

"That's all right," I responded. "We were in Fort Macleod for the weekend."

"That's what I'm calling about," he stated. "I'm in a real dilemma. Both Yvonne and the other girl were absent from Sunday School yesterday and the teacher told me that with the two girls gone, she was finally able to teach her class." I was speechless. "She said she would resign if the girls stayed. We can't afford to lose her." Still, I couldn't find my voice. This came as a complete shock. "We've been thinking," he went on, "that we'll give you the Sunday School material and a room where you and the other mother can teach your girls."

Disappointed and dejected I said, "It would be easier to teach Yvonne at home. The reason I want her in a class is for her to have social contact with the other kids."

"I can understand that," he said sympathetically, "but we're really in a bind."

I fought back tears but managed a determined response. "No. I will not teach her in a separate room. And I won't bring her to that class. I'll have to think about what we're going to do." After hanging up the phone I grabbed the telephone directory, sat on the edge of the bed and noisily flipped through the yellow pages till I reached the heading "Churches." I was in a defiant mood. I would not attend a church where Yvonne could not participate.

The memories of a pleasant weekend just spent were instantly erased. Memories of acceptance in this church faded in the light of my tangled emotions of hurt, anger, bitterness and sheer disappointment. I told Peter about the call and firmly stated, "We'll just have to go to another church." We were used to church-hopping but I hoped it would be different here. The pain was intense. Perhaps I felt it more because this occurred in a Mennonite church, a church of our own denomination. I also expected more from a teacher who claimed to have experience and to be open to the challenge. I was totally let down.

Soon I thought of the other mother. She was a member but we were only visitors. How would this affect her? What would she do? I didn't have to wonder long. The phone rang. She received the same call. She too refused the offer of a separate room. She felt hurt and planned to stay home. That night I tossed and turned; it was a long sleepless night.

Wednesday evening I got an unexpected call from the pastor. "I'm sorry about the call you got Monday," he started. "It came to my attention and we've just had an emergency meeting to discuss the situation. I'd like to tell you what we're proposing. Yvonne will be in a class closer to her age with the six- to eight-year-olds. The younger girl will be with the four- to five-year-olds. Each will have her own volunteer." He gave me the name of the woman who volunteered to be with Yvonne. "I hope you'll find this acceptable?" he asked kindly.

The muscles in my body relaxed. I had only dared dream of such a solution. I murmured, still astounded, “It’s wonderful. I appreciate it.” I was relieved and thankful that we wouldn’t have to church-hunt, after all.

At the time, I found the week’s experience very painful. Upon reflection, however, I learned some valuable lessons. I realized that running away from a situation in search of something ideal would never be the answer to solving problems. I realized that as a parent, I needed to voice my dream. How else would people know what we really wanted? I realized that after expressing my dream I should be part of the team to help find solutions to make that dream come true. I further realized that I needed to be patient with people who have limited experience in working with a child with a disability, and through our personal experience I needed to help them to understand our vision.

With these thoughts and the realization that much work needed to be done in accepting and involving people with disabilities, Peter and I spent much time discussing what we might do. He began attending meetings and courses in this field. More and more, we realized that support services for people with handicaps were gravely inadequate. This knowledge reinforced our thinking that now was the right time for Peter to consider a career switch. Many biochemists were looking for jobs; they could easily fill Peter’s position. Workers in the field of mental retardation, however, were greatly needed.

In April 1979 we contacted the Mennonite Central Committee (MCC) office in Winnipeg about the possibility of working as volunteers in the field of mental retardation. MCC is an international service and relief agency of the Mennonite and Brethren in Christ churches in the United States and Canada. We had met the Canadian director of the Voluntary Service Program, Dave Dyck, two years earlier in St. John’s, as part of his MCC work in the region.

Dave replied swiftly; his letter was encouraging. Recently he had met with the assistant deputy minister of Social Services in Newfoundland who expressed “a strong interest in having MCC workers come to Newfoundland with a view to helping the mentally handicapped, particularly with regard to public education.” Dave cautioned, “It is premature at this time to say whether or how such an assignment might develop, but we do intend to expand our involvement in the Atlantic provinces and this might well be one area that we will look at very seriously in terms of voluntary service involvement.”

Dave also told us about the need for house parents for individuals with a mental handicap in Winnipeg. It seemed that various service opportunities were available. We, however, wouldn't be available for another year-and-a-half since Peter needed to work a full year after his return from a sabbatical. Still, we each filled out a personnel information form which MCC sent. We noted the available date: September 1980. We were open to an assignment anywhere in Canada, but our preference was the Atlantic region. We agreed that later on our way back to Newfoundland, we would stop at the head office in Winnipeg for a personal interview to complete the application procedure.

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During this year in Edmonton I expected to have plenty of time to write. I began but eventually shelved the project. Our calendar was filled with appointments. I helped at Teresa's school and Yvonne's school. I attended meetings and courses on mental retardation. We went to cultural events such as symphonies and opera; we saw the Ice Capades, and participated in bowling and church events.

The church asked me to speak at the annual meeting of the Women in Mission in Tofield, Alberta, on the topic "Be a Pattern." I had never spoken at a conference before. I was nervous but saw this as an opportunity to share with others our approach of "accepting and involving" a child with a handicap.

Our calendar also logged weekend trips to southern Alberta to visit our brothers and sister and their families. They in turn drove north to visit us. Family from Manitoba arrived as well. The year passed quickly.

Yvonne made definite developmental gains during this time, largely in gross motor and socialization, and to some extent in communication. The school had a wide assortment of equipment such as inclines of various heights, a swinging tire and a trampoline. At first, Yvonne was fearful of them all. Later she tolerated these experiences and much later she even enjoyed the activities. This became a pattern in her behaviour. We learned never to give up involving her in new experiences, even if just briefly.

I continued writing out teaching programs and initially recorded all attempts. By using the structured approach, Yvonne learned to turn pages of a book, page by page. She learned to spin a top, put pop-beads together, and take stairs alternating her feet. As Yvonne became more successful in complying with the activity, I quit recording and the activity was done on a purely fun basis. I made no progress, however, in teaching her to dress herself. She found dressing difficult and became frustrated. Eventually I quit trying; it was more important for her to learn other things.

We were delighted that Yvonne was communicating more. Or were we finally understanding what she was expressing? One evening, close to bedtime, she stood by the front door crying. Peter finally asked, "Yvonne, are you telling us you want to go for a drive?" She stopped crying and looked at him. "Yvonne," Peter said, "I understand you want to go for a drive but it's late. It's bedtime. We'll go for a drive tomorrow." Yvonne accepted Peter's explanation and went to bed willingly.

Another time Yvonne's crying baffled us. She had just finished eating a snack so she couldn't be hungry. She had, however, eaten her apple very slowly. Peter checked her mouth and found a loose tooth. "Yvonne," he sympathized, "your tooth is loose. I know it hurts." She looked at him and smiled. She was happy he understood.

On yet another occasion, Yvonne was having her daily bath and swished the water back and forth vigorously. Watching her I mused, she's having fun. After awhile, Yvonne stood up but wouldn't step out. Instead, she bent over and swished the water with even greater vigor and looked distressed. Finally it dawned on me. "Yvonne, you want me to warm up the water?" Her face brightened. She remained standing while I added hot water and swirled it around to even the temperature. Then she sat. Yvonne saw me time after time swirl the water while filling the tub. She connected this motion with warming up the water. "Yvonne," I praised, "you're very smart! Mommy was pretty slow to figure this one out!"

I thought back to other times. Was the swishing motion always intended as a message, which I interpreted as playful activity? This incident made me realize the difficulties she faced in making us understand what she was saying. I vowed to observe her actions even more closely in an attempt to limit her frustration and to encourage her in her unique methods of communicating.

During this year Yvonne also learned to make choices. Food was a great reinforcer, particularly raw vegetables, fruit, raisins and nuts. I laid out a stick of carrot and a piece of celery about seven inches apart. Pointing to each one, I explained, "Yvonne, this is carrot. This is celery. Which do you want?"

Yvonne picked up the carrot. Immediately I removed the celery from her view. Her eyes expressed puzzlement. I felt mean, but how else could I teach her to choose between them? After Yvonne took a bite of carrot, I laid it down and presented her with the same choice. Her reaction was the same. I used this approach for several days. Finally she grasped the concept. Now she took her time before reaching out!

Being certain that Yvonne understood, I introduced pictures of these foods. If only Yvonne could tell us what she wanted by pointing to pictures. I realized, however, I had to teach her to point. Until now she only grabbed or touched an item. Earlier Yvonne resisted any touch to her hands; now that she accepted contact I could teach her the skill of pointing.

The moment Yvonne made her choice by placing her hand on the celery or carrot stick, I removed it from her grip and stated, "Yvonne, you want a carrot. That's great. Can you point to it?" I held her three fingers and thumb, and placed her right index finger on the carrot. "That's great, Yvonne!" I praised, tremendously enthusiastic. "You're pointing! You want carrot." I got carried away with my exuberance, but it helped to get the message across. Yvonne learned to point, and this became an essential tool for her to communicate her choices.

Yvonne learned to choose her own clothing. I laid out two items on her bed. Whichever she pointed to, she would wear. Clothing, however, was not reinforcing to her at this time, and often she touched an item just so I would quit asking her.

I also wanted Yvonne to choose her own fun activities, but this was more difficult. First I had to figure out if she understood the connection between a picture and the real thing. I knew she recognized certain pictures of foods, but activities were more abstract.

I experimented by using pictures of Yvonne's favourite activities: a swing and a tricycle. The Wilsons had a swing set in the backyard. Yvonne had an oversized tricycle which we just bought for her eighth birthday. I placed the tricycle near the swing and explained, "Yvonne, this is a tricycle. This is the picture of a tricycle. This is a swing. This is a picture of a swing." I repeated, then asked, "Yvonne, point to what you want." She pointed and I exclaimed, "Yvonne, you pointed to the swing! All right, I'll help you onto the swing." By engaging her in the activity immediately following her pointing, she had a better chance of understanding the use of pictures.

We thought that pictures might take the pressure off Yvonne to speak, and perhaps speech would follow. Yvonne had tried to express herself verbally; she concentrated on my mouth movements and looked deep into my eyes with dilated pupils as she moved her mouth and tongue, but no sounds came out. She tried very hard, and all I could do was reinforce her by saying, “Yvonne, I know you are talking. I just can’t hear you. Talk louder!”

She relaxed, knowing I believed she was talking. An article I read stated that some people found it extremely difficult to combine the visual and auditory senses. Was this a problem for Yvonne?

The teachers suspected Yvonne had a perceptual problem and they referred her to an occupational therapist. I had never heard of one and didn’t know what to expect. Yvonne’s appointment was at the University of Alberta Hospital. The occupational therapist, Dr. Madill smiled, spoke gently, and conveyed a feeling of unpretentious confidence. I liked her immediately and sensed Yvonne did as well.

As part of the assessment Dr. Madill placed Yvonne in a swivel chair and spun her for several revolutions. She stopped the chair abruptly, and gazed into Yvonne’s eyes. “Just as I thought,” she said, “Yvonne has little eye movement.”

The procedure flabbergasted me. The test was so simple. What could it possibly tell her? Dr. Madill explained, “Yvonne is lacking inner-ear balance, and she needs to be stimulated to develop the sense of dizziness.”

I was overcome with surprise. This explained why Yvonne could spin around and around and around, then walk away without being dizzy! Yet no one suggested a problem with her inner-ear balance. Dr. Madill interrupted my thoughts and asked, “Do you own a swivel chair?”

“Yes. The Wilsons have one; we have one at home too.”

“Good. I’ll show you what to do.” Dr. Madill then helped Yvonne to sit back in the large swivel chair, crossed her legs and rested her hands on the arms of the chair. Smiling she said, “Yvonne, ready? Here we go!” She spun Yvonne around and around counting to twelve. She stopped the chair and looked into Yvonne’s eyes. She repeated this procedure several times. “There!” she proclaimed joyfully, “We’re getting something now!”

I, too, saw a definite waver in Yvonne’s eyes and an unusual smile. Yvonne then blinked and maintained a steady gaze. Dr. Madill encouraged me to try this at home on a daily basis. She warned me that Yvonne could get sick to her stomach if I overdid it at the beginning.

"Swinging," she said, "is also good therapy." This surprised me. I enjoyed taking Yvonne to the park and putting her on the swing even as a baby, yet I never realized the potential benefit; I only thought of it as a fun activity.

Now that I understood about a perceptual problem it became clear to me why, at the age of four years, Yvonne wouldn't step over the small rise onto the new living room carpet. She stood and cried until I picked her up, or she eventually got down on her knees and crawled through the doorway. I now also understood why she always hesitated to take the last step on a set of stairs and required assistance. She also hesitated taking stairs in public places which were unfamiliar. A perceptual problem explained Yvonne's refusal to step over the silver bar in the elevator.

Memories vividly flashed through my mind. Yvonne used to crouch down and scream when we approached an elevator. To help her overcome this fear, I took her to Memorial University on Saturday mornings. While Peter worked in the lab, I steered Yvonne to the elevator. We rode it up and down, stepping over and onto the silver bar. She looked terrified, but I persisted and made the exercise into a game alternating between the elevator and the stairs. Eventually she overcame her fear. Still, she was cautious each time we approached an elevator.

A perceptual problem also explained her terror of escalators. These we avoided like the plague. When an escalator was unavoidable, it took two people and physical force to get her onto it. Soon however, we discovered a better approach. I stepped on first, turned around and held out my hands to help Yvonne while Peter assisted from the back. This approach was more dignified and blocked the frightening downward view.

Could doctors not have identified Yvonne's perceptual problem earlier? Dr. Madill brought my thoughts back to the present. She was speaking about Yvonne's hands. Yvonne kept her left hand clenched and continually rubbed it into the palm of her right hand. She always resisted my attempt to hold her left hand or to get her to hold onto an object. Dr. Madill was pleased that the school used different fabrics and materials to rub and stimulate Yvonne's hands, particularly the left one. She now advised me to purchase a vibrator to provide further stimulation.

"Of course," I replied immediately, "where can I buy one?"

"You'll have to go to the Love Shop," she stated in a matter-of-fact tone, and gave me the address.

"The Love Shop?" I had expected a store which sold specialized medical equipment. The following day, while Yvonne was in school, I drove to the address to buy the vibrator. I opened the ground floor door and stepped into a red and black carpeted room. The glass counters and the walls were embellished with a variety of personal items. Only then I realized why they called this the Love Shop! I glanced over my shoulder and looked out through the large store window hoping no one saw me enter. Smiling, a clerk approached and asked if she could help.

"Yes," I faltered, "I'm looking for a vibrator to stimulate my daughter's hand." The clerk smiled. I continued innocently, "The occupational therapist sent me here. You see, my daughter doesn't use her left hand."

Smiling, the clerk nodded. She went to a counter and returned, still smiling, holding a six-inch personal vibrator. Momentarily, I remained speechless. Then, thinking she hadn't heard me correctly, I emphasized, "It's for her hands."

With a smile pasted on her face, she held it out to me. It was no use trying to explain. I paid for it and fled. I jumped into the car and sped from the area. My cheeks flushed when I realized the clerk probably hadn't believed me. Mortified, I wondered, what won't I do to help Yvonne!

I used the vibrator on Yvonne's left hand, and as I expected, she pulled back and cried. With time, however, she held onto it and eventually, through the stimulation, she used her hand occasionally. On our final appointment late in June, Dr. Madill seemed pleased with Yvonne's progress. We in turn were grateful for her help. Dr. Madill's pleasant personality, positive attitude, practical assistance and interest in Yvonne were the key to her success.

"I will make a referral for Yvonne to see an occupational therapist in St. John's when you return to Newfoundland," she said.

"I don't think there is one," I said disappointed. "I hadn't heard of an occupational therapist, until we came here."

"Oh yes, there is," she said with full knowledge, and gave me her name. Then why had doctors not referred Yvonne to one? She broke into my thoughts. "I'll send my report immediately and stress the urgency. In that way, Yvonne should get an appointment as soon as you get back."

Working with a professional who believed in Yvonne was so refreshing and encouraging. Her parting remark took me by complete surprise. "You know," she said, "Yvonne is not retarded and I don't understand why you accept that label."

I was standing but quickly sat down, feeling faint. Soon I recovered and said, "For years we've been accused of not accepting the label of retardation. Now we're accused of accepting it. We had to accept the label," I explained, "otherwise we wouldn't get any services. Besides, Yvonne is 'retarded' because she can't do the things she should be doing at her age."

Dr. Madill insisted, "Yvonne is not retarded. No one can measure her intelligence because of her difficulty in communicating."

I valued her comments. If only we had known her earlier. After this, we detested labels. If a label helped to identify and understand the condition, that was one thing. Even then, labels were usually used in a negative way creating barriers to involvement. Yvonne was who she was—period. All we ever wanted was for her to be accepted for who she was and to have every opportunity to further her development.

The school year finished on June 28 and that evening we left for Manitoba to attend our oldest niece's wedding. After the wedding we visited with family and friends. Then I drove Peter to the Winnipeg airport where he boarded a flight to Toronto to attend the annual biological meetings. The girls and I stayed in Winnipeg until Peter's return on July 13.

As we waited for Peter at the airport, Yvonne became increasingly excited. She ran with her hair flying, stopped abruptly in front of a stranger and squealed with delight. The stranger smiled when I explained she was waiting for her father. After two more episodes, I took Yvonne to a secluded spot and asked Teresa to wait for Peter at the luggage area and then come for us. It was interesting how much Yvonne missed her Daddy.

The following night we packed up the car in readiness for an early start back to Edmonton. We needed to pack up our belongings and clean the Wilson's house which was our home during the past year. Then we would drive to Alaska. We always dreamed of touring the Yukon and this northern state. This summer was the ideal time.

We stopped in Whitehorse to visit Walter and Patricia who had lived in St. John's. We were delighted to see them and their comments about Yvonne's improvement encouraged us. We then toured Alaska, and looking out over Cook Inlet to the mountains across the salt water, I suddenly felt homesick and anxious to return to Newfoundland.

Chapter 8

The Developmental Centre

Our sabbatical year and vacation trip officially ended August 19, 1979 with a canoe trip on Gushes Pond, Newfoundland. As we pulled the Sportspal ashore, I wondered, what will this year be like? Will it be like canoeing at the water's edge with the waves gently lapping at the sides, or will it be like bucking whitecaps in the middle of the pond?

My answer came the next morning. I phoned Mr. Dicks about Yvonne's school program. He told me, "She has none, at least not yet. The School for the Handicapped closed down after you left and since then, we've been planning to set up a Developmental Centre. Treasury Board, however, turned down the proposal. Recently a parent group has lobbied government to fund a revised proposal. We're hopeful that they will approve the funds. The Developmental Centre was scheduled to open this September."

I was concerned. Again we faced uncertainty about Yvonne's schooling. Teresa, on the other hand, was returning to school in September. She was excited but also apprehensive as this was her first year at MacDonald Drive Junior High. She had the consolation, however, of being with friends from Vanier Elementary and they too faced the same orientation. Yvonne, however, didn't know which school she would attend, who her teacher would be, nor any of the students. The system seemed so unfair.

I asked Mr. Dicks about getting Yvonne into an interim program. He immediately said that Pine Grove wouldn't be suitable. He floored me. Two years earlier, the teachers applied pressure to have Yvonne transferred to Pine Grove. Now he claimed it wasn't suitable. As we didn't want Yvonne in Pine Grove anyway because of the large number of handicapped students, I was glad he voiced his assessment.

"Have you tried a preschool?" he asked casually.

"She has outgrown preschool," I replied indignantly, "She's eight years old."

"Yes," he replied after a contemplative moment, "you're right."

“There have to be alternatives,” I continued. “I’d like to meet with you. When would be a good time for you?”

“Well,” he began, in a soft voice, “as you know, I will soon be taking a one-year study leave. I would suggest you make further contact with Mr. Andrews, the director, or Mr. Downey, the assistant director.”

“That’s even more reason for us to meet,” I argued. “You’re so familiar with Yvonne, you could help Mr. Andrews or Mr. Downey. It would make sense to ask them to the meeting.”

“Let me check my appointment book,” he replied. “How about August 28 at 10:30?”

“That’s fine,” I stated, anxious to get something in place for Yvonne for September. Before hanging up, I asked, “How can I get in touch with the parent group you talked about?”

“You can call Mrs. Hanley, the secretary of the Vera Perlin School. She can give you the name of the president of the Parents Group for Impaired Children.”

Thanking him, I contacted the president. He affirmed what Mr. Dicks said. “I met with the premier myself. I’m confident Treasury Board will approve the funds.”

I was awestruck. He met with the premier? Wasn’t he an ordinary parent? Or did he have political connections? Meekly I offered to be part of the parent group and to help in any way.

Meanwhile, I phoned everyone who I thought might be helpful in getting Yvonne into an interim program. Noel Browne, previously a behaviour management specialist but now director of the Direct Home Services Program (DHSP), was understanding and supportive.

“Since Yvonne is eight years old,” Noel stated with regret, “She can no longer be part of our program. You could call Dr. Lyle Wray, he’s the director of the Division of Mental Retardation; maybe he can help. Then there’s the TMR class (Trainable Mentally Retarded) in Torbay. They use the Portage instructional material. You should talk to Mr. Dicks about that.” I was puzzled. Why hadn’t Mr. Dicks mentioned the class in Torbay?

Noel then told me about the parent group from the DHSP. “You might want to join. The parents meet every Wednesday evening in the Direct Home Services resource room. They decide the issues, topics and speakers. I’m there to help in any way I can. They want me to give a course on child management." He took me by surprise with his next statement. "I heard you took an extensive behaviour management course in Edmonton. How about helping me on this one?" I found myself agreeing without hesitation. He was always helpful to us and I wanted to help him wherever possible.

I called Dr. Wray, as Noel suggested. Dr. Wray in turn, advised me to call the psychologist, Dr. Kaufmann, who was in charge of the Vanier Project. He was also the new director of Exon House, the institution where a psychiatrist once pressured us to place Yvonne.

Dr. Kaufmann sounded pleasant. "The Vanier Project is a pilot project," he said, "set up a year ago for eighteen children from Exon House. The program is in the portable section of Vanier Elementary School. There are nine teachers: three from the Newfoundland Teachers' Association and six staff from Exon House. It's an excellent program and discussions are in the talking stages to expand the program into other schools, as more children from Exon House need this schooling. We can't accept children from the community into this program, however, until we meet the needs of the children from Exon House."

"In other words," I stated sharply, "if we had placed Yvonne into Exon House, she would qualify for an excellent program but because we kept her home we need to lobby and fight for her schooling. It doesn't make sense to me."

This disparity increased my determination to get Yvonne into an interim program at the beginning of September. Dr. Kaufmann recognized my frustration and offered to make some calls; he promised to phone me back.

Meanwhile, I called the child development specialist. She strongly advised Pine Grove School; she couldn't understand why Mr. Dicks said Yvonne wouldn't fit in. She suggested I visit the school and meet with the principal. I did not want Yvonne in Pine Grove School, but I remembered Yvonne's frustration the previous year when Teresa went to school but she stayed home until mid-September. What should I do? It was only a temporary program, should I consider it? I resolved to try all other possibilities first.

I was curious about the other children who previously attended the School for the Handicapped; where were they? I called a parent.

"Because of you," the mother shouted angrily, "the school closed!"

I should have realized the parents would be mad at me, but I never dreamed to what extent. I tried to interrupt, I wanted to explain, but it was pointless. Holding the receiver away from my ear, I let her express her anger until she ran out of breath.

Then, with firm conviction, I calmly stated, “The school would never have closed down if it really was an excellent program. Remember, we all expressed concerns, and if we had accepted the program as it was, those teachers, because of their years of teaching experience, would be considered the most qualified in the field and be promoted to top positions. What kind of program would we have then?”

She let me speak without interruption. When she spoke, her voice was subdued. She must have recognized the truth of my statement. Still she refused to tell me where her daughter was attending. I didn’t push it. With time I hoped to regain her trust.

True to his word, Dr. Kaufmann, called me back. “We had summer students working on a project with handicapped kids,” he said. “The project ended this week; I called the best students to see if they would be potential employees. A few were interested. If Yvonne had her own worker, she could be in a classroom setting at Pine Grove.”

“Where could we get the funding?” I asked.

“Why don’t you call the assistant deputy minister of Social Services, Mr. Compton? Ask him for an appointment and request funds for a worker for Yvonne.” We had written to people in higher positions in government, but now he advised that I request a meeting. Would an assistant deputy minister really meet with me? What if he refused?

Hesitantly, I dialed the number. To my surprise, he agreed to meet with me. I then called Peter at work, “You’ve got to come to this meeting with me.”

On Friday Peter and I arrived at the Department of Social Services and spoke with the secretary.

Mr. Compton arrived shortly. He welcomed us with a smile and a handshake, then ushered us into his office. I froze. I saw three men seated in the room and was thankful Peter was with me. I scanned their faces. Then, recognizing a familiar face, I relaxed. It was Dr. Steer. I took several of his courses and workshops in which he stressed the value of all people and promoted community supports. He portrayed the image of a kindly grandfather; I was glad he was at this meeting. Mr. Compton introduced the others: Dr. Wray and Dr. Kaufmann. This was a pleasant surprise. During the past week, I spoke with both on the phone; now I was meeting them in person.

The meeting opened with a recitation of the developments regarding the Developmental Centre, from the first proposal and its rejection to the present revised proposal. Smiling, Mr. Compton stated, "The funds were approved today for the Developmental Centre."

He then said that Premier Peckford had stressed, "This is not a single department effort. The Departments of Education, Social Services and Health will all be involved."

At the time we didn't understand the implications. We were only too glad to hear Mr. Compton's next statement, "The Department of Education will now advertise for three teachers and six program assistants and they have asked Social Services to train the assistants."

In spite of their optimistic timetable for the Centre to open in two to four weeks, I knew it would take longer. Yvonne, therefore, still required an interim program. I raised this with Mr. Compton and explained, "When school opening was delayed last year, Yvonne cried and hit her chin and jaw in frustration."

Mr. Compton was compassionate and understanding. He agreed to request funds from the Department of Education, to provide support for an interim program.

The group again talked about the Developmental Centre. Concerned, Dr. Kaufmann said, "The word is out, the developmental program will be in Pine Grove School."

Horrified, Peter and I glanced at each other. I sat upright and blurted out, "That would be expanding Pine Grove, which already has a hundred handicapped students, and slamming the door on integration!"

Dr. Steer, a consultant on mental retardation, rushed to our support. "I will not train the teachers' assistants if it's in the Pine Grove setting!"

Distressed, I added, "I understood the proposal suggested Harrington or Holloway School."

"Yes," verified Dr. Steer. "I can give you a copy of the proposal. Stop by my office Tuesday. I'll leave it in a manila envelope with your name on it. I probably won't be there."

I thanked him. Determined I announced, "The parents will need to get together and stop the move."

Dr. Kaufmann swiftly volunteered to give me the names of the children who would be attending the Developmental Centre. I was puzzled. If people in these positions supported an integrated program, who was pushing for Pine Grove?

I received a copy of the proposal, and the names and phone numbers of the sixteen children. I called the parent of each child: "Hi! I'm Irma Penner. I'm a parent whose child will be attending the Developmental Centre. I understand your child will attend this program as well. I'm calling to see if you'd be interested in joining a parent group to keep ourselves informed about the program and discuss any questions: Where will the program be located? What kind of program will our children have? Would you be interested in being part of the parent group?"

The responses were all positive, but due to conflicting schedules the first meeting wouldn't take place until October 11.

During September, I maintained contact with the parents. We shared every bit of new information pertaining to the Centre. Parents, who opposed Pine Grove kept the pressure on the superintendent of the school board and the director of Special Services to have the program in a regular school. Dealing with the superintendent and director, however, was most frustrating. Their statements contradicted each other. Each said they had a memo that the other had called but they were unable to get in touch with each other. Yet the parents could reach both.

In my conversation with one mother we talked about past experiences. She told me how doctors pressured her and her husband to place their son, shortly after his birth, into Exon House. "The doctors," she said, "told us he would never recognize us as his parents; that he was deaf; that he would never walk; that he would never talk; that he would be a burden and we should just forget him." Outraged by the attitudes of the professionals, they kept him home. They loved him. They cared for him and worked with him and they proved the professionals wrong. "The only thing they were right in," the mother declared, "is that he doesn't talk, but if he did," and she laughed heartily, "boy, could he tell them a thing or two!"

The mother continued, “You know, I was a teacher for five years, two at the School for the Deaf. After our son was born, I stayed home. Now that he’s going to school, I applied for a teacher assistant position at the Developmental Centre.”

With her qualifications, I was surprised she hadn’t applied for the teacher’s position. I, too, applied for an assistant position and was interviewed. Dr. Steer was on the hiring committee, and I remembered him smiling and whispering confidently, “Oh, you’ll get it!”

One day a friend who worked at the Janeway called. “I hear Yvonne is still home. Have you heard about Mrs. Earle? She teaches autistic children, on an outpatient basis, at the hospital.”

“No. I wonder why no one from the Departments of Education, Social Services or Health, told me about this? I’m going to check into it!”

I called Mrs. Earle immediately. Then I called the director of Special Education, the superintendent of the school board, the child development specialist and the hospital. After a week of phone calls, I finally made progress. The child development specialist agreed to write the referral.

“I almost gave up trying to reach you!” A bold voice exclaimed, breaking into a raspy laugh.

“Ginna! Hi! I’m surprised you got through. Let me tell you what I’ve been up to.”

“My dear! You must be utterly exhausted. These people just don’t understand what parents go through.” Changing the topic, Ginna said enthusiastically, “Irma, I have to tell you about the Prep Program. It’s a physical education program designed to teach play skills to handicapped kids. It’s simply marvelous.” Without stopping for breath she explained who was involved, where it was, the cost per session, and about the equipment.

“You know Ginna,” I responded, “that sounds like the week-long prep course I took in Edmonton.”

“That’s where these materials came from,” she said astonished. “It must be the same thing!” She registered her son for the ten-week after-school gym program held at the YM/YWCA. I immediately registered Yvonne.

However, the program was threatened by the sudden withdrawal of two professionals. Disappointed, parents volunteered to take over. Eventually the YM/

YWCA administrator consented. Four parents, including Ginna and myself, acted as instructors and we recruited other volunteers to work with the twelve children enrolled in the program. This was a challenging undertaking at such short notice.

Yvonne and the other children enjoyed the gym and benefitted from the activities which were modified to meet each individual's needs. At first Yvonne was terrified on the trampoline. Later she smiled when Teresa, who often volunteered at these sessions, laughingly sent her flying in the air or bouncing on her seat. Yvonne also overcame her anxiety of hanging on the parallel bar; she even enjoyed a light push, causing her to swing. She hung on tightly and developed strength in her hands. This was another activity where she had to use her left hand.

I tried Yvonne on the balance beam. Standing behind her, I held onto both of her hands. She was tense, however, and dug her nails into my flesh. This perplexed me. I hadn't expected her to be afraid. On the sidewalk, Yvonne always walked on the curb if it was on her right side. She flicked her hands casually, and not once had she tripped or fallen. The balance beam was as wide as the curb. Why was she so afraid of the beam?

The beam dropped off to the right and to the left. Could it be that her perceptual difficulties were largely or solely on the left side? I'd have to raise this with the therapist. Meanwhile I persisted in my efforts. By the end of the semester Yvonne required only a light touch of support to her right hand to walk the beam.

Several times a week Yvonne had therapy sessions with the occupational therapist at the Children's Rehabilitation Centre near the Janeway. At first Yvonne was frightened and stiffened her muscles when they rolled her on a huge ball, held only by her ankles. This activity developed her depth perception, defensive reflexes and balance. Eventually Yvonne became less tense and occasionally smiled as they rotated her to the floor and back up again.

The therapy sessions also focused on stimulating her hands. The therapist rubbed a variety of fabrics and materials, ranging from soft velvet cloth to sandpaper, on her palms and fingers. She cried and pulled back. The therapist smiled and spoke pleasantly to Yvonne. Her kind and gentle approach paid off eventually. Yvonne relaxed. At times she even opened her clenched left fist, when the therapist asked her. Yvonne was at least getting occupational therapy and exercise through the gym program, while we waited for an interim program and the opening of the Developmental Centre.

Six parents attended the first parent meeting on October 11. Parents shared information they had gleaned from the Departments of Education, Social Services, and Health. To date, the teachers and program assistants were not yet selected. To our further dismay two locations were being considered: Virginia Waters (a school with thirty-one physically handicapped children, the majority having cerebral palsy), and Pine Grove (a school with over a hundred mildly and moderately mentally handicapped students).

One parent piped up, "I was talking to a parent from Pine Grove, and those parents are objecting to the Developmental Centre being in their school. They would have to move twenty-four of their children out to Holloway School to make room for the sixteen children from the Developmental Centre."

"WHAT?" a chorus of voices shouted in unison. "We don't want our children in Pine Grove! We're the ones who want our children in Holloway! None of this makes sense. Who is making these decisions? We'll need to find out."

The parents met again on October 24. The group chose a name: Parents for Developmental Progress (PDP). Hal was elected president, Marie treasurer, and I secretary. At this meeting parents heard that the director of Special Services, who ordinarily was cautious about confirming any decisions, acknowledged, "All the children would start at Virginia Waters School in the Blackall School building. The program should get underway at the end of October or early November."

After some discussion the parents agreed to hold a special meeting before the opening of the Developmental Centre. We requested to meet in Virginia Waters School. To us, it was important to meet with everyone involved, and we invited representatives from the Departments of Education, Health and Social Services, and asked them to invite the teachers and program assistants. Parents wanted a school program where home and school worked cooperatively.

This special meeting was well attended. Among the teachers and program assistants was a familiar face. I had met Val the year before we left for Edmonton; she had experience working with autistic children.

Val was bubbly and enthusiastic and took a real interest in Yvonne. Now she was a teacher at the Developmental Centre, and more than that, she would be Yvonne's teacher! Denise, previously with Direct Home Services, would be Val's assistant. I no longer felt discouraged that I and the other parent were turned down for an assistant position.

At this meeting, they told us that the children would begin school on November 14. Parents intended to hold them to this date, whether the renovations were completed or not. Any further delay would likely result in postponement of school until after Christmas, and this wouldn't be acceptable.

The secretary of the interdepartmental administrative committee for the Developmental Centre spoke with a heavy English accent. Her dark eyes conveyed a serious expression. She was a little short, both in stature and in understanding of the parents and the children. She informed the parents that only twelve children would be attending the Centre; she gave no explanation about the other four. "Six children will attend the morning session," she said, "and six the afternoon. They will begin a full day, when they are ready."

Parents glanced at one another and at her, silently questioning, When they are ready? We had heard this before. This readiness approach didn't make sense and we detested such excuses. Hesitantly, she responded to the glances, "Probably, in early January." Parents nodded knowingly; they'd see to it that in January the children would have a full day.

Another committee member then talked about the incomplete renovations. "The children will have to use the washrooms down the hall until the renovations are completed, probably over the Christmas break."

Parents protested. "Why can't they continue to use the regular washrooms? It's not normal to have a washroom in the classroom. We want our children to experience a normal environment."

Reasoning with the committee was futile. Exasperated, one parent exclaimed, "It's ridiculous! I don't have a toilet in every room in my house. Our bathroom is upstairs and I have to carry our daughter up fourteen steps. The washroom at the school is just down the hall. What's wrong with using that one?"

Stoically the committee member replied, "It's a committee decision. These children need a washroom in the classroom." The secretary of the committee then introduced the coordinator of the Developmental Centre. She smiled broadly, spoke kindly and giggled with enthusiasm. She informed us that assessments would be done on each child before Christmas, and an individual program would be set up in cooperation with each parent. Parents nodded approval. This was precisely what we wanted. We looked forward to a good working relationship with the teachers.

The Developmental Centre opened as promised on November 14. The committee wouldn't dare suggest delaying the opening. Yvonne enjoyed going to school. She was up early every morning and waited impatiently at the front door for the van to pick her up. I was happy she was anxious to go to school.

Christmas arrived and our calendar filled with activities. Yvonne, however, cried and was restless. Soon I realized she worried that she wouldn't be going to school anymore. I explained, "Yvonne, this is a holiday. Teresa is home, too. When Teresa goes back to school, you'll go to school!" I marked her calendar and crossed off the days, counting down the number of "sleeps" before school started. She was skeptical until the day I got her ready for school.

With Yvonne in school, I channeled my energy into other areas. I joined the Direct Home Services Program parent group in addressing the need for a respite program. Many parents, including ourselves, found it increasingly difficult to leave their child in the care of teenagers. At times teenagers were unable to handle the complex needs or the negative behaviours which occurred because of frustration. Although Teresa was excellent with Yvonne we couldn't expect her to always provide respite for us, nor could we expect our friends to provide support regularly.

This parent group, with the child developmental specialist and officials from the Department of Social Services, submitted a proposal to government. Eventually they approved funds for a respite program. The Department of Social Services then hired workers who were available during the day, Monday through Friday, between 9:00 and 5:00. This, however, was not what the parents asked for. The program did not meet the need for evening relief, weekend relief or emergency relief. Since most of the children were in school during the day, this respite program was of no value.

Several parents, including myself, met with government officials. We knew that it cost government $50,000 a year for each child in Exon House. We knew that many parents were pressured to place their children into this institution but refused. We explained that a respite program, which would meet our needs, would enable us to continue to keep our children at home and cost government only a fraction of this amount. Our reasoning obviously made sense because government eventually approved funds for a more comprehensive respite program which finally got underway in September 1980.

Meanwhile, parents from the Prep Program continued the gym program during the spring and summer semester. This group was also involved in helping the YM/

YWCA administrator and the recreation council plan a workshop conducted by Dr. Watkinson, the designer of the Prep Program, from Edmonton, Alberta. The workshop provided recreation workers, teachers, social workers, parents and rehabilitation workers with specific skills to help children with developmental disabilities to acquire basic skills used in play. Participation from across Newfoundland and Labrador was limited to twenty-five. We needed to deal with many details, from equipment rental to lodging arrangements. Helping to organize this event was a new experience for me.

One February evening I received a call. “Hi, this is Joe.”

My mind scrambled for a visual image of the caller. I didn’t know a Joe.

“Joe Cawthorpe. I’m with NIMR, the National Institute on Mental Retardation in Toronto; but I live in New Brunswick. I heard about you and Peter, and your struggles with the medical people and the problems getting your daughter into school.”

I was still puzzled about the call. “Would you be willing to share your experiences with a group of social workers tomorrow afternoon, from one to two, at the Hotel Newfoundland?”

I was speechless! He continued, “We need a parent’s point of view. Social workers have no idea what parents experience. They need to meet parents like you who have an accepting attitude.”

His last two words were the key reason for my consenting. Promoting accepting attitudes was precisely what we were trying to do. Now we had an opportunity to do just that with social workers. Peter agreed to take time off work and we stayed up most of the night preparing a presentation: “A Parent’s Viewpoint.”

The social workers seemed shocked by some of our experiences but they seemed interested in supporting families like ours.

Two months later the education coordinator with the Newfoundland Hospital Association approached us to participate in a provincial conference called “Health: A Social Concern.” Panelists would provide two viewpoints: “Provider Talks to Consumer” and “Consumer Talks to Provider.” I was dumbfounded. The health profession was asking for our viewpoint! I spent weeks writing and revising my part of the presentation to address publicly our experiences with the medical profession and the issues that we thought were important.

Meanwhile, the coordinator of the Developmental Centre requested assistance from the parents. The school needed equipment such as inclines, steps and scooter boxes for gross motor development. Several parents, including Peter, readily volunteered to make them.

The coordinator also asked that parents help on the bus run and during the lunch hour. I volunteered to help with both, every Monday. I was assigned to Keith. I worried, what if Keith choked? What if he had a seizure? What if I didn't position him correctly? The coordinator reassured me, "We'll show you what to do. One of us will always be nearby if you need us."

Keith was one of the most handicapped of the children. His mother once told me about her experiences and the frequent trips to the Janeway and how the nurses voiced astonishment, "You mean you have him living at home with you?" The mother's rhetorical question, revealed her feelings, "Are they nuts or something; where else do they think he lives?" Annoyed by the nurses' attitudes, the mother learned to deal with Keith's grand mal seizures and other medical problems and only took him to the hospital when absolutely necessary. "Can you imagine," she said, "when I got this call about Keith going to school? I laughed in their face. Yet they were serious, I couldn't believe it!"

With each passing week, I became more relaxed and confident in helping Keith with his lunch and exercises. I began to look forward to Mondays and noticed the improvements from one week to the next. Although Keith often sat slumped or propped up in his chair, or lay on a mat unable to roll over by himself, he was gaining strength. The therapist predicted to the mother that someday he would eat by himself and even transfer from the wheelchair to his bed.

Keith, however, never got that chance. He died the following year. One night as I sat with his mother at his hospital bedside, tears rolled down her cheeks as she quietly stated, "I told them to check for pneumonia, but they wouldn't listen to me. Finally they checked. It's too late now; the medication isn't helping."

Two-and-a-half weeks later I looked down on his peaceful body in the casket. I recalled his fight to live. I recalled the various expressions in his huge brown eyes which spoke of joy, love, determination, mischief, pleading, frustration and even a look of forgiving, but never had I seen a look of anger or hatred. Wiping away my tears I thanked Keith for all he taught me. I would always remember him and someday his story too would be told.

Keith taught me that it doesn't matter how handicapped a person may be, he is still a person with feelings, desires and needs just like anyone else. He taught me to look beyond the physical limitations and see the value of life in every human being. He taught me, just as Yvonne did, to communicate by observing the eyes and other body movements. People like Keith and Yvonne have had much to say, but how many people have understood?

* * * * *

Three months after the Developmental Centre opened the parent group, the PDP (Parents for Developmental Progress), heard about a seven-and-a-half-year-old girl who was refused admission to the centre. The committee told the child's mother, "The centre cannot accept any more children." The PDP agreed to help this parent lobby for additional classroom space. At the same time the PDP informed the public of the Developmental Centre through a newspaper article. As a result, two new parents contacted the PDP.

The PDP then approached the St. John's Association for the Mentally Retarded for support to lobby for classroom space for the three children. The St. John's AMR, however, did not help the PDP. Their primary interest was in maintaining the segregated preschool at the Vera Perlin building, the adult workshop in the basement of the same building, and the school at Pine Grove.

Subsequently, the PDP asked the Direct Home Services Program parent group for support. These parents recently named themselves SNAG (Special Needs Action Group); they favoured integration. They also had access to resource people from the NIMR through Noel Browne. NIMR soon helped the parents plan a strategy to force the St. John's AMR to represent the needs of all handicapped children. They advised the parents, "Get a SNAG representative elected to the St. John's AMR board of directors." After intensive campaigning the SNAG representative, Bob Johnston, was elected to the St. John's AMR board at its annual meeting in April. His involvement made a difference.

The PDP was constantly on alert. In May, parents heard rumors that the school board might sell the Blackall building. If this happened, where would they move the Developmental Centre? The president of the PDP immediately contacted the superintendent, but was nonchalantly told, "We do not expect to sell it this year." Nonetheless, every parent remained watchful.

In June, Dr. Steer told the PDP, "If you're interested in having your children in a summer program, you can apply for a grant through the Employment

Opportunities Program; the deadline is at the end of this week." Parents agreed, and I found myself heavily involved helping to organize the summer program.

Through the Employment Opportunities Program and the Division of Recreation, Department of Tourism, Recreation and Culture, we hired seven staff. Parents volunteered to help, one each day. This enabled one-on-one support for the eight children who attended daily. We arranged schedules around each family's vacation. The ten-week program, held at the School for the Deaf in Torbay, provided continuity of skill development and fun activities both outdoors and indoors. This prevented negative behaviours, due to boredom or worry over school closure. Later, when school opened in September, the teachers remarked on the improvements in the children.

Before returning to school in September we left the island for our usual trip across the country. This year, though, our vacation was different. We drove to Philadelphia, partly for nostalgic reasons but largely to meet with Howard and Mary. They worked with handicapped children; Dave Dyck from MCC suggested we visit them. Their project was a possible voluntary service assignment for us. This project, interestingly enough, was in the Germantown area where we had lived nine years earlier. A move there would be an easy adjustment. We had reservations, however, about the work and wanted to be open to other opportunities.

We continued our trip west and northward to Winnipeg. Although we visited our families, our primary reason was to participate in a ten-day orientation with MCC. About forty volunteers, some with children, from Canada and the United States, converged on the Mennonite Brethren Bible College on Henderson Highway. Dave had arranged for Grace Unruh, a mature teenager, to be with Yvonne while we participated in the sessions.

Grace and Yvonne went with the other children on outings to the zoo and parks, but Grace soon realized Yvonne didn't like being in a large group. They then went by themselves. Yvonne liked Grace, as did we. We appreciated her understanding and support which made it possible for us to participate without concern about Yvonne.

After the group orientation, we had a private session with Dave where we discussed specific needs concerning mental retardation. Although support services were necessary, we sensed the promotion of positive attitudes within the service sector and the public were needed most. An advocacy approach, however, was new for MCC. Until now, MCC provided "direct services."

Since the assistant deputy minister of the Department of Social Services in Newfoundland had expressed an interest in a project to promote public awareness, Dave supported MCC involvement with us as voluntary service workers. We realized our knowledge of the political and social service systems in Newfoundland was a great asset. We were also glad to stay in Newfoundland.

On our trip back to St. John's we stopped in Toronto at the NIMR and CAMR (Canadian Association for the Mentally Retarded) offices on the York University campus. Here we heard about and met Bruce Kappel, Alan McWhorter, Joe Cawthorpe, Andy Baxter, Bob Gall, Aldred Neufeldt, Hugh Lafave, Allan Roeher and Malcolm Jeffries. These men formed an alliance promoting normalization and spoke of people with mental retardation with dignity and respect. They were against segregated living and enthusiastically promoted community involvement for everyone, regardless of the degree of the disability.

Our adrenalin flowed. We were excited about working on a project that was not yet outlined on paper. In the months that followed, MCC and CAMR worked on a proposal to obtain funding for the Community Involvement Project, which we anticipated to begin January 1981.

Meanwhile Peter taught his final course in biochemistry and wrapped up his research at Memorial University of Newfoundland. Some of his colleagues couldn't understand his leaving the academic science career. Other colleagues, however, understood; still, some suggested he take a leave and not resign a tenured position. We realized, however, that we could not accomplish much in two years. Our work in the field of disabilities would be a long-term commitment.

Chapter 9

1981

On January 5, 1981, Peter and I drove to the CAMR Newfoundland and Labrador Division office, our workplace for the next two years. MCC agreed to cover our expenses for the first year of a two-year project while we waited for a response to the proposal for outside funding. We scouted for secondhand office furniture, organized the books and brochures, read, and got to know Malcolm and

Moya. CAMR hired Malcolm Jeffries as executive director and Moya Walsh as secretary. She was friendly and talkative, yet swift and efficient.

Malcolm was hard working and serious. Nevertheless, he appreciated humour and laughed heartily. Though some people found him intimidating, he commanded a high degree of respect for his integrity, farsightedness and ability to plan long-range strategies. He always placed the interests of people with disabilities first, while maintaining a positive working relationship among people in CAMR, government and service systems.

We valued the opportunity to work with Malcolm. He was our greatest teacher. I would always remember his quiet, but confident assertion, "There's a solution to every problem; you just have to find it." His commitment to people with disabilities, despite the condition or degree of severity, was unfailing. He believed that professionals should support families who are the main resource in the lives of people with disabilities. This conviction was the foundation for our work.

Malcolm wrote the detailed proposal to the Health Promotion directorate, Department of National Health and Welfare for our project: "A major problem for people with retardation is inadequate access to basic services." He addressed the "lack of awareness in general as to the social and environmental conditions affecting the general health and well-being of individuals who live with a mental handicap" and "these problems can be resolved by facilitating communication among parents and between parent groups and professional entities within the health care system." We waited for a positive response to the seventeen-page proposal.

In February the federal minister signed the contract approving the project. The office buzzed with activity that same afternoon as we completed the multiple mailings to publicize the project. We sent a news release to twenty-three newspapers across Newfoundland and Labrador. Each of the nine local CAMR associations across the province received a lengthy memo. We wrote notices to public health nurses, social workers and special education teachers province-wide.

Peter designed a logo for the letterhead by superimposing the CAMR and MCC logos onto a miniature map of Newfoundland and Labrador with the inscription: The Right to Belong. This was the message we wanted to convey to parents and professionals. Everyone, regardless of their handicapping condition, has a right to live with a family, a right to go to school, and a right to participate in activities and events in the community where they live.

We hoped to give parents greater understanding about the ways in which handicapped children could live more healthful, dignified and normal lifestyles. We wanted to meet with families individually, help identify available services, and determine the kind of services that families wanted developed in their communities.

In our excitement to work on this project I blotted out any concern about eventual overnight trips. It wasn't long, however, before we faced this reality. How would Yvonne react to our absence? How would this affect her in school? How would she react to a "stranger" in our home? Could this person manage? Finally I convinced myself I was foolish. Many parents left their handicapped sons or daughters for a brief time. I even convinced myself that Yvonne might appreciate experiencing time away from her parents.

I arranged for Mary, a former program assistant from the Developmental Centre, to provide the live-in support. I wrote out a detailed schedule of Yvonne's routine, starting with her arrival from school, through supper time, evening, night and morning. But my greatest consolation was the assurance that Teresa was there and could provide the feeling of security for Yvonne.

Our visit in Marystown was a new experience. We spoke at a general meeting of the Burin-Marystown Association for the Mentally Retarded and later met with a family and their adult son. He was home without work or educational opportunities. Because he was bored and frustrated he became aggressive toward his mother and people in the community. We had no answers; we needed direction from Malcolm. We left the following day before noon, promising to be in further contact by phone. Peter drove faster than usual. We wanted to be home before Yvonne arrived from school. "Why are you slowing down?" I asked incredulously as Peter eased his foot off the accelerator.

"Look behind us," he stated with annoyance. A vehicle with a flashing red light signalled us to pull over. The policeman handed Peter his first speeding ticket; this was painful in itself, but we were more distressed because we wasted valuable time. Now we had to drive even slower. If only the policeman could understand our situation, and the pressure we were under! We arrived home just as the mini school bus pulled into our driveway.

Peter and I exclaimed, "Yvonne! We're happy to be home! We missed you!" We tried to hug her. Yvonne, however, raised her elbows to keep us away. She wouldn't look at us and ran out of the room. Her rejection and withdrawal were heartbreaking. Memories of the past flooded back. Now we blamed ourselves for this relapse. Would she come out of it?

Yvonne sat with us at the supper table but she wouldn't eat. Teresa told us about the past day, and added, "Everything went really well." At this, Yvonne burst out crying. I guided Yvonne to her bedroom. I put her on my lap, placed my hand under her chin, and looked deep into her eyes. "Yvonne," I began quietly, trying to get her attention between sobs, "Mommy and Daddy are so proud of you for staying home alone." She stopped crying. She looked puzzled.

I repeated. At the words "so proud," Yvonne laughed nervously. "That's right! We're so proud of you!" She laughed. She allowed me to hug her and together we laughed.

Telling Yvonne that we were proud of her was the key approach to future trips. Soon Yvonne looked forward to our going away just like any other child. Her response was so normal.

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Peter and I remained involved with the PDP and helped three new parents in getting their children into the Developmental Centre. The committee, however, still insisted on expanding the program into Pine Grove and blamed the PDP that these three children were not yet in school. The new parents, with support and guidance from the PDP and the provincial and national CAMR, insisted on classroom space in a regular school. We all knew that one classroom in Pine Grove would lead to a relocation of the whole program into that setting. We couldn't let this happen.

The Division of Special Services, Department of Education, recently hired a new director, much to our delight. He was the same friendly supportive man who had earlier gained the parents' trust and respect while he was with the Department of Social Services. Now we felt assured of support from the Department of Education to expand the Developmental Centre into a regular school. Relieved, Peter and I concentrated on other issues.

Our work schedule across the province intensified. We received calls from CAMR board members, parents, teachers and social workers. Following our trip to Marystown, a social worker called from Clarenville with an urgent request to help a family with twin girls who had Down Syndrome. We agreed to first stop at the Social Services office; together we would drive to the nearby rural community and visit the family. The social worker opened a file and gave us information about the family to prepare us for the visit.

The mother was friendly but looked perplexed. Soon we too were perplexed. Why were we here? What was the need? The mother never expressed one. The family was doing everything quite naturally. The mother beamed as she talked about the twins. "They'll be attending kindergarten in the fall."

We soon left. In this short visit we learned a few hard lessons:

1) We would never visit a family solely on a social worker's request. We would ask the social worker to either encourage the family to call us directly or get the family's consent for us to call.

2) We would meet with a family alone, without a social worker and without outdated information from their files.

3) We would set a time convenient to the family when both parents (if there were two) would be present.

4) We would not carry an intimidating portfolio, but rather a small notebook tucked into my purse.

5) We would dress casually, no blazer nor sports jacket. Our image and our credentials should be those of parents and not of social workers.

6) Most importantly, we realized that in the eyes of this social worker, the label "handicapped" precipitated a "need," especially since there were twins. Of course, people who have a handicap have extra needs. In this instance, however, the family's needs were met because the community accepted and included the twins.

In contrast to this experience, I received a call from a distraught parent from the west coast of Newfoundland. For the past few years she brought her son to the rehabilitation centre in St. John's for one or two weeks of respite, but this summer they turned down her request. They told her they didn't have the staff to manage him. Greatly disillusioned, she called Exon House, but they too refused to take her son. With a choked voice, she asked for our intervention.

Clearly this family's needs were monumental. She explained about having locks high on the doors and windows of their home to prevent their ten-year-old son from running out. The family got little sleep as he roamed through the house in the dark, unable to sleep. Their kitchen cupboards were nailed shut to prevent breakage of dishes. He went to school in a locked classroom, but when the sedating medication wore off, the teachers couldn't handle him and he was bused home. The mother, never knowing how soon he would return, was unable to relax. The parents couldn't go out together because no one could manage their son.

Over the phone she pleaded, "I need a two-week break! If I don't get it..." her voice fell silent. Then, in a cracked voice, she continued, "I'll have no choice but to admit him for total care into Exon House. We can't do it on our own any longer." She paused. "I called the minister of Social Services; he told me to call CAMR."

I was shaken by her story. I had no answers. Hoping to reassure the mother and confident that Malcolm could help, I stated with surprising calm, "I'll call you back; I'd like to get some advice."

Malcolm listened intently as I relayed the situation. After a lengthy discussion Malcolm pronounced, "Let me make a phone call."

He returned shortly and said, "Joe will accompany you on this trip. This is what I'd like you to do: call the mother and arrange a time convenient to them. Then call the regional director of Social Services and the principal of the school, and set up appointments with them. And when you're speaking with the mother, let her know, kindly but firmly, that CAMR does not support placement nor relief care at Exon House, but we'll work at getting something more appropriate."

"You can also tell her," he added, "that the provincial government completed a study through NIMR, headed by Aldred Neufeldt, which recommended phasing out Exon House. These children will return to their home communities with support. Assure this mother that her request for respite and other needs will receive top priority because both government and CAMR don't want any more admissions into Exon House."

We arrived at the family's home. Their circumstances overwhelmed us. Joe, however, having worked through a variety of difficult situations, soon outlined a plan. After two intensive days of meetings and phone calls, the regional director made a commitment with approval of funds through the minister's office to help the family.

The parents could plan their two-week out-of-province trip, and Social Services would identify a respite worker to provide support to their son in their home. The principal of the school also gave the family a commitment that with funding, their son would be in school for the full day. An experienced behavioural psychologist would be involved and the teacher would receive appropriate training and instruction. The family physician would review the medication and make appropriate changes based on the family's wishes, in consultation with the psychologist. In addition, Social Services promised the family regular respite every month.

Now it was the mother's turn to feel overwhelmed. A host of strangers descended into her life and she would get support.

To help the mother further and remove additional pressure, it was my role to follow up with Social Services, the doctor, the psychologist and the principal, always maintaining close contact with the mother. During a follow-up call, I told the mother about the upcoming CAMR annual conference. "I was never able to go," she said, "but now that I've got respite, I can." And she did.

The provincial CAMR annual conference took place in May. This was the International Year of the Disabled, and the theme appropriately proclaimed "Progress Through Participation." The conference provided "a greater awareness of the rights, needs and potentials of citizens who live with a developmental handicap."

The keynote speaker was Doreen Befus from Red Deer, Alberta. A press release introduced her "—as a young child Doreen was labelled 'retarded,' told that she would never get past Grade 3, and could never be responsible for herself. Because of this, Doreen (at seven years of age) was put in the Provincial Training School now called the Mitchener Centre. At the age of ten, Doreen was considered uneducable; she was taken out of classes and put to work in the institution. Finally, after thirteen and one half years behind locked doors, Doreen was allowed out. She spent twenty-nine years working and living with families in rural Alberta until finally she had the opportunity to move into a group home in Red Deer. Then, while taking a life skills course at Red Deer Community College and with a growing belief in her own abilities, Doreen found and rented her own apartment. As part of the People First movement, Doreen has become a remarkable advocate for the mentally handicapped."

Doreen was a gifted speaker. Speaking without notes she was vibrant, moving an audience of 159 parents and professionals to laughter and tears as she spoke about "The Right to Belong: A Personal Experience." Her message was clear, "Many of the 18,000 Canadians living in institutions need not be there."

Speaking on the heels of Doreen, I felt inadequate in my presentation. Not straying from my notes, I conveyed the message that "One Parent Can Make a Difference." I emphasized that "As a parent, decide what you want for your son or daughter in your community; that someone has to take the initiative to get things going and it takes only one parent. Find other parents who have similar needs. Use the resources and resource persons available in your community. Work together, think ahead, anticipate the problems you might come up against. Never give up and finally, when you are successful in getting the kind of program you want in your community, stay involved."

I also gave examples from our experience and relayed the story of the psychiatrist who urged us to move to England "where the services were." But refusing to move, we stayed and worked toward developing services where we lived. We got services. As for the psychiatrist we heard he had moved to England!

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Requests for us to meet with parent groups and individual families across the province kept increasing. Our visits often took place around the kitchen table. We shared experiences and built a trust with the parents. Once a mother told us her woeful story. "My adult son has never and can never participate in any community activities." We explained how we included Yvonne in all our family outings and how she benefitted.

"Yes," the mother shot back, "but she can walk. My son is in a wheelchair."

"Yes," I acknowledged, "that does make it more difficult. But your son can speak. Yvonne can't talk."

The mother gasped. "She can't talk? That I couldn't handle! At least my son can speak." Suddenly we were on the same wavelength. Her change in attitude was incredible, she no longer felt sorry for herself. She was interested in knowing how people using wheelchairs could participate in the community. "Except," she pointed out with returned skepticism, "most buildings aren't accessible."

"I agree they need to be made accessible; but you'll also need a ramp on your home."

"We can't afford to build a ramp," she replied.

"Well, let's make a request to Social Services. After all, if your son could walk, he would be working and bringing home an income. He's not able to walk, however, and you're incurring additional expenses. The community needs to shoulder some responsibility. And Social Services is wanting to support families in their home communities." Astonished at this possibility, the mother's face brightened. We asked about any additional needs and promised to call in a day or two.

The following day Peter wrote out a proposal based on what we learned from Joe stating the family's situation, their need, a solution to the problem and a budget to cover the costs. The mother approved sharing this with the president of the closest local AMR who could help lobby for support if necessary.

Moya typed the proposal, mailed it to the regional director of Social Services, and sent a copy to the family and the local AMR. This approach became a pattern with all our family visits. We followed up each proposal after we submitted it with phone calls to the family. Meetings at the district level usually resolved differences regarding the requested supports. If not, we supported the family by appealing to the minister.

Most family visits addressed needs for respite or special equipment, but many also involved vocational and educational issues. A mother called from Normans Cove. Her daughter was six years old and Social Services cut her off from the Direct Home Services Program. The mother explained how much her daughter had advanced through this program and asked me to intervene to get it reinstated.

I explained that Social Services provided home-teaching support until six years of age and then the school system took over. "No!" she interjected. "My daughter is handicapped. She can't go to school."

I told her about Yvonne and the other children at the Developmental Centre. I also told her that the provincial government recently passed a Right to Education Act which included children with a mental handicap.

The mother stated firmly, "I won't send my daughter to school. My daughter is too handicapped."

I called this mother often, trying to convince her of the benefits for her daughter. One day she agreed to a visit. "We might bring our girls along for the drive," I said. "Would you like to meet Yvonne?"

"Yes," she said, "that would be nice."

After a brief visit, Teresa took Yvonne out for a walk. The mother recognized that their daughter had more abilities than Yvonne. "If Yvonne can go to school," she reflected, “and she enjoys it, then maybe my daughter could go as well.” Meeting Yvonne was the turning point for this mother.

We promised to write a proposal to address their need for respite and educational support in the classroom. I phoned often. Later in the fall, she called and said, “My daughter is in a classroom with four handicapped children in a regular school and she is happy. She even sleeps better at night!” Before long, this mother became the driving force to get a parent support group established in her community.

Some communities, unfortunately, had sad stories. A mother told us that her eighteen-year-old son refused to go to school. He was home, bored and getting into trouble. After listening to her son, we understood why he wouldn’t go back to school. He had been in a special class with students ranging in age from six to nineteen in an elementary school. “I want to go to the high school with the big boys and play basketball,” he said. “I don’t want to be in an elementary school with the little kids!” But the teacher and administrators had not listened to him.

We couldn’t comprehend how educators, with supposedly normal intelligence, could even contemplate putting a six-foot, eighteen-year-old into such an environment. The mother asked us to attend a meeting with several school officials. We could not persuade them, however, to accept her son at the high school. Lamely they claimed he had already checked himself out of the school system.

Before this meeting, the mother enrolled her son into an adult vocational program. The staff, however, claimed they couldn’t handle him, he was too violent. We questioned, “Did the staff not understand that he was becoming aggressive because no one was listening to him?” He was forced to use this approach to get their attention. First the system kept him through his teen years in an elementary school, then the adult program focused on teaching him self-help skills, such as grooming, dressing and doing laundry. The guy was smart. He could do those things. He wanted to do something meaningful.

Eventually the Department of Social Services provided funding for a male counsellor to help him at a worksite stacking shelves in a grocery store. Finally, with a friend, he was doing something useful and something he enjoyed. The funding, however, was time-limited and eventually his placement fell apart.

Sadly, but not surprisingly, the lack of appropriate schooling may have been responsible for his actions which led to a criminal record later.

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A school board official from Springdale asked us to help with educational needs for adults. On our arrival, he proudly said, “First, we’d like to give you a tour of our integrated program.” Peter and I couldn’t believe it. Two classrooms of children with disabilities of all ages in the school board office building! This was integration? We challenged them, but knew that only assertive parents from the community could change this situation.

Soon they ushered us into a large boardroom. They gave us plans for the construction of a woodworking workshop. Thinking I misunderstood the nature of our visit, I interjected, “Excuse me, I understood we were here to discuss educational needs for adults.”

“Yes,” the chairman replied, “we have too many handicapped adults who are finished with school, walking and loitering on the streets. We need to set up a building, a workshop, for them.”

“Is that what they want? Have you spoken to them or their parents?”

“No,” he replied, “we haven’t. Other communities have workshops. We assume they want one too. We’ll build it and when it’s finished they can use it.”

Peter and I explained the importance of meeting with the young adults and their parents. As kindly as possible I said, “You need to develop something according to their interests.” We told them about Vera Industries, a sheltered or segregated workshop in St. John’s. Male clients worked on carpentry in the basement of the building, and female clients worked upstairs hooking mats, photocopying and stuffing envelopes. A young man hated carpentry, yet they placed him there. Repeatedly he asked to photocopy and collate. No one listened until he became frustrated and violent. Finally, when they allowed him to work in the office, he was a happier person. It made sense. His father and brothers were either teachers or lawyers; none had woodworking skills. Why should it be different for the person with the disability?

Our next trip to Springdale was of a different nature. We visited a family and then stopped at the local hospital to see the Developmental Maximization Unit. This unit was set up as part of the phase-out of the two childrens’ institutions in St. John’s: Exon House and Children’s Home. The sixty residents in Children’s Home were multi-handicapped; a number were bedridden and permanently tube-fed.

The national CAMR and NIMR had conducted a second study for the Government of Newfoundland and Labrador which “reviewed and evaluated institutional and related community-based services for developmentally delayed citizens within the Province of Newfoundland and Labrador.” The Developmental Maximization Unit was the first step of a two-stage demonstration project to prove that even the most severely disabled individuals need not live in institutions but could be supported in homes. The six most severely handicapped residents of Children’s Home in St. John’s were identified and moved into the Developmental Maximization Unit in the Springdale Hospital.

With some apprehension Peter and I walked up the stairs to this unit. We were warmly welcomed by friendly staff. Eagerly they showed us around. The rooms were painted and arranged to reflect a more homelike atmosphere. The staff took pride in telling us about the residents. All six were off tube feeding and eating solid food. One teenager having developed a cold, wasn’t eating and needed to be tube-fed until he recovered.

Then we met Gloria. She was the oldest, being twenty-one. She was lying on a mat on the floor, her body twisted from years of lying without exercising. I went down on my knees to be closer, held out my hand to touch her and said, “Hi Gloria!”

Her face broke into a wide smile. Her head moved slowly back and forth, she moved her mouth from side to side, and with great effort uttered what could have been “Hi!” Maintaining eye contact, she slowly raised her bent arm and jerked it forward. I touched her hand. Excitedly, she uttered “Hi!” repeatedly.

A female attendant on our right beamed. “Gloria is our greatest success! When she came here six months ago, we couldn’t get a single human response. She lay unresponsive to our voices and our touch, and look at her now!”

During the visit we learned that initially all staff at the hospital were given the opportunity to work with the six people on the unit. Then only those staff who clearly expressed a desire to work with them were chosen to be part of this project; this helped ensure success. The second phase of the project was a move out of the hospital into a group home in the community.

The People in Communities study, under the direction of Bruce Kappel from the national CAMR, demonstrated clearly that even severely disabled people, with proper supports, could live in homes in their community.

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The Labrador-West Branch of CAMR in Labrador City invited us to speak at their general meeting. Since Yvonne accepted our absence for several days, we looked forward to visiting Labrador.

Arriving in Lab City, as everyone called it, we were treated like honored guests. They gave us a tour of the town and, to my dismay, set up appointments for radio and TV interviews. While school was in session, we saw Notre Dame School and J.R. Smallwood Collegiate. Emerson and Donna Coish, a husband and wife teaching team, were leaders in the field of integration. They pointed out how students with disabilities mingled with their classmates.

Just before our evening presentation, a board member told us about a new mother who needed help. They encouraged her to come to the meeting and hoped we would talk to her afterwards. The meeting room was full. We spoke about our project and Peter emphasized, "The intent is to help at least one family in every community across Newfoundland and Labrador get the necessary supports. We hope that through this experience the service system will learn how to respond to other families' needs and provide the required supports."

After an informal question and answer period, the meeting adjourned but people stayed to talk. Soon we were introduced to the new parent. Her female companion hung onto her elbow but, sensing the mother's discomfort, said, "I'll see you tomorrow," and left.

My raised eyebrows questioned, who's the leech? The mother responded, "That was my social worker. She advised me not to come to this meeting."

"What?" I asked bewildered. I knew a CAMR board member encouraged her to come.

She hesitated. "My social worker said that 'the Penners are bitter parents who can't accept that their daughter is handicapped.'" Peter and I were speechless. Confused the mother continued, "I didn't see that at all. Why would she say that?"

The wheels were turning in my head but now was not the time to deal with this. "I'm glad you came," I stated honestly.

"So am I," she replied. "The social worker told me that if I went to the meeting I shouldn't go alone, that the St. John's office instructed her to go with me and stay by my side."

Flying home from Lab City we remained puzzled. Who from St. John's would say that?

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During some family visits, discussions included experiences involving the church. A Roman Catholic family on the southern shore confided they had quit attending church because their handicapped son was not allowed to take part in Holy Communion. Several families of different denominations told us they had quit attending church because of the barriers they encountered.

We shared our experience and emphasized that we as parents have to work within our churches to get our sons and daughters with disabilities accepted. They too need spiritual growth and we need to approach the clergy and members of the congregation for support. "It's much easier to stay home," I acknowledged. "We did that too; but who will open the doors and set the example?" I challenged this mother, "Someone needs to pave the way for acceptance and participation."

Many months later, this mother called, "I wished you could have seen my son at his first communion. We were so proud of him! People came up to him afterwards, shook his hand and praised him. He grinned from ear to ear; he knew they accepted him!"

Chapter 10

The Integration Game

Integrating students with disabilities into regular schools became a hot political issue. The government had passed legislation in 1979 to amend the Schools Act, making school boards responsible for the instruction of all children. At the same time, the government developed a policy supporting integration.

Up to that time most children with disabilities had remained at home or attended segregated schools operated by local Associations for the Mentally Retarded. The St. John's AMR had started at a downtown location and in 1966 moved their program into a new building which became the Vera Perlin School. In 1971 the government assumed responsibility for these students, aged six to eighteen years, and a few years later transferred these classes to a larger building, the Pine Grove School.

During 1979 and 1980 government officials met with teachers and parents at Pine Grove to discuss a move into special classes in regular schools. Teachers and parents alike fiercely opposed moving students out of the sheltered environment. Endless meetings and debates followed.

The parents from the Developmental Centre, (PDP, Parents for Developmental Progress) on the other hand, wanted classroom space in a regular school, and fought against having the centre transferred to the segregated setting at Pine Grove. They knew the government planned to first integrate students who were mildly or moderately handicapped; consequently, the children at the Developmental Centre who were labelled severely or profoundly handicapped would be the last to be integrated and might never have this opportunity.

Realizing this, the PDP adamantly resisted Pine Grove. They also argued that it would make more sense to integrate these children, whose parents favoured this policy, and the parents would help to make integration successful.

The PDP was also active in helping the three families whose children were still not in the Developmental Centre. They prepared a study paper, with input from each of the three families, to the minister of Education noting the positive aspects of the centre and expressing expectations for an expanded centre. The minister and the deputy minister met with five members of the PDP and the three new parents to discuss the document. These eight parents were well received and encouraged by the minister's understanding and support.

A few days later parents were told that classroom space was secured at St. Joseph's School. Two weeks later, however, the director of special education said, "The classroom in St. Joseph's School is not available after all. Public Works predicted that the fire marshall would condemn the classroom for the handicapped children. The only alternatives are Pine Grove or the School for the Deaf."

Parents expressed their disappointment about St. Joseph's School, and were angered by the alternatives. The director swiftly responded, "The school-aged youngsters must be in a program, and I would appreciate your help. You could contact the school boards and put pressure on them." Schools in Newfoundland were still operated by religious denominations; St. John's had three school boards: Roman Catholic, Pentecostal, and the "Integrated" or Avalon Consolidated.

The director also suggested that parents check for possible space at the St. John's Boys and Girls Club, and with principals in schools throughout the city. He then advised, "In the future, all parents should enroll their children in their local schools to exert pressure on the school boards to provide space." At the same meeting, the director encouraged the parents to submit a proposal for next year's summer program. I volunteered along with two other parents and a program assistant. Parents left the meeting with heavy workloads.

The following day two parents and I divided the list of elementary schools and phoned the principals. If classroom space was available, the calling parent requested a meeting with the principal. Three parents visited the St. John's Boys and Girls Club, Holy Cross Elementary, and Cowan Heights.

At the next regular PDP meeting parents learned that the interdepartmental committee rejected all three locations. The director again stated, "Pine Grove is the only alternative." Frustrated, the PDP agreed to bring the classroom issue to the attention of the minister again.

The minister reaffirmed her commitment. "The children from the Developmental Centre will not go to Pine Grove. Senior officials are looking at several other possibilities, one or two of which are with the Integrated school board."

Parents were relieved, but continued their search. Bishop Field, a downtown school, had a classroom used only for storage. The principal welcomed three of us warmly. The classroom on the second floor was large with a high ceiling and tall windows. The pale blue walls presented an atmosphere of brightness and freshness. The principal asked many questions about the present program. He looked satisfied and said, "I would welcome the children to this school." We were ecstatic. The principal had a positive attitude and the classroom, across the hall from a regular elementary class, seemed ideal. We wondered why the interdepartmental committee or the school-board superintendent hadn't identified this space.

The director applauded our efforts and said he would make the necessary contacts. Several days later he met with the PDP. "Regrettably, the classroom at Bishop Field is not suitable."

"What! Why not?" parents exclaimed.

"Public Works said that installing plumbing into the second floor of the old building would be too difficult."

“Plumbing?” parents asked simultaneously.

The director calmly replied, “For this kind of children you need a washroom in the classroom.”

Outraged, parents responded, “A washroom in the classroom is not necessary! We addressed this before; we want a normal environment.”

The director ignored our comments and talked about the high cost of renovations. Recognizing our frustration, he encouraged us to see another room in the same school on a lower level and stated, “It has an easy access for a fire escape.”

The two parents and I returned to the school wondering why the principal had not shown us this classroom on our first visit. His cool attitude puzzled us. Quietly we followed him down a short flight of stairs then entered a pale yellow tunnel. The large heating pipes hissed and crackled above our heads. We cringed. The tunnel was long, or so it seemed. Near the end, a door opened to the left. The room was half the size of the upstairs classroom; it was dark blue. Children who were outdoors for recess peered down at us through the narrow iron-barred window. We shuddered. Leaving the room the principal pointed to a short door on our left, “That’s the fire escape.”

We were totally dejected. Could anyone really expect us to accept this as a classroom for our children? The principal shook his head and shrugged his shoulders. “I’m sorry,” he said genuinely. Clearly he was doing as directed, but who was directing? How could the interdepartmental committee have suggested this as a possibility!

The PDP then instructed the new president to write the minister of Education. The letter outlined the parent’s concerns. “The parent group has reluctantly come to the conclusion that, without help, the present committee will not find space outside Pine Grove School. We do not know who is blocking progress in this area but we do know that it is being blocked. Specific points which lead us to question the committee’s commitment to integration are:

i) The parent group has been told repeatedly that there is no space in the regular schools. There are no other alternatives but Pine Grove School. They say this at a time when school boards are reserving space into which to move Pine Grove children next September.

ii) A year ago the assistant director of Special Services said our children would go into Pine Grove and it was only the opposition of Pine Grove parents to having their children moved into Holloway School which prevented this.

iii) An excuse is always found to reject available space.

iv) Dr. D. rejected the basic principle on which integration is based, that the school environment is an important part of the programming. She claimed that severely handicapped children could not model from their 'normal' peers because the differences in developmental level were too great.

v) Dr. D. bluntly stated that it was only because of parent opposition to Pine Grove that five children were without programming. She implied that these children would not get into school until we dropped our opposition to a segregated school setting.

vi) We asked Dr. S. why he favoured integration a year ago when the centre was set up, but now did not support it. He had no answer.

vii) Dr. S. publicly refused to acknowledge the validity of Mr. Browne's appointment to the committee as a representative from the Department of Social Services.

We have been subjected to tremendous pressure as has the one teacher at the centre who favours integration. We therefore request that your Department:

i) expedite the finding of space for our children, and,

ii) try to sort out the political problems involved in implementing the integration policy so that our children and others are not made to suffer unduly because of internal opposition to this policy."

The minister met with the parents to discuss this letter. She reiterated the government's position that local school boards would eventually take over all classes for handicapped children, including the Developmental Centre. The parents also raised the desire to have a parent representative on the interdepartmental committee. The minister replied that the three deputy ministers, from the Departments of Education, Health and Social Services would review our request.

Soon the minister informed us that classroom space was being negotiated in Newtown Elementary in the town of Mount Pearl just outside St. John's. The PDP, confident that this classroom would be secured, asked me to write the minister thanking her for her intervention. In this letter I alluded to the parents' nagging concern, “Despite the problems encountered in obtaining classroom space, we hope that the anticipated move can be carried out with a minimum of delay and disruption to the children’s programs.”

Parents appreciated the direct involvement with the minister. They also discovered another pipeline to her—a program assistant at the centre was a close friend of a supportive school board member who was a friend of the minister. This ally informed the parents, “You’ve got Newtown.”

Six days later the coordinator of the centre sent a memo: “We have classroom space at Newtown Elementary. There will be no change at this time in the present groupings and staffing. Mrs. Allan [and her two assistants] and her group of six students will be relocating to Newtown Elementary. Our five new students will enter the Developmental Centre at Blackall School. We are hoping this move will occur Monday, March 16, 1981.”

Yvonne would finally have the opportunity to be in a school where she could hear, see and interact with regular students. “Yvonne!” I said, “you’ll be going to a new school with lots of other kids—who can talk!” Sensing the excitement, Yvonne smiled and watched each night as I crossed off the days on her calendar.

Moving day drew nearer. The coordinator had said that the equipment and supplies would be moved to Newtown, Friday the 13th, and the students would transfer on Monday.” Thursday, however, parents received another memo: “It seems very probable that the move to Newtown will not take place Monday.”

Parents would not accept what they perceived to be a stalling tactic. Two parents and I kept the telephone lines busy among ourselves, the school board member, the Department of Education and the coordinator to sort out the reasons for the delay. The committee member from the Department of Education told me, “The new program assistants cannot begin Monday because we need a signature from a senior staff, and he is out of town.”

“Earlier,” I retorted, “you told us that the school would use substitutes if appropriate staff wasn’t secured in time. Well, you could go with substitutes on the sixteenth.”

When the coordinator raised the problem of “transportation,” the parents got a truck and moved the equipment themselves, on Friday.

That same day we also received confirmation of the location for the summer program, at the Mount Cashel Orphanage. This facility in the east end of town was more central and more suitable than the School for the Deaf.

[The Mount Cashel institution, at that time highly respected in the community, was levelled, ten years later, following many charges of physical and sexual abuse. The news came as a shock. To think that Yvonne had been in this building and we didn't know that many residents were suffering such abuse. This revelation reinforced my long held belief that abuse of any kind is more likely to occur and more easily concealed in a segregated environment.]

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Yvonne adapted extremely well to her new classroom at Newtown Elementary. She was happier and more alert. She verbalized vowels: "e, o, u" and five consonants: "b, w, h, d, k." At times she used them in combination and laughed at the sounds she produced. Val, her teacher, encouraged Yvonne in making the sounds. She also developed a communication booklet using nine pictures which were reinforcing and meaningful to Yvonne: orange, cracker, raisins, sandwich, milk, lunch box, jacket, school bus and toilet. Val was convinced Yvonne understood. "Yvonne is smart! It's all there. Someday we'll find the key and when it's unlocked, boy, won't she have a lot to tell us!" Val's belief in Yvonne resulted in a positive parent-teacher relationship. But more than that, it developed into a lasting friendship.

Val used the pictures regularly. Yvonne was interested and complied more quickly than at the previous school. She held her head up. Her bright smile and sparkling eyes spoke the words she could not speak.

The president of the PDP wrote to the minister and expressed sincere gratitude to her and those involved in securing classroom space in a regular school: "The parents and teachers of these six children are delighted over the children's quick adjustment to Newtown School. Their faces tell us they are excited about being around other children; the regular students have been fantastic to the newcomers. They help bring the children from the bus to the classroom in the mornings, they are eager to visit them during recess and lunch hour. Our goal is to see the remaining children from the centre attend a regular school as well. Our experience has shown that integration can be successful regardless of the degree of disability, if, i) the teachers have the right attitude, ii) the parents are involved, and iii) the principal of the school, the staff and the students have an accepting and positive attitude. How can we really measure the success of the integrated program? Just look at the children; they cannot speak but still they can tell you."

Parents gave credit to the elementary students and staff for disregarding the advice of the interdepartmental committee member from the Department of Health who, at an orientation meeting before the move, stated, "These six children, although eight to ten years of age, are functioning at a two-year level or less—and should be treated accordingly."

Although six children with severe disabilities were now in a regular school, integration remained political. The program was by no means secure since the classroom at Newtown was only leased from March 16, 1981 to June 30, 1981 and from September 1, 1981 to June 30, 1982. Senior staff of the national CAMR advised the PDP to thank the minister publicly for her efforts in securing classroom space for the six children. The PDP placed notices in newspapers in the minister's riding and in St. John's. Letters of thanks were also sent to the chairman of the school board and the supportive board member. By thanking people publicly, and pointing out the positive results, the program had a greater chance of survival.

Meanwhile parents supported the teacher and assistants and worked together to show that students with very challenging needs could be integrated.

Yvonne's teacher Val had an overwhelming task. Her six students were the most active and difficult. Five had autistic characteristics, displayed odd hand and body movements, uttered loud sounds, and became easily upset over changes in routine. Val's positive attitude and bubbly personality, however, was the key to the smooth transition into the new environment. She developed an immediate rapport with the principal and staff in the school. She welcomed the regular students into the classroom during recess and lunch time and soon, because the class was over-filled, had to post a sign-up sheet to limit the number of friends per student.

Sherry developed an immediate friendship with Yvonne. She was a bright, inquisitive, cheerful Grade 4 student who asked Val all kinds of questions about Yvonne. When she interacted with Yvonne, she was very natural. Each day I asked Yvonne, "Did Sherry play with you today?" Most days her face answered radiantly. Yvonne truly had a friend!

Not long after the move, Val called, "I wish you could have seen Yvonne; she went up and down the incline, as though she had done it all her life. Sherry got her to do it! I tried for months but Yvonne wouldn't do it for me!"

Val looked at ways to increase the participation of her students with the rest of the school; the principal supported her and she told the parents about her plans. As a first step toward real integration she wanted her students to have recess outdoors, weather permitting. She wanted them included in the assembly and the cafeteria. Eventually she hoped to include her students in the gym and art room.

At this time the Department of Education asked the national CAMR to do an evaluation of all special education programs in the city, including the Developmental Centres at Blackall and Newtown. The program at Newtown rated the highest overall and was cited as a model for across the province.

The success of the Newtown program evidently displeased the interdepartmental committee; they soon put restrictions on the teacher. Val was no longer allowed to take her students down to the cafeteria, nor involve them with regular students.

Parents met with the committee, and were told, "Your children do not have the skills to eat in the cafeteria. They first have to learn appropriate skills in the classroom, then they can go down to eat."

"At home our children eat at the table with us," parents responded, "and when visiting friends and relatives, they are always included. That is how they learn to model appropriately. It only makes sense for them to eat with their friends at school." Committee members shook their heads defiantly. I explained how Yvonne enjoyed eating at McDonald's, and how on a weekend trip to Head of Bay D'Espoir we stopped at a restaurant where they had white linen tablecloths and linen napkins. The expression of the new committee member from the Department of Health suggested she had just heard a truly fabricated story. If she didn't want to believe me, then nothing I could add would convince her otherwise.

The committee then reminded the parents, "The classroom is only leased from the school board; the school is under no obligation to include your children in any regular activities." Why was the committee doing this to our children who had made progress and formed friendships with regular students? Why was the committee trying to sabotage a good program?

At a PDP meeting the Newtown parents shared their frustrations with the parents from Blackall School. These parents, however, were satisfied with their children's program, and were annoyed at hearing about our problems at Newtown;

some even questioned the value of integration. A rift developed between the two parent groups.

Discussing these issues became difficult because teachers and committee members attended all PDP meetings. The Blackall parents encouraged their attendance, but neither teachers nor committee members reciprocated by supporting the parents' request for a representative on the interdepartmental committee. Nevertheless, the PDP received a letter from the minister, inviting two parent representatives to a liaison committee. Two days later the director of Special Services, invited two parent representatives to an advisory committee. This confused the parents. The functions of the two proposed committees were significantly different. Eventually, the Department of Education struck an advisory committee. Parents were divided. Some argued that participation would block access to the minister; others countered that we could influence the committee. Most parents voted in favour of joining the advisory committee.

Despite the growing differences, parents realized the importance of remaining united. The programs in both locations were insecure, dependent on year-to-year leases. Although three parents had tried to register their children with the school board, they were denied. This prompted action by the whole parent group. Every parent agreed to register their child: thirteen with the Roman Catholic school board and five with the Integrated board.

The vice-president of the PDP wrote the chairmen of both school boards. He asked for their support in approaching the minister to transfer funds from the Division of Special Services to the school boards, giving school boards the authority to operate the programs. "We are talking about a better social and learning environment for our children, a better long-range outcome for them as contributing members of society. This would also provide an opportunity for other children to learn acceptance and understanding of people who live with various disabilities."

The superintendent of the Integrated school board responded, "The board has requested professional staff to develop a five-year plan for the education of children in the school district with special needs."

The chairman of the Roman Catholic school board replied, "This board has adopted a policy which acknowledges the board's responsibility to provide educational services for all Roman Catholic children. It is not possible for us to do so at this time." Clearly both school boards would not register the children from the Developmental Centre for many years. We needed help to speed up the process.

Peter and I kept Malcolm, Joe and other CAMR staff informed about the Developmental Centre. This was a critical time, not only for our children, but for children with disabilities across the province. The director of Special Services, responsible for the Developmental Centre, was also a resource to many school boards throughout Newfoundland. They regarded him as an expert in the field of special education. The provincial CAMR was concerned about the director and interdepartmental committee's opposition to the minister's policy on integration. A senior staff from CAMR explained, "Never is a whole committee bad, there is always a ringleader and if you can get rid of the ringleader, the committee will fall into line and do the right thing." We held many meetings in the CAMR office to discuss education and plan strategies to deal with problems on the administrative and policy level.

As staff with CAMR and as parents on the executive of the PDP, Joe advised Peter and me to request a luncheon meeting with the minister and present to her the problems and our findings. "The minister would have lunch with us!" I scoffed.

"Yes," Joe replied seriously. "She is a public servant, voted in by the people. She will meet with you."

She did, at the Act III restaurant in the Arts and Culture Centre. The minister brought the deputy minister. We were joined by the PDP president and another parent. The minister listened, and appeared shocked; in fact, she told us so. The deputy minister, on the other hand, shuffled his feet nervously under the table and at times turned beet red. Clearly he had knowledge of what we were saying. Near the end of the meeting, the spokesperson calmly stated our request, "We are asking to have the director removed from the interdepartmental committee and from all aspects of our children's program."

The deputy minister responded instantly. "Do you realize what you are asking? This has far greater implications than that. We're talking about a major reconstruction of the department. It could take five years, and twenty years of a man's life."

"Asking this is hard," replied one parent, "the director was a friend for three years, but now he's destroying our children's program. Before the move to

Newtown he threateningly told several parents, 'If Newtown goes ahead, it won't work. Look at the Vanier project.'"

The Vanier project had been a pilot program for integrating children from the Exon House institution into the portables at Vanier Elementary. "A teacher," I said, "told a few parents, 'the director assured the staff that the children would fit in, but he deceived them. Some students were larger than the teachers; their average age was fourteen-and-one-half years. Some were in their twenties—in an elementary school.'"

The meeting concluded with the minister requesting to meet again. The deputy minister remarked, "The ball is now in our court. The next move will be up to us."

It sounded like a game. People were playing games with our children's lives! We didn't like it. Our only reassurance was our trust in the minister.

In August 1981 a committee member told the PDP that the school board was selling the Blackall School building, and in September the Developmental Centre would move into the portables at Vanier Elementary. This location, stigmatized by the Exon House experience, meant that parents would need to work hard to develop positive relationships with staff and school administrators.

The Developmental Centre grew rapidly; while the Newtown program remained at six, the Vanier program had eighteen, with three classes of six students. The PDP president had moved out of St. John's, and parents elected a mother from the Vanier program. Friendly but firm, she was the ideal person to advocate for integration at Vanier. However, it did not happen.

Near the end of September, this new president phoned the CAMR office. "I have to resign as president," she said, her voice quivering. "I got implied threats that Social Services will take our foster daughter."

"What?" I exclaimed. "If there is no evidence of child neglect or abuse, they can't just remove your child!" She insisted they could. I suggested she meet with us the next day. We advised her to write down what she was told, when and by whom; CAMR would support her.

Before we could take any action, she called and tearfully said, "It's no use, they are coming to take her." Exasperated, I told her to appeal it; we'd support her. With guidance from our executive director, I attended the meeting at the Department of Social Services with her. This was my first meeting with this official; he had a cold attitude. He wouldn't speak about her eight-year-old foster daughter. Instead, he focused on her two natural children, stating that both had some problems during the summer. The mother acknowledged this. "They had followed the lead of older children and got into mischief, but we resolved that. Besides, we're not here to talk about those two children, we're here to talk about the child Social Services is taking away from us."

"Oh," he said threateningly, "we're very much talking about your other children."

He terrified the mother by threatening to take custody of her natural children, and we got nowhere regarding her foster child who was part of their family for five years.

A few days later she called, "I'm at the airport with my children. I can't live with the fear that Social Services could snatch them when they come out of school. Don't tell anyone I've left. I'll call you." She later called from another province, greatly relieved but hurting. A letter soon followed. "I should never have listened to the social worker. We had wanted to adopt our foster daughter but the social worker persuaded us to keep fostering her. She told us we would get more benefits and not to worry, we wouldn't lose her; her natural parents wouldn't want her back. We brought her from helplessness to participation. We loved that child as our own. If we had adopted her, we would be in a legal position, but we have no legal rights. They have effectively removed me from the PDP."

This family's life was torn apart because the mother became a threat by advocating for integration.

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The St. John's AMR, after intensive lobbying by pro-integration members, in 1981 elected a new president who worked in close cooperation with the provincial CAMR. Education was now on the agenda of every local and provincial board meeting.

The PDP kept CAMR informed about the actions of the interdepartmental committee. The Developmental Centre continued to expand and the need for classroom space remained a constant issue. The director's repeated claim, "The only space available is in Pine Grove," caused much concern.

The mother who once had yelled at me over the phone regarding the closure of the School for the Handicapped now called the CAMR office for help to get her daughter into the Developmental Centre. "The Division of Special Services," she said, “wants to put my daughter in Pine Grove, but I don’t want her there.” Committee members pressured her and four new parents to visit Pine Grove, claiming it had a good program and parents could not reject it unseen.

I agreed to go along with the five parents to observe everything, the good and the bad, and to ask questions, but not to argue. This was a fact-finding mission. We would then write a report on what we heard and saw.

The scent of fresh paint was detectable as we stepped into the old building. The Department of Education had recently renovated the structure—an army barracks during the Second World War, then, a Tuberculosis sanitarium, and now, “the school for the retarded,” as it was commonly called.

We found the principal’s office. Smiling, she rose from behind her desk and welcomed us. With painstaking detail she described the technical aspects, from assessments to the individualized education plans for each student. She seemed pleased by our positive comments. Then she gave us a tour of the school.

We walked through a maze of corridors and saw many empty classrooms. “The students are integrated in the community,” she said proudly. “A bus load went to the swimming pool.”

“With regular students from another school?”

“Oh no,” the principal replied seriously, “they couldn’t cope.”

Further down the hall, we turned left to see the art room. The principal pointed to a small storage closet behind us and casually said, “That’s the time-out room.”

“Time-out room?” gasped a parent.

With a wave of her hand the principal dismissed the concern. “That’s only for the very difficult children. Usually they’re only in there for five minutes.” A parent, her face ashen, pointed toward the closet and was about to explode her objection. Instinctively I raised my finger to my lips. With regained control and a hint of a grin she understood; this would be the evidence that would put the lid on Pine Grove. We maintained our cool and resumed the tour.

On the parking lot, we released pent-up emotions and vowed that our children would never, ever go to Pine Grove. In our report, we gave credit to the positive aspects of the individual education plans. However, Pine Grove, with seventy students, was very much segregated. Also we objected to the time-out room. “We do not want our children to attend this school, but we fear that the Division of

Special Services still wants to put our children into Pine Grove." The report, signed by the six parents, was sent to each interdepartmental committee member and the minister.

Parents intensified their efforts to enroll their children with the local school boards. They were distressed, however, when the superintendent of the Integrated School Board stated, "We would not be free to register students who are presently under the control of the Department of Education. We have pledged to work with the Department of Education and to integrate handicapped children in accordance with policies worked out with them."

Frustrations increased when parents heard the director of Special Services with the Department of Education declare on an open-line talk show, "Special education has become massively expensive. It's incredible, it's like a great big bucket just gulping up money!" They speculated that the director's statement was a tactic to deliberately discourage school boards from accepting responsibility for these students.

The director was actually making special education outrageously expensive. He was securing the employment of a separate principal; he supported the committee in hiring a full-time nurse for the Developmental Centre; he promoted a change in staffing policy and class size from six students to four, per special education teacher.

The parents from Newtown protested, not only the unnecessary cost, but more importantly, that these changes would clearly promote and entrench segregation. The parents at Vanier, on the other hand, were persuaded by the teachers to accept the additional resources. This caused a split among the parents, who then voted to separate into two groups: the Newtown PDP and the Vanier PDP.

In September 1982, enrollment at the Developmental Centre grew from twenty-four to fifty-seven. The coordinator was replaced by a principal—from Pine Grove. She administered the Developmental Centres, now in four locations: Pine Grove, Vanier, St. Pat's Primary, and Newtown with two classes of four students each.

Prior to the change in class size the Newtown parents met with the director, the supervisor, and the assistant deputy minister (ADM) and stressed the importance of keeping the class at six, which in fact was a policy stated in the Developmental Centre Policies and Guidelines, Province of Newfoundland. They expressed concern that the changes would jeopardize the program. The ADM assured the parents that the program would not be in jeopardy.

Yet, before the end of September the program was a disaster. Many changes had occurred. Students now had to be with a special education teacher at all times; they were not allowed to be left with volunteers or even teacher assistants. When either of the two special education teachers at Newtown went on a coffee break or for lunch, they lumped the classes together, creating chaos. Students started wetting their pants because the special education teacher couldn't leave the classroom until the other teacher returned. The teachers' assistants stood by helplessly as they were now forbidden to take students to the washroom. Students were no longer integrated because of the change in staffing policy. The once orderly classroom where Val could leave the door open, as did other teachers, was now closed. Closed to contain children who had become emotionally upset.

Val was not allowed to talk to the Newtown principal; everything was controlled by the new principal of the Developmental Centre. She barred parents, who had volunteered in the past, from the classroom unless they signed a confidential volunteer form. This would restrict parents from telling anyone what was going on at the school.

This principal had the assistance of a vice-principal, and together they planned activities such as swimming, bowling, skating and field trips, which brought the various groups of children with disabilities together.

The model program at Newtown had disintegrated. We had predicted failure, but never to this extent. The teacher Val, her assistants, the children and the parents were devastated. Our only hope lay with the minister.

The parents' meeting with the minister brought quick results. Parents were again allowed to volunteer and integrated activities were reinstated. The parents and Val were pleased, but teachers from the other centres sniped, "Who do those parents think they are?"

Friction continued between the Newtown parents, and the new principal. Parents remained watchful but even so, she managed to ruin the Christmas party. She insisted that all fifty-seven students from the four centres attend the celebrations at Vanier Elementary, even though Val had arranged for her students to be part of the assembly with the students in Newtown. The two teachers and assistants were instructed to be present at Vanier. The parents, upset and angry, wouldn't sign permission slips for this outing. With no staff, however, our children were forced to stay home.

The Newtown PDP again wrote the minister, stating that the ADM had assured parents, “Your children will not be made to participate in joint activities with handicapped children from other locations.” Yet it had happened.

Unexpectedly in February, parents heard that the director was moving to Australia. He left quickly and quietly. No parties, no celebrations. He just vanished.

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Teresa had been keenly aware of our exasperations during our struggle for integration and heard us talk about who was a hindrance and who was supportive. She used the family chessboard and gave a name to each of the sixteen white and sixteen black chess pieces for a visual image of the Integration Game. Teresa even remembered some quotes we had mimicked and connected them to the various chess players. “You shall return good with compassion, and evil with justice.” “There’s a solution to every problem, you just have to find it.” “Parents make the best teachers.” “I don’t see a problem.” “Correct me if I’m wrong.” “But don’t quote me on this!” Within our family, we made a game of integration. We had to maintain some sense of humour.

The struggle for integration, however, affected Teresa’s life in other ways. Years later she wrote:

“I am Yvonne’s sister. I’d like to make a few comments and appreciate this opportunity to share them. First I thank my parents for their love, acceptance, perseverance and patience. I also thank them for doing as much as we did together as a family. I have fond memories of our many camping trips, times at the park, hiking, canoeing and so on. I’d like to thank Yvonne for the joy she’s brought me—seeing the sparkle in her eyes when she is enjoying something, or hearing her contagious laughter. I also appreciated sharing the joy when she learned something new after weeks of hard work.

“Second, I’d like to share about feelings of bitterness that I struggled with a few years ago. I found myself feeling angry when situations would arise that I felt were unjust or unfair. This resentment, I feel, stemmed from experiencing a loss of my parents’ time. Not only did Yvonne require extra help from Mom and Dad, but many hours were spent on the phone and going to meetings in the evenings regarding the fight for integration. I’m glad they strove for integration and didn’t give up because it gave more happiness, enjoyment and fulfillment to Yvonne to be in a class with her peers in a regular school.

"But still, because of this, I felt a loss of a closer relationship with Mom and Dad. Yet recognizing I had bitterness was the first step, and then God, who is a part of my life, changed my attitude and feelings. I would like to encourage any sibling of someone with a disability not to feel you are alone if you have feelings of anger or resentment. I hope that sharing my experiences may be helpful to someone."

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I, too, struggled with feelings of frustration and anger. I knew my feelings of hostility at the very sight of the director or the mention of his name were contrary to Christian principles and that it was his actions I resented. Yet each time I saw the man I fumed over what he had done to Yvonne and the other children. How could I not be upset and provoked? By sharing with other MCC workers I eventually gained spiritual strength and one evening, in the quiet of our home, a passage of Scripture released me from the hatred and hostility. In its place, I felt sorrow for him. Sorrow that a man of his intellect had the need to use children who were unable to speak for themselves, and sorrow, because one day he too would be accountable for his actions. The reversal of feelings was strange, a combination of inner peace for myself and a concern for him.

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Yvonne had clearly benefitted from interacting with regular students during her two years at Newtown. Her friend Kim, a Grade 5 student, invited Yvonne to join Girl Guides. Yvonne was in a club with non-handicapped children, with friends her own age—a dream come true!

Late in spring, the leader drew me aside. "I don't know if you're going to believe me, but last year this was the most difficult group I had. I even thought of resigning. This year, however, they have been the best behaved." I was puzzled why she wanted me to know this. She then continued, "Most of the girls wanted to help Yvonne, and they have all become more considerate and caring." I was astonished. I had seen the benefit to Yvonne, and now the leader told me how the other students had benefitted. This was the greatest compliment imaginable, one that I would always treasure.

Yvonne wore her Girl Guide uniform and sat proudly at the annual Parent and Daughter Banquet in the gymnasium at Newtown Elementary. She blended in with the other girls. Her friends included her in conversation. She was truly one of them.

This experience was a positive ending to her school years at Newtown. Since the classroom lease expired in June, the program had to relocate in September. The parents, however, were not told until August that these students would be divided between Vanier and Pine Grove.

Yvonne, however, was not affected as we had decided to move to Fredericton, New Brunswick. CAMR-New Brunswick Division had approached MCC for service workers for a family support project similar to that in Newfoundland. MCC approved the project and asked we would be interested in this position when our present project ended in June.

We had thoroughly enjoyed the opportunity to meet many families across Newfoundland and Labrador and felt rewarded each time a family member with a disability received the necessary support. We had also made some gains with the service system; we were even asked to lead several training workshops for social workers and special education teachers in communities across the province. Social workers in particular, became more understanding and responsive to a family's need. Although advocacy would need to be ongoing, a good start was made in many communities. Now we had an opportunity to do much the same in New Brunswick.

We explained to Yvonne that we would move to Fredericton, and she would go to a new school; and Teresa would go to a new school in Fredericton, too.

Knowing how much Yvonne enjoyed camping, I said enthusiastically, "Yvonne, we'll have a long summer of camping. We'll get a truck and we'll put the table and chairs, beds and clothes, toys and dishes in the truck. Daddy will drive the truck and Mommy will drive the car. You can be in the car with Mommy or sometimes in the truck with Daddy. We'll take the ferry and drive to Fredericton. We'll camp at Mactaquac Park and look for a house in Fredericton. Then we'll drive to Manitoba and Alberta, and tent along the way. When we come back to Fredericton, we'll get you into a good school."

Yvonne listened intently, her eyes focused on mine, searching, wanting to know, wanting reassurance. Plainly and carefully I repeated what I had said. Her face relaxed; she managed a slight smile. Hugging her, I promised, "It will be good, Yvonne. It will be good."

Chapter 11

New Brunswick

We knew that in New Brunswick, just as in Newfoundland, children with disabilities were not registered with the local school board. To our further dismay children in New Brunswick, were first assessed by the Department of Mental Health, who then made a referral to an auxiliary class usually in a segregated school operated by a local branch of the CAMR. The Fredericton-branch was one of the province's more progressive associations in advocating for integration. They attained a milestone in January 1982 by obtaining a classroom in a regular school. In September of that year two other schools provided classrooms. The following September when we arrived, they had secured five auxiliary classes in four regular schools. Only two classes with the most severely disabled students remained at the Murray F. Humes Memorial School.

We spoke with the president of the Fredericton CAMR about Yvonne attending a regular school. The president to our surprise urged us to place Yvonne into the Murray F. Humes School. Shocked and disappointed I asked, "Why?"

She replied, "Some parents at Murray Humes are doubtful about integration. You could influence them to see the benefits."

"The best way to influence the parents about the benefits," I pointed out, "is to show them. We can't show them if Yvonne is not integrated."

Our strategies clearly differed. Or was the difference in strategy for another reason? Could it be that the president feared that Yvonne was too handicapped to fit in and that her behaviours might threaten the integration process which they had carefully worked out for students who were mildly or moderately disabled? Integration was fragile because it depended on the goodwill of a few principals and teachers. Still we couldn't put Yvonne back into a segregated school; she belonged in a regular school.

First we needed to deal with the assessment. Peter and I were opposed to Mental Health assessing Yvonne, and between ourselves we talked about challenging this system. That would mean, however, during that time we could not enroll Yvonne in a program and she would have to remain at home. With Yvonne at home we couldn’t do the family support work. Therefore we went along with the system. We would, however, insist on placement in a regular school.

We approached the appointment with Mental Health at the Victoria Health Centre with anxiety but also with determination. Arriving at the office, we introduced ourselves to the receptionist. Soon a psychologist appeared and welcomed us warmly. We followed her down the hall and entered a room with two tall windows overlooking the street. Furnishings in the pale yellow room were surprisingly sparse. A child’s table stood against the far right wall with a few toys and books. Yvonne wandered over to this table but she didn’t sit on the small chair. The psychologist gestured toward four adult chairs grouped on the left side of the room and invited us to sit. A second psychologist soon joined us.

We told the psychologists about Yvonne’s educational background. We emphasized the benefits of the special class in a regular school and gave them copies of Yvonne’s report cards. They scanned the reports. They listened and took notes, all the while observing Yvonne picking up objects, dropping them back onto the table, and walking about the room. At times Yvonne cried. I was surprised Yvonne wasn’t more upset. She was in a new environment, she was with strangers, and we were talking about her. These were valid reasons which I would address if they said she couldn’t be in a regular school because she was too upset.

At the end of the appointment the head psychologist said, “Based on your wishes and Yvonne’s past program, I will recommend an integrated placement.”

We were given a favourable recommendation, without a fight. We had not expected an answer then and there. Our usual experience was to wait for a written report. Thanking her, I asked, “What happens next?”

“The recommendation,” she said, “will go to the director of Special Education in the Department of Education. You should be hearing from her about Yvonne’s placement.”

Relieved that this hurdle was behind us and that we had the support of the psychologist, we concentrated on looking for a house and our summer plans.

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Since leaving St. John’s, we phoned the realtor in Newfoundland daily to ask about the sale of our house. The realtor had good news on June 29. “I had an offer,” he said, “but it’s low and I think you should negotiate.”

The following day we looked at several houses on the north side of Fredericton, but we were under no pressure to decide quickly. We still had two months and besides, our house hadn't sold yet. Then, on the long weekend, July 1, we drove 300 kilometers northwest to Edmundston to be with Peter's brother Alvin. If our house in Newfoundland didn't sell, we'd continue driving west as far as Alberta. If our house sold, we would go back to Fredericton and continue our search.

That evening our lawyer called, "They accepted the counter offer and are signing the papers." It was indeed a weekend to celebrate! Monday, we drove back toward Fredericton and set up camp at Mactaquac Park, 28 kilometers west of the city, then drove into town to meet the realtor. Our previous agent was on vacation; her partner showed us several homes, including two new listings on the south side near the CAMR office and the high school.

Yvonne was very patient as we walked through one house after another. Eventually she had enough; she cried and hit her nose. This put us under immense pressure to see a house quickly, not an ideal way to decide. After conferring with Teresa, we left both girls at the campsite for our next evening appointment. We felt uneasy but what else could we do? We knew Yvonne would enjoy a hike in the campground with Teresa and would willingly go to bed. We gave Teresa the realtor's phone number, and she knew the location of the pay phones at the campground.

We returned after dark. Yvonne was asleep. Excitedly we told Teresa, "We saw a house we liked and it's in our price range. We've made an appointment to see it again tomorrow afternoon. We want you to see it too."

The following day we left Yvonne with our friends, the De Jongs, while we looked at the house on Beaconsfield Street. The decision was unanimous. We made an offer and they accepted it.

We spent the next day relaxing and hiking in the campground and found sweet wild strawberries on a grassy path. Yvonne took them from the palms of our hands. She loved them! In the evening, when Yvonne and I walked back to the campsite from the washroom, she walked toward a grassy area and stamped her feet. This was unusual. She looked at my puzzled expression and smacked her lips. Finally I caught on. "Are you telling me you want more strawberries?" She smiled brightly.

Again Yvonne's resourcefulness in communicating struck me. She had seen us pick the berries and now, in her unique way she told me she wanted more. For her to get a message across must be like living a life of charades. I then wondered, how many clues does she have to conjure up for each thought before we finally understand? How often does she eventually give up because we don't understand? If Yvonne hadn't given me the lip-smacking clue, I could have interpreted her stomping as a tantrum, yet not known why. Still, I mused, if she knew the strawberries were there, why wouldn't she bend down and pick them?

This incident reminded me of the importance of watching Yvonne's actions and figuring out what she was telling us. Dr. Madill and Val and Joe were quite right. "Yvonne is not retarded." She comes up with clever ways to get her messages across.

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At the end of August 1983, Peter and I had several meetings with the president of the Fredericton CAMR and the administrator of the auxiliary classes at the Murray F. Humes School. We discussed an appropriate school placement and program for Yvonne. The president and administrator were surprised at the recommendation from Mental Health, but they showed no enthusiasm. Despite their lack of support, we used the psychologists' report to insist on placement in a regular school and cited their statement, "an integrated placement but one where Yvonne will receive considerable supervision and individual educational programming." The administrator finally agreed to enroll Yvonne into one of the two auxiliary classes at Smythe Street School.

The school year started well. Yvonne adjusted surprisingly quickly in the class of six students, with a teacher and one aide. The teacher was young and friendly, she spoke quietly and seemed happy to have Yvonne in her class. She wrote daily notes telling me about Yvonne's activities and reactions.

The teacher and the aide worked on self-help skills such as teaching Yvonne to pull up her slacks after using the washroom, washing her hands and face, and brushing her teeth after eating. Other skills related to activities in art, gym, music, storytime, swimming and skating. They also used pictures to increase Yvonne's communication. In early December, the teacher wrote, "Yvonne correctly pointed to a cracker from among five other pictures. Great!" Clearly, the teacher was pleased with Yvonne's responsiveness.

The teacher, with the assistance of a psychologist from the University of New Brunswick, proposed two behavioural modification programs. The first was to reduce Yvonne's constant hand-flicking especially at mealtimes, and the second was for Yvonne to swallow her saliva.

Both home and school had tried to eliminate the hand-flicking in Newfoundland but with little success; Yvonne had concentrated hard but she couldn't quit completely. External stresses, such as having a substitute aide, or talk of a teacher's strike, or assessments to decide the following year's school placement and program, all contributed to relapses. At times, Yvonne's hand-flicking intensified so that she rubbed two fingers raw to the point of bleeding.

Cautiously we now consented to the program. After several weeks, two university students conditioned Yvonne to place her hands on her thighs after each mouthful of food. As before, stresses soon interfered and wiped out the gains.

The teacher worked on the second behavioural task designed for the child "who drools not because she cannot swallow but because she simply forgets she must periodically swallow the saliva that pools at the front of the mouth." This explanation seemed reasonable to me. I often wondered why Yvonne sometimes swallowed, yet at other times didn't, and I followed her wiping her mouth and the furniture. Her behaviour was socially unacceptable and I was determined to help her overcome this.

The psychologist gave a copy of the Drooling Control Programme to the school and us. Both used the agreed-upon approach. When we saw a droplet appear on Yvonne's lower lip, we placed a tissue into her hand, helped her to wipe her mouth and reminded her to swallow. When she did we praised her, which she liked.

One day Yvonne tested me. She wouldn't swallow. The program did not address procedures for a test situation. I tried various approaches including an ice-cream cone. But when Yvonne realized this was part of my teaching program she felt tricked and wouldn't swallow. When everything else failed, I gently tilted her back until she was forced to swallow. She didn't test me anymore! After this incident, she only needed an occasional reminder to swallow.

Through this experience I recognized Yvonne's genetic trait of determination. I recalled Val once saying, "Boy, Yvonne has some determination! But look where she's got it from, not only one but both parents. Watch out!"

On the positive side, Yvonne's strong will and determination might be the key to her survival. I often marvelled at how forgiving she was of people and a system that seemed determined to exclude her when she wanted so much to be included. I had to give her tremendous credit for her overall cheerfulness, determination and perseverance.

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Early in the new year, Peter wrote a proposal to the Department of Education requesting extra classroom support for Yvonne and another student. The teacher found it difficult to give the one-on-one assistance which was essential to the students. Volunteers helped but they weren't consistent nor adequate.

The Department of Education sent consultants to observe the classroom and review the program. After the review, the department said they would not recommend additional staff at this time but suggested that a resource person help carry out several of the recommendations: "The teacher is to develop a very structured schedule of daily and weekly activities for individual children and the group; restructure the physical setting of the classroom by using partitions, dividers or bookcases; provide classroom and behaviour management; initiate more integrated activities between the two auxiliary classes and the rest of the school."

Naturally we agreed with the need for more structure and more integration of the auxiliary class with the rest of the school. However, we found the general response disheartening. They didn't mention additional staff.

Following the influx of visitors to observe the classroom, Yvonne's level of frustration increased. She sensed the stress and responded as she usually did under such circumstances by hitting her face. She arrived home on April 30 with a black eye, bruised lip and nose, and severely bruised and swollen hands. For Yvonne to arrive home with a bloodstained blouse or jacket from a nosebleed was not uncommon, but never in a condition like this!

Over the weekend we wrote a cautious letter to the administrator. We learned from experience to present the facts and offer solutions. We wouldn't gain anything from writing an emotional letter or taking an adversarial position. In this letter we wrote, "Yvonne hits herself for various reasons. We want to discuss possible causes and help find solutions. At home, if we talk about the problems, Yvonne feels reassured and relaxes." We asked to meet as soon as possible with everyone involved, especially since a substitute teacher would fill in for the next few weeks.

I listed some reasons for Yvonne's hitting, starting with the least threatening to the teacher: learning a new task (at first she generally rejects it), being exposed to a new situation or environment, uncertain of what to expect, being too warm or too cold, strong smells (perfume, cigarette smoke), excessive noise, boredom, talking about her in front of her, going somewhere without fully explaining in advance, too many visitors in the class (especially if they are talking about her and the other kids), discussions between staff regarding plans for September (she senses this uncertainty or stress) and questioning her when she can't respond (she has to be helped to answer).

In my notes I highlighted, "Making eye contact with Yvonne and explaining things to her is crucial, uncertainty is a major cause for her hitting. She needs to feel secure and know the daily routine. If you make changes, you need to explain them to her."

At the meeting we discovered a few other reasons for the problem. The classroom had a high ceiling and voices echoed. Ordinarily, Yvonne could tolerate loud sounds but when she was under stress this created a major problem for her. Yvonne was the oldest student in the class and the three young children often cried or vocalized high-pitched sounds. This too would cause Yvonne to cry and hit herself.

The teacher and one aide couldn't manage this situation. The Department of Education, however, refused to supply additional staff. Instead, they gave the teacher a four-week leave. Meanwhile the substitute teacher, older and more mature and with assistance from a resource person, brought stability to the classroom. During those last weeks of school, Yvonne's frustration decreased and the year ended on a more positive note.

I was incensed, however, by Yvonne's year-end elementary school report card. This eleven-page checklist, under headings: Daily Living/Gross Motor/Fine Motor/Cognitive and Social Skills, began with "Allows being fed from a spoon, child holds spoon, child accepts liquids." The Toileting section began with, "Soils and urinates in pants, shows no discomfort." I couldn't read on. Emotions of anger and disbelief ripped through my head. How could the administration provide such an inappropriate checklist? How could a teacher even waste her time on such garbage?

My anger then gave way to another emotion and tears welled in my eyes at the realization that this was what educators thought was the functional level of the students. Dejected and disgusted I was about to tear up and discard the report, but reason prevailed. I put it into a three-ring binder; someday I would write about it.

We could only hope for a better year in September. Yvonne, at age thirteen, would enter junior high school.

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Meanwhile, we continued assisting families in obtaining necessary services and supports. The Conservative government under Premier Hatfield promoted community-based services. A cooperative relationship developed between the government and CAMR-NB which saw the development of a service system that was responsive to the needs of persons with a mental disability. In particular, the government supported early intervention and in-home supports to families.

Some CAMR-NB board members, with executive director Paul LeBlanc and office manager Lorraine Silliphant, carried out political advocacy and negotiations. Our role was to become familiar with and understand the political and service structures, but to deal only with the lower levels of bureaucracy up to regional directors.

Our approach to meeting the needs of individuals and their families was much the same as in Newfoundland. Most often the need was for respite, special equipment and educational support. Other times the need involved vocational support and residential alternatives for adults. After each visit, Peter wrote a proposal and I maintained contact with the family until they received the required supports. Some supports were easier to obtain than others. We discussed difficult situations with Paul and Gordon Porter, chairman of the Planning for Community Living committee of the provincial board, who then lobbied at a higher level for the individual.

Some parents struggled on their own, day after day, year after year. The only alternative was to admit their son or daughter to a mental institution which was unacceptable to most parents. For years they had survived the stress and pressure, but as they grew older they found it more difficult to continue.

I received a call at the office with a desperate plea: “Could you please help my parents? My sister is in a wheelchair; she is unable to care for herself. My parents have always done everything for her. My father sold his business so he could stay home to help my mother but now he is in poor health. She can’t do it on her own.”

“Yes, we would gladly visit your parents,” I said, “if they want us to.” I called the mother. Reluctantly she agreed to our visit. Arriving at their home, we understood why she had been reluctant. She showed us a stack of letters they had written to the government. They also had newspaper clippings, where in desperation they had gone public, pleading for help concerning the needs of their thirty-four-year-old daughter. Still they had received no help. No wonder the parents were hesitant to meet with us. What could we do that they hadn't already done?

As their story unfolded, we empathized with the family in their struggle. Our determination to influence a service system which was highly unjust intensified. Society expected these parents to provide twenty-four hours of support, seven days a week, month after month, and year after year. A nursing home, however, claimed that staff could not provide the care that their daughter required, and asked the parents to pick her up before the end of a two-week respite period. Trained staff couldn't manage; yet they expected parents on their own to manage.

The Department of Social Services was quite prepared to place this young woman in a costly extended care unit in a hospital if something happened to the parents. Yet the government refused to help the parents while their daughter lived in their home.

We were convinced that decision makers in the government could be made to understand that, given the necessary supports, the parents could continue to provide for their daughter. The cost to government would be much less, and the person would have a better quality of life.

Peter wrote a proposal and, keeping the executive director informed, we lobbied at every level open to us. In this case, Social Services made some supports available and the family soon noted the benefits. Due to the father's serious health problems, however, they had to address the long-term out-of-home plans earlier than they had hoped. This required CAMR-NB to intervene at a higher level of government.

The sad reality was that parents were forced to plead for support, and only when they were in crisis would the system come to their rescue. By then it was too late for some.

The government to its credit was attempting to provide appropriate and adequate support services for children from birth to twenty-one years. Families in Fredericton now put the government's commitment to the test. Six families had lobbied government for a group home because, without support, they could no longer cope with the intensive needs of their son or daughter. The government however, rejected their proposal. They adopted a new philosophy fully supported by CAMR-NB that children live with their families, and supports be made available in the home.

Peter and I visited these families. The number asking for residential alternatives had grown from six to thirteen. We talked about the new philosophy of family support. After our visits, we noted that twelve of the families wanted to keep their son or daughter at home if the supports were available. They expressed reservations however, about the government's commitment. One family, who had already experienced the pain of placing their child into a group home (in another community), was understandably most skeptical. If their child returned home, they would live in fear of government reneging on its commitment to provide support. They couldn't live through that a second time.

Peter wrote the usual proposals expressing each family's needs. Every family stated that regular respite outside the home was essential. We gave this information to the Fredericton Residence Committee, a community group originally organized to support the parents' request for a group home, which now negotiated with the Department of Social Services for a respite program.

The Department of Social Services agreed to provide support for the requested needs of each family. In response to the need for out-of-home respite, the Department of Social Services eventually provided funding to the community group, now renamed Opal III Fredericton Respite Services Incorporated. Opal III, chaired by Nan Doerksen, hired a respite coordinator to recruit provider families. The coordinator matched a volunteer family with a family needing respite. An apartment was also set up for emergencies.

The Opal III respite program began under the umbrella of Opal Inc. which several Mennonite families living in the Havelock-Petitcodiac area, with a few families from Fredericton, had established. They opened a group home in Havelock and then several satellite homes in that part of the province to serve the needs of adults with a mental disability.

The Honourable Nancy Clark Teed officially opened Opal III in December 1984. Then in August 1986, with its own board of directors, Opal III was separately incorporated. Parents referred to the respite program simply as "Opal."

In other communities, we encouraged parents who needed in-home support to contact the Department of Social Services in their area. A social worker then visited the family, met the child and discussed specific needs. In order to obtain support, Social Services required all parents to go through a "means test." Parents found it invasive and demeaning to provide detailed information about their finances. Parents also had to sign a form under the Child Protection program; this gave Social Services legal guardianship of the child. The government, however, assured the parents and CAMR-NB that this was not the intent and parents shouldn't worry, it was only a formality to access funding.

Still, parents were leery about signing such a form. Yet if they wanted support they had no choice. One family who challenged the procedure and refused to sign the form was denied services which other families received. Peter and I went along with the system, leaving it to the CAMR-NB board to address changes at a higher level of government.

The Department of Social Services employed a social worker, Carolyn Green, to work specifically with families who had children with a mental disability. Carolyn was the most sensitive, understanding and caring social worker we had experienced to date. Following Carolyn's visit in our home, we received a monthly cheque which enabled us to hire someone to provide respite for four hours two Saturdays a month, and one evening a week at four hours an evening. We had the flexibility however, to change the hours according to our need. Social Services also approved funds for a weekend of respite four times a year and one day a week for the summer. This would supplement the anticipated three days a week summer program. Since Yvonne was still incontinent at night, they covered the cost of Attends.

The rationale for our request and for encouraging other families to ask for assistance was because these expenses were due to the disability. If it wasn't for her disability, Yvonne, at thirteen years, could be left on her own; she could even be babysitting and earning her own money. As it was, she required constant supervision.

Teresa often stayed with Yvonne, but she too needed a break. We called on friends or people identified through the Fredericton-Branch CAMR. Our friends Siegelinde and Elizabeth willingly kept Yvonne at their homes especially when we had late afternoon appointments or if we were out of town.

Although we had a busy schedule, being home for supper as a family was important to us. Years later though, we realized our table-talk had centred too much on our work and Yvonne's schooling. This was not fair to Teresa. In retrospect, this is one thing I would change. As it was, Teresa just listened and occasionally added her comments.

Teresa was studious and worked nightly on her homework. With Teresa home and Yvonne usually in bed quite early, Peter and I found it easy to schedule family visits or attend meetings in the evenings. Occasionally Teresa had other plans, but with a long list of people to call on, we always got someone to stay with Yvonne though sometimes it took hours to make one respite arrangement.

Our most intensive day was the one to Saint John combined with Newcastle. We left the house at 8:00 a.m. immediately after the school bus picked up Yvonne. We arrived in Saint John just after the start of the presentation, Social Role Valourization, by Dr. Wolf Wolfensberger. The workshop ended at 5:00. Only someone familiar with Dr.Wolfensberger could really appreciate the intensity of this workshop with its prolific jargon. His message focused on treating people who were labelled mentally handicapped with respect and dignity.

Leaving Saint John and driving north to Newcastle we ate the sandwiches I had brought along, knowing that our schedule would be too tight to stop to eat. We had a two-and-a-half hour drive; the meeting with the Miramichi-Branch CAMR was scheduled for 7:30. While Peter drove, we discussed the issues and I took notes. This became our routine.

Arriving home after midnight I sighed with weary satisfaction, “That’s what I call a full day.”

* * * * *

We attended the Baptist church within walking distance of our home. Eric Davidson was the pastor, and he and the congregation made us feel welcome right from the beginning. Each Sunday Yvonne received the same warm hug that the pastor gave to others. Other members welcomed Yvonne with a hug too. She smiled but withdrew from an embrace. We shrugged our shoulders, uncertain why she wanted to back away. Yvonne knew, however, that she was accepted and treated like the others. This was important.

We chose to sit near the back of the church because Yvonne still stood up during the service. Occasionally she made loud sounds. I then guided her to the washroom and explained that she needed to be quiet. Later the pastor kindly told me, “Yvonne’s standing up and making sounds doesn’t distract me. You don’t have to leave the sanctuary." I appreciated his understanding and his interest in Yvonne; still she needed to learn appropriate social behaviours.

Several months later, a Sunday School teacher invited Yvonne into her junior class. Delighted, I volunteered to help. To my surprise Elizabeth replied, "You need a break yourself. The other kids can help. Let me give it a try." Her understanding and thoughtfulness floored me. Each Sunday Elizabeth gave every student, including Yvonne, a copy of the Counselor. On Yvonne's first copy, February 12, 1984, I wrote, "A very special day! Yvonne in Sunday School for the first time at Skyline Acres Baptist Church in Fredericton, and Mom didn't have to stay with her!"

With Yvonne in the junior class, Peter and I attended the adult class. At first I found it hard to concentrate; deep down I worried how the teacher was making out. With time, however, I learned to relax. I was happy for Yvonne to be with children her own age and not to need her mother's assistance.

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In spring 1984, the parents of the Fredericton CAMR discussed plans for a summer program for students from the auxiliary classes. Ten parents wanted their children to participate with support in activities in the community. These parents submitted a proposal, "Creative Community Involvement for Multi-Handicapped Children" to the summer Canada Works Student Employment Program which requested funds to hire ten university students to provide one-on-one support to each child.

They approved the proposal, but funding was limited to five students. This meant we had to assign each university student to two children. The two families who shared a student arranged a schedule where each child had one-on-one support for three days a week during the two months of summer. The arrangement worked well and was flexible enough to allow for changes when the need arose.

Yvonne's student-helper was Lisa. She had a bubbly personality and formed an instant friendship with Yvonne. Lisa had known Yvonne only a short time when she asked if she could take her to Green Hill Lake Camp for three days with the junior high girls. I gulped, "Yvonne to a camp? Overnight? Without us?" Lisa's confident persistence persuaded us to agree. Besides, Teresa would be a junior counselor at the same camp, and Green Hill Lake was less than an hour's drive from town. We could drive up in a hurry if necessary.

The day for camp arrived. “Yvonne,” I said with mixed emotions, “can Mommy take a picture of you leaving for camp?” Standing on the front step of our house I put her small, red nylon gym bag into her hand. She looked apprehensive. This didn’t surprise me; I too was apprehensive!

We drove Lisa and Yvonne to camp where we met Teresa who was there since Sunday. Yvonne and Lisa would share the cabin with Teresa and nine other girls. The cabin was small. Six sets of metal bunk beds filled the entire floor area except a small gap between the beds and a narrow walkway. How would Yvonne sleep in such close quarters?

Peter and I arrived home to an empty house—a strange feeling indeed. It was the first time since the girls were born that we were home alone, overnight. Teasingly I remarked, “So this is what parents experience when they have typical teenagers.” I never dreamed that this would be possible for us.

Each time the phone rang I jumped up. It wasn’t Lisa. I heard a noise and dashed into Yvonne’s bedroom. By the second night our feeling of nervous apprehension gave way to partial relaxation. “They must be making out all right,” I surmised, “since no one has called.”

Friday evening we picked up Lisa and Yvonne. Yvonne had a great time! She was even on the group photo, a lasting reminder of her first camping experience with her peers. Thanks to Lisa, Yvonne too could enjoy a life experience that many teenagers across the country look forward to with excitement and anticipation every summer.

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During this summer, we dubbed our home “The Penner Inn.” Friends from Newfoundland travelling west took time to visit. We gladly billeted resource people connected with MCC and CAMR-NB, and family came as well: Alvin and Ewa, Clara and Robin, Mom Penner and Hertha, Jake and Bea with Daryl and Valerie, Art and Henrietta with Michael, and Mom Wiens. Our vacation was spent touring the Maritimes with our visitors.

We had a heart-thumping experience at the Woodleigh Replicas on Prince Edward Island. We had just climbed up the stairs and stepped into the Bloody Tower when Mom Wiens, seeing the glassed-in full scale reproduction of the famous Block and Axe, felt revulsion and fled out of the tower. I motioned to Peter that I would follow her. Peter motioned that he would take the steps down to the dungeon.

Elbowing tourists, I finally caught up with Mom Wiens. She still seemed shaken so I directed her to see the finer things, such as the full-scale replicas of the British Crown Jewels. We spent some time admiring the jewels when Peter and Teresa joined us. I looked behind them, casually questioning, “Where’s Yvonne?”

Peter replied matter-of-factly, “She’s with you.”

“No,” I stated, still believing this was his idea of a joke.

With a serious expression he accusingly said, “I thought you took her with you when you left the tower.”

“The tower!” I gasped. I raced toward the tower, my heart beating wildly. Gross images flashed through my mind. She’ll have smashed her face. She’ll be a bloody mess! But why don’t I hear her crying? Could she have attempted the narrow spiral steps on her own and be lying in the bottom of the dungeon? Feeling sick, I bounded the two flights of stairs to the tower. I stopped abruptly. One step down from the entrance to the Bloody Tower stood Yvonne flicking her hands at waist level, looking unconcerned. Reaching out I hugged her and cried and laughed simultaneously, oblivious to the tourists around us. Finally I pulled myself together and explained, “Yvonne, Mommy thought you were with Daddy, and Daddy thought you were with Mommy!”

We started down the steps and met Peter and Teresa. They looked relieved! Continuing down the second flight I said, “Wait a minute, Yvonne, I want to get a picture of you at the tower.” I knew I would always remember this experience, still, I wanted a picture as well.

It took us a long time to get over the shock of that incident. A few years later, Peter and I again had our signals crossed. We were in a mall, having parted to shop at different stores. After a frantic search, I saw Yvonne at the outside door which led to the busy parking lot. Someone was opening the door for her. My heart leaped into my throat as I dashed to the door. Still, it was the experience at the Bloody Tower which gave us the gravest feeling of having lost Yvonne.

Chapter 12

Challenging the School System

September 4, 1984—a date to remember. Yvonne entered junior high school. This year CAMR no longer administered any programs since the Department of Education negotiated with the local school districts to assume responsibility for all students with special needs. The teachers, formerly employed by CAMR, were now part of the New Brunswick Teachers Federation and responsible to the principals of their schools.

I had high hopes for a well-structured program for Yvonne. At the end of August we had met with the auxiliary class teacher and the outgoing administrator of auxiliary classes at the Murray F. Humes School. The teacher had expressed reservations about having Yvonne in her class, but we weren't too concerned. To us, this teacher's very posture and language expressed confidence and firmness which we thought Yvonne needed. This teacher had nineteen years of experience in a segregated school and had just returned from a study leave with a master's degree in special education. This would be her first year in an auxiliary class in a regular school.

I drove Yvonne to school on the first day and introduced her to the auxiliary class teacher and the new aide. I was happy for Yvonne; she was in a regular school setting with students her own age. For the first time, Yvonne was the youngest pupil in the class. With no younger children crying and most students at a higher functioning level, I was confident this could be a better year.

I sent in a notebook, as in past years, noting daily anything significant which might be helpful to the teacher. The reply, however, from the aide was the same day after day: "A good day!" Naturally I was glad Yvonne had a good day, but I couldn't talk to her about her activities because I had no idea what she was doing. I allowed the teacher a week to get settled in before asking for information about Yvonne's daily program.

A week later Yvonne's lunch box contained a copy of the weekly timetable. At the sight of "Romper Room TV," I was furious. That evening I showed the timetable to Peter and exploded.

The following morning, after a nightlong discussion, I wrote a note, "Could we please have a meeting early next week to discuss Yvonne's schedule? Thanks."

The teacher scheduled the meeting after class. Peter and I arrived punctually. The classroom through the open door appeared like a regular classroom, until we stepped inside. To our left we stared in disbelief at a preschool setup. A piano, and bookshelves holding an assortment of Fisher-Price toys and a television, partitioned off a small area. A table with puzzles and a few chairs stood inside this cordoned-off space. If this setup in a junior high school was meant to give us a shock, it had the desired effect.

Smiling, the teacher approached us, asked us to sit and opened the meeting. We soon discovered she had no expectations of Yvonne. Yet at times she went to the other extreme. I clenched my teeth and sat up straight. Over the years, we had learned not to blow up at a teacher, no matter how bad a situation might be.

In the past, teachers had tagged us with a variety of labels. Parents were still called "irrational" if they raised their voices in frustration or "unstable" if tears surfaced. Parents then had difficulty getting professionals to take their concerns or complaints seriously. The key was for parents to remain calm and focused, and collect as much information as possible. Reasoning with the teacher was also important, but if that failed, we could use the information obtained to advocate for changes at a higher level.

With this in mind, we firmly told the teacher, "We want 'Romper Room' removed from Yvonne's schedule of activities."

The teacher stated, "We are teaching Yvonne to sit still and watch TV. When she gets older, that's all she'll be able to do." I worked hard to maintain my composure and thoughts. "Romper Room," she continued, "is even above her level of comprehension." In this statement, I detected a note of malice but I wouldn't rise to her bait.

As calmly as I could, I retorted, "Yvonne will not just sit and watch TV when she is older. We expect her to continue to be active: to hike, skate, ski, go boating. Besides, Yvonne doesn't like TV; the only program she shows any interest in is "Three's Company." As for Fisher-Price toys, we've packed them away. I'm teaching Yvonne to hold a pen and to print her name. I hope the school will work on this too."

The teacher snapped back, “She’ll never learn to write her own name. She can’t use a pencil or paint brush because she grabs like this.” The teacher gave a vehement demonstration. “She doesn’t have a pincer grasp!”

Yvonne did have a pincer grasp, but arguing was pointless. I then asked the teacher about the piano. “At home,” I said, “Yvonne enjoys playing on the Bontempi chord organ.”

She retorted, “Only I, or the teacher-aide, play the piano. The children are not allowed to pound on the keys.”

I explained that Yvonne had a gentle one-finger approach on the keys. The teacher, however, disregarded my comment. I tried another approach. “At home Yvonne enjoys activities in the kitchen. Could we get her into a home economics class?”

The teacher’s response made no sense. “Yvonne can’t learn to cook until she’s mastered self-help dressing skills.” Frustrated, I almost asked how dressing skills related to cooking, when I heard her say, “The better students go to home ec.”

This last comment reflected her whole attitude. As former principal of a segregated school she always handpicked her students, and naturally they were the higher functioning students. She had been averse to having Yvonne in her class. Was she now retaliating by confining Yvonne and the two less-able male students in a play area?

Although the teacher had no expectations of Yvonne, she expected Yvonne to be outdoors for recess and during lunch hour with the rest of the students—without special supervision. Alarmed, we explained that Yvonne could walk onto the street and wouldn’t recognize the danger. The teacher snapped, “You want integration and normalization. Well, the other 500 students don’t have special supervision. Two staff are on duty for all of the students.” A knot formed in the pit of my stomach. She was either ignorant or being obstinate. Somehow, I sensed the latter.

I needed to know what the other parents were experiencing. I called a few. One parent was irate; her son had begun to wet his pants at school. Apparently the teacher wouldn’t allow him to go to the washroom except at the scheduled time.

I thought back to our meeting with the teacher. I had explained how Yvonne communicated her need to use the washroom, but the teacher had not indicated she would change her approach. She listed Toilet and Dressing Skills on Yvonne’s daily timetable at specific times. Her approach was both restrictive and regressive. This could result in setbacks and problems as now displayed by the other student.

The parents of the three isolated students met and invited the supportive social worker who was familiar with these students. Parents agreed to request a meeting with the new director of the auxiliary classes who was responsible for supervising curriculum and instruction. We wanted an IEP (Individual Education Plan) developed for each student by the end of October. We wanted the plan to reflect the goals which were important to us. We wanted a commitment from the director to have parent involvement in the development of the program. The TV and Fisher-Price toys should be removed immediately. We would request three "regular" student volunteers, one for each student, for a peer-buddy system. Parents wanted to help build a vision where the school would accept our students like other students.

The director of auxiliary classes agreed to meet with the parents at the school board office. At the meeting we informed her about the present regressive program and presented our vision. She told us that the Department of Education had just made available the newly developed provincial Curriculum and Resource Guide for Teachers of Pupils with Long-Term Developmental Special Needs. She assured us that each student would have an IEP and parents would have input. Furthermore, she would assist the teacher, address our other concerns, meet with the principal of the school, and talk about possibilities for integration.

The next week the director invited the parents to a meeting at the school with the teacher and the principal. The principal was surprisingly open and stated, "Everything at the school is open to all students." He saw no problem with the auxiliary class students using the art room, the gym with the equipment, or the home economics room. "But," he stated clearly, "I will not become involved in developing the program. I have no experience in this field. I will leave it to the expertise of the qualified teacher."

I wished the principal were involved. He claimed he had no experience but he had the right attitude. The meeting ended and each parent received an appointment date to discuss an IEP for their son or daughter.

The meeting concerning Yvonne's IEP was held on October 23. We asked a member of the Fredericton CAMR education committee to accompany us. After our earlier meeting with the teacher, misunderstandings and rumours circulated: "The Penners want Yvonne to watch 'Three's Company' at school." We wanted to avoid any further misunderstandings and the presence of an advocate could do just that.

At this meeting the director of auxiliary classes spent excessive time going over the whole assessment procedure which was self-explanatory. On the other hand, the teaching programs and the daily schedule were only briefly discussed due to lack of time. However, we did manage to talk about the goals and objectives which were important to us. The director said, "The teacher will write out the IEP and send it home with Yvonne for your approval and signature."

The day after this meeting, the director of auxiliary classes called and said, "The teacher complained about you bringing an advocate along. I'm asking you and Peter to come to the school board office to explain your need for an advocate. Other special education teachers are now worried that they too will be faced with an advocate at their meetings."

"You know," I stated sharply, "I don't understand why parents aren't allowed to have a support person. At every meeting that we've ever had about Yvonne, the teacher has always had a support person—either the principal, a committee member, supervisor or director. We've often gone to meetings not knowing who would be present, and we've been surprised to find three, four or more people. Besides, you were at the meeting." She stammered, but insisted that we meet. I told her, "I'll get back to you."

That evening Peter and I discussed the situation. On the one hand, we would have the opportunity to meet with the assistant superintendent to express our views. On the other hand, this could set a precedent where other parents would be called to the school board office to explain their need for an advocate. This would intimidate most parents. We decided against attending the meeting.

In the morning, I called the director of auxiliary classes about our decision. I then called a member of the CAMR education committee, because the Fredericton CAMR still had input in the auxiliary classes through three members on the eight-member advisory-liaison committee.

Parents often need moral support as it can be intimidating for a parent to sit at a table with a group of professionals. Sometimes parents need clarification or forget something that was discussed. Later these parents are accused of being noncompliant or having misunderstood. An advocate could provide interpretation, and his or her presence could ease the pressure and tension that most parents face.

Clearly the right to have an advocate needed to be addressed but not by individual parents. The committee would have to deal with this.

The atmosphere between home and school remained strained. To overcome this, the director suggested regular communication through the notebook and a weekly telephone call. The phone calls, however, led to distortion of issues. Soon I received a phone call from the principal. He wanted to meet with Peter and me.

The principal invited us in to his office. He smiled and his quiet confident manner put us at ease; I again got the impression he was a compassionate person. We were floored when he asked point-blank, "Do you feel your daughter's teacher is competent?"

After a thoughtful moment I replied, "I think she could be."

He raised his eyebrows. "Could be?"

We had a lengthy discussion. As if to reassure himself, he questioned, "So you are not building a case of incompetence against her."

"No!" Peter and I exclaimed in unison. Surprised by the accusation, Peter continued, "We just expect the teacher to do her job."

I added, "We always hear about her nineteen years of experience and a master's degree in special education. Don't you agree we should expect a better program than what we have?"

The principal looked relieved that we were not trying to oust the teacher but were merely trying to get her to do her job. "The teacher," he said, "feels under pressure from all the meetings and contacts," and he listed them all. He asked us to "cool it with the meetings" and "let things ride" until the parent-teacher interviews in late November. We agreed to his request, but hoped he understood our frustration in not knowing what Yvonne was doing in school.

We talked a bit more and the three of us recognized that the teacher was not used to having students with such challenging needs and the involvement of parents. The principal commended our involvement and stated, "I wish parents of all students would be more involved."

I pointed out, "Parents generally get information from their sons or daughters. Yvonne, however, can't tell us what's happening at school, therefore we have to be involved."

He then raised the issue of the advocate, which the teacher found threatening. We explained why we took that approach. He supported our bringing an advocate if we told the teacher ahead of time. We agreed.

Before leaving I told him, "You know, we as parents of children with special needs have to put up with a lot. At our first meeting with the teacher, she told us that Yvonne had no receptive language and no expressive language. Her goal for Yvonne, by the end of June was for her to learn 'go, come, sit and stand.'" Silence enveloped the room.

The principal's expression showed that he understood our frustration. Perhaps that's why he did become more involved and attended most meetings concerning Yvonne.

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Yvonne had developed a curved back, in Newfoundland, when she was twelve years old. I had taken her to the family doctor who referred her to the Children's Rehabilitation Centre. The physiotherapist claimed that exercises wouldn't help since Yvonne resisted the movements.

The physiotherapist then scheduled an appointment for Yvonne to see a team of doctors. The doctors were puzzled. I couldn't understand it. Surely this wasn't a unique medical problem?

Somehow it was. The doctors decided to try a molded back brace. They custom designed it, stage by stage. First they applied a plaster of Paris paste to Yvonne's back to make a mold. She cooperated surprisingly well. Then, using the hardened mold as a template, they shaped a heavy piece of plastic which was warmed to make it pliable. The completed back brace reached above her shoulder blades, down past her waist and around her sides. They lined the inside with a layer of perforated foam which extended across her front. Two long padded straps attached with rivets at the top went over her shoulders, under her arms, crossed behind her back and buckled around her waist at the front. Another belt with a serrated buckle kept the brace snug around her waist. The plan was for Yvonne to wear this brace daily, beginning with ten minutes and gradually increasing the time. Tightening the shoulder straps increased the tension.

While Yvonne wore the brace at home, I read to her or played her favourite tapes and records. I wanted to take her mind off wearing the brace. During these times she often wore the large headphones which a teacher suggested for increased auditory stimulation. Peter attached a long cord with an adapter from the tape player to the headphones enabling Yvonne to walk around and not feel confined. Most often, though, she preferred to lie on the living room carpet resting on her elbows. Sometimes she smiled during these therapy sessions. Other times she cried. Generally she accepted the brace well at the start of the session but became visibly uncomfortable after an extended time. Despite the added padding, her shoulders became red and chafed. For extra protection, she wore the brace over her clothes but only at home, as I was always conscious of her appearance. For a short time she wore the brace at school with a sweater on top, but the teacher found the brace cumbersome. Since the end of the school year was near, we decided against sending the brace to school.

Yvonne wore the brace periodically during the summer, but in the heat she perspired. The holes drilled through the plastic for ventilation, were not sufficient and she became very uncomfortable. Doctors had said Yvonne would need to wear the brace twenty-four hours a day, for several months to be most effective. This we knew would be nearly impossible. Soon we became concerned when someone cautioned us, “Yvonne’s muscle tone will weaken if she becomes dependent on the brace.”

What should we do? If we continued with the brace and she lost her muscle tone, we would be worse off than before. We couldn’t follow up with the doctors who had designed it because we had moved to New Brunswick. Therefore we decided to discontinue the brace and try exercises instead. I helped Yvonne to lie on her back on the living room carpet and bent her knees up to her chest and back down. I moved her arms individually and together up over her head and down. I crossed her arms over her chest. I helped her with sit-ups. During these times I would talk to her, sing to her or play a tape. Sometimes she relaxed and allowed me to do the exercises; other times she stiffened up.

I worried if I was moving her legs and arms incorrectly. Was I harming rather than helping her? I needed professional advice and called the Forest Hill Rehabilitation Centre. After an initial examination the doctor referred Yvonne to the Centre’s pediatric team. A physiotherapist, an occupational therapist, a speech-language pathologist and a special education teacher then assessed Yvonne.

Each professional arrived at the same conclusion. Assessing Yvonne was difficult and she needed to be in a familiar environment. Each team member wrote a brief summary compiled into a single written report. The speech-language pathologist reported, “I think Yvonne would respond better to her parents and teacher whom she is familiar with.” She then gave us a home/school program to improve eye contact, to point to objects on request, and to imitate gestures. She scheduled several follow-up appointments.

The occupational therapist also provided a home/school program to develop fine motor skills, to correct the “left neglect” and to improve Yvonne’s posture. She too scheduled follow-up appointments.

The physiotherapist stated, “Yvonne has a moderate thoraco-kyphosis and walks with her left arm held in a flexed position with a tight fist. She appears to have full range of movement in all joints of left upper and lower extremities. She seems to have functional strength.” The physiotherapist requested more appointments before she could provide a home program.

The special education teacher reported, “Yvonne is not the type you can assess in an hour. The teacher in the auxiliary class knows her and works with her.” With this, she withdrew her involvement from the team.

Yvonne liked Martha, the speech-language pathologist, Marlien, the occupational therapist and Maria, the physiotherapist. Still she was unhappy each time we arrived at the Rehab for the follow-up appointments. Sometimes Yvonne cooperated and the therapists immediately rewarded her with enthusiastic praise. Nevertheless, when the appointment was over, Yvonne ran out of the building.

At home I continued to work on the home/school program which the therapists provided. They gave the school a copy too. The teacher at Smythe Street elementary had used this program, although not every day. This year in junior high I doubted that the Rehab program was used at all.

During this year, we had many difficulties. After numerous meetings, however, the auxiliary class teacher did develop an IEP and used some of our suggestions. The IEP listed three or four short-term objectives for each long-term goal in each curriculum area: gross motor, fine motor, self-help, speech and language, life skills and social skills. For the most part, we accepted the teacher’s short-term objectives but asked her to remove “standing on tiptoes.” Years earlier we had read that children with autism often walked on tiptoes and needed to be taught to walk naturally. We did not want to create a problem for Yvonne. Therefore, we asked the teacher to replace it with “reaching.” The Rehab had suggested “reaching” to help develop the muscle tone in Yvonne’s back.

Even so, we remained suspicious that the teacher did not use the Rehab program. I spoke with the principal about Yvonne's therapy and stressed the importance of home and school cooperating by working on the same activity and being consistent with the teaching approach. The principal agreed to call any resource people who might be helpful. I gave him the name and phone number of the physiotherapist, the occupational therapist and the speech-language pathologist at the Rehab.

Of the three therapists, Eleanor, the new speech-language pathologist, was the most enthusiastic. She took a keen interest in Yvonne and expanded the communication program. She taught matching skills as a preliminary language skill. Eleanor set up a program to teach Yvonne to match an object to one of three.

At first Yvonne was puzzled. After I demonstrated, Yvonne scored eighty percent. A few days later, her score plummeted to forty percent or less. I was certain this was due to boredom. For variety, I changed objects and their positions; I varied the number of items between two to four.

Sometimes Yvonne placed an object incorrectly and then laughed. "Oh Yvonne!" I accused teasingly. "You're playing games." She laughed even louder. Then she placed the object appropriately. It was her way of expressing a sense of humour. Other times, however, Yvonne's incorrect responses were from neither boredom nor her sense of humour. How could she not distinguish a common object like a spoon from two very different objects?

Eleanor recognized that Yvonne had ability and there was a reason for her inconsistent responses. She mentioned that the lighting, interfering noise or the angle of the object could be factors. She thought of solutions and was always supportive of Yvonne. In my view, Eleanor would be an excellent resource to the teacher at the school.

The principal soon called the Rehab and scheduled a case conference with the three therapists, the social worker, the teacher, Peter and me. The director of auxiliary classes had arranged for a substitute so the teacher could attend. On the day of the meeting, however, the principal came in her place. "The teacher," he said apologetically, "is attending a funeral." I must confess to cynicism. In the margin of my notes I had scribbled, "One of her cats?"

The meeting was excellent. The therapists focused on doing normal activities and the physiotherapist gave examples how specific exercises could be incorporated into regular gym activities. All three therapists emphasized that communication was the key, and should be a focus throughout the day. They offered to come to the school to provide in-service training.

The principal readily agreed, "I'll speak with the teacher and we'll work it out so you can come one at a time." We were hopeful that we would finally get a good program for Yvonne.

Soon the principal arranged for Yvonne and each of the other students from the auxiliary class to be a part of the regular gym program. He chose an age-appropriate class for each student and was careful to place only one student with special needs per class. In this way the regular teacher was not overwhelmed, and could provide guidance directly to the student or the teacher's aide.

One afternoon I arrived at the school to take Yvonne to an appointment. An orthopedic surgeon recommended a back X ray, as the curvature of her back had become more pronounced. Soon the teacher brought Yvonne from the classroom and told me, "We went on a field trip, to the mall."

"That's nice," I smiled, "Yvonne enjoys going to the mall."

The teacher became agitated. "Yvonne was flapping her hands the whole time!" Astonished I looked up, and she continued, "I will never, ever take Yvonne out in public again."

My only thought was to get Yvonne away from the teacher's rage as quickly as possible. "We'll talk about this later," I shot back. Picking up Yvonne's lunch box, I rushed her outside. How could a special education teacher be so insensitive and say something like that in front of Yvonne?

Naturally this incident resulted in another meeting. I explained how Yvonne at four years began to rub or flick her clenched left hand into her right palm. "Over the years," I explained, "we've tried to stop her from doing this. She can quit flicking if she's doing something meaningful, like holding a spoon or a pencil, but when she drops the item or lays it down, she starts again." I mentioned how I was teaching Yvonne to carry a small nylon gym bag and suggested the school could work on this too. Instead, the teacher and the director asked us to take Yvonne to a behavioural psychologist.

Two months later at a case conference, we discussed Yvonne's IEP and the appointment with a behavioural psychologist. The teacher asserted, "I can't work with Yvonne until the hand-flicking behaviour is treated."

Peter jokingly responded, “Yvonne could be doing worse things with her hands.” The teacher wasn’t amused.

I calmly but firmly stated, “We will agree to take Yvonne to the Izaak Walton Killam Hospital in Halifax to participate in the five-day behavioural treatment/ training program—on one condition. We want the teacher to participate on the final day or two.”

This had the effect of shock treatment. I scanned the silent faces around the table: the advocate, the social worker, the principal, the teacher, the director of auxiliary classes and the assistant superintendent of the school board. The assistant superintendent spoke cautiously, “The school board has limited resources. We can’t make extensive in-service available for teachers—”

“Excuse me, sir,” I broke in, “we have limited resources too. If it’s important, however, we’ll find the resources, but we will not go if the teacher is not going. What’s the point in our bringing back a behaviour modification program and explaining it to the teacher? It won’t work. The teacher needs to hear directly from the psychologist.”

Interestingly enough, after this meeting they didn’t talk about Yvonne seeing a behavioural psychologist to correct her “deviant behaviour,” as the teacher called it. Meanwhile Yvonne continued to flick her hands.

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We always looked forward to having visitors in our home and enjoyed hosting John Longhurst from the MCC head office in Winnipeg. John was travelling through the Atlantic provinces to visit MCC service workers and wrote an article about the work that each was involved in. He listened as we talked about our work and our frustration with the education system. We acknowledged, however, the principal’s effort to integrate the students. We also commended the government for promoting community-based services. John took notes and requested a picture of Yvonne to accompany his article.

The article appeared The Mennonite Reporter in spring 1985. Shortly after, I received an unusual phone call, “Hi, this is Jim Chism from Montreal. You don’t know me, but....” I recognized the name instantly and felt guilty. A year earlier Dave Dyck, the MCC Coordinator of Canadian Programs in Winnipeg, suggested that we contact the Chisms if we drove through Montreal. They too had a daughter with autistic tendencies. However, we had whistled through Montreal and not taken the time to call them. Jim continued, "I saw the article in The Mennonite Reporter." The picture of Yvonne makes me wonder if she has Rett Syndrome."

"Rett Syndrome? I never heard of it." Concerned about yet another label, I proceeded cautiously. "What is it?" As he spoke, I took notes: "Rett Syndrome. Known since 1983 in North America when translated into English from German. Known in Austria: Dr. Andreas Rett, 1966. Also Dr. B. Hagberg (Sweden 1980). Affects only girls. Hand-wringing. Coordination problems. Wide-based walk. Thin small build. No language. Autistic traits, becoming more sociable. Hyperventilating. Curvature of spine. Seizure activity."

Everything up to seizure activity fit the description of Yvonne. Still I was wary. Could it be, after all these years, that we could get a more accurate diagnosis of Yvonne's condition? My interest was stirred and I asked Jim if he had any literature.

"I'll send you copies of what I have, including notes from a recent conference in the United States where Dr. Rett diagnosed our daughter. Now I'm not saying, that's what your girl has, but looking at the picture I'd say she has Rett Syndrome." He encouraged us to visit them if we drove through Montreal. I promised we would in a few months.

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We looked forward to the end of the school year. We would have a break from the "war of letters," as the principal once called it, and a break from the endless meetings where we tried to address policies around curriculum planning and implementation and parent involvement. We would also have a break from direct contact with a teacher who, we sensed, could provide a sound program but chose not to because of a negative attitude toward Yvonne.

Her attitude surfaced again near the end of the school year. I arrived early to take Yvonne to a therapy appointment. Classroom doors were open and, nearing the classroom, I heard a strange horrible sound: "Yuk, yuk, yuk!"

The teacher, standing in front of Yvonne with a look of distaste on her face, vigorously waved a tissue across Yvonne's mouth and chin. Two Grade 7 students, part of the peer-buddy system, stood in line beside Yvonne with their shoulders raised to their ears, hands cupped over their mouths snickering. Seeing me, the teacher instantly changed her tune. "There," she said in a soft voice. Smiling she dabbed at the saliva on Yvonne's mouth.

I almost lost control! Fuming I contemplated, should I lay into her? Or should I run to the principal? Or should I just pull Yvonne out of school? I looked at Yvonne. She stood motionless, hands clutched behind her back, a pose I saw only once before in a moment of fright. Her eyes, however, focused on the teacher, frightened but pleading, brought me under control. I walked up to Yvonne, ignored the teacher, put my arm around her shoulders and gently said, “Come, Yvonne. Let’s go.”

Inwardly, I was tormented. Yvonne was humiliated in front of her friends! Yet if I made a scene, it would upset Yvonne. If I went to the principal, the teacher would paint a different picture. If I removed Yvonne from school, the teacher would be delighted. What was my choice?

Driving to the appointment in a daze, Yvonne’s pleading look, “Please believe in me!” burned before my eyes. My heart bled for her. How could I make school a happy experience for her? Then I thought about the days when Yvonne was happy and realized these were the days she was integrated. Perhaps the key was total integration. We should get Yvonne out of the auxiliary class!

Peter and I wrote a letter to the director of the auxiliary classes. “We wish to encourage and challenge the school board to look at options and resources outside the auxiliary class system in planning for next year’s program.” We referred to a recent workshop, “Education for All,” sponsored by CAMR-NB and endorsed by the Department of Education. The presenters, a team from the Wellington County Roman Catholic Separate School Board in Guelph, Ontario, described their fully integrated model “which had been working since 1977, with all children attending regular classes regardless of exceptionality.”

We stated that the New Brunswick deputy minister of Education, as a participant at the workshop, said, “We want to develop along the lines of what these people are talking about.” With a public political statement such as this, we felt confident in making our request. We asked the director for a meeting to discuss next year’s program and placement for Yvonne.

Two days later, the director of the auxiliary classes called with an appointment for the following week. During this meeting, we realized the school board was not prepared for total integration. Realistically we understood. After all, this was the first year that the school board was assuming responsibility for students with special needs and they themselves were still learning. We challenged them though to increase integration as a step toward full integration.

The assistant superintendent, still puzzled, asked, “How can Yvonne participate in a regular program? Say she’s in the gym program, and in the fine weather the class is outdoors playing baseball. Yvonne can’t play. Will she just stand and watch?”

I smiled and contradicted him, “She can play. Yvonne would stand at the batter’s plate. A student would help Yvonne hold onto the bat. The pitcher would leave the pitcher’s mound and come to within three or four feet of the plate. The student would help Yvonne swing the bat and help her run to first base.”

A look of understanding swept over his face. “All you are asking is to have Yvonne join the other kids and modify the activity to a level where Yvonne can participate?”

“That’s right.”

With a bounce in his voice he said, “I see no problem with that.” Turning to the director, he kindly instructed, “I’d like you to contact the regular teachers about integrating the students.” I cannot put the feelings of surprise, joy and calm which swept over me, into words. The assistant superintendent quickly pointed out, “This does not mean it will be full integration.” Somehow we weren’t surprised, but we were satisfied. We were making gains.

The rest of the discussion focused on school placement for September. We had the option of sending Yvonne to another junior high. The director of auxiliary classes even pressured us to transfer Yvonne. She elaborated on the positive aspects of the school: the cafeteria, gym, home economics program, an active student body, a receptive principal and a teacher who “wanted” Yvonne.

Still, Peter and I were adamant. “We want Yvonne to remain where she is. Yvonne is familiar with the environment and she is just getting to know some regular teachers and students. We want Yvonne to have continuity and stability. The principal is supportive and he promised to increase integration.” We implied that if the teacher didn’t want Yvonne, she could request a transfer for herself. This was Yvonne’s school. Yvonne had a history of placement upheavals; we believed she deserved stability. Besides, we doubted that the auxiliary class teacher at the other school could do a better job. We heard complaints from parents about his class. We stood our ground; Yvonne would stay and we would do what we could to make the next school year positive.

Having resolved the school issue, we looked forward to our vacation. Immediately following Teresa's high school graduation, we headed west on a three-week camping trip. This was our first vacation without Teresa as she had a summer job as counsellor at Camp Medley near Gagetown. Travelling without her felt strange. The 1984 Dodge Aries, which we bought the previous fall, was crowded compared to our station wagon. With only three of us, however, we adjusted. We had also compacted our camping equipment; a nylon tent replaced our bulky canvas one.

I had worried if Yvonne would accept the new tent, so to prepare her, we set it up in our backyard. She showed no interest; perhaps she knew it was out of place in our yard! At least she didn't show a negative reaction.

The next evening we arrived in Montreal and spent time with the Chisms. The similarity between Genny and Yvonne was striking. Both girls had the same slender build. Yvonne, a few years older, stood looking down into Genny's eyes, who looked up at her; each rubbed their hands at waist to chest level, smiled, and hyperventilated. We wondered what they were thinking.

Chapter 13

A New Diagnosis: Rett Syndrome

The Chisms gave us more information about Rett Syndrome. A newspaper article from February 1985 reported on a Rett Syndrome conference held in Baltimore. Dr. Rett said, "A Rett Syndrome baby appears normal in every way for the first seven to eighteen months of life. Then she starts regressing. Within a year-and-a-half, as her brain atrophies, she withdraws to the point of becoming autistic, quits talking and may appear to be blind or deaf. She also loses facial expression, becomes severely demented and strikes up a repetitive hand-wringing that can be mutilating."

This description of a normal development up to the first eighteen months of life, followed by regression, was the first affirmation of our persistent description of Yvonne's early development. Since this disorder wasn't known in North America until 1983, we now understood why specialists were unable to recognize the condition in Yvonne.

Another article reported a comparison of children with autism and those with Rett Syndrome. “Four main symptoms separated the two groups:

1) Those with Rett Syndrome spent more time looking at objects and people rather than handling objects. The opposite was true of autistic children.

2) Uniform stereotypic movement in Rett Syndrome consisted of the hand-washing and bringing hands together in the midline compared to autistic children who showed a variety of motor movement, swiftly alternating in speed and shape.

3) Rett Syndrome children showed a broad-based stand and ataxia, but the gait in autistic children was normal.

4) Chewing was noted to be abnormal in Rett Syndrome children but not in autistic children.”

The last point intrigued me. I recalled how Yvonne, in her younger years, swallowed chunks of food and choked, and how I struggled with this problem but eventually came up with a solution.

We were disheartened to learn that seventy-five percent of Dr. Rett’s patients were confined to a wheelchair or bedridden by adolescence. Dr. Rett reported that physical therapy was necessary to stem the muscular atrophy, but he cautioned against forcing the child into a rigid training schedule with fixed daily sessions. “The child’s tolerance level,” he said, “could vary from day to day.” I now understood why Yvonne sometimes cooperated with exercises and at other times she resisted them.

The literature, describing “the loss of purposeful use of the hands,” suggested that the person couldn’t do anything constructive. In our case, however, we recognized that Yvonne could do certain useful things. She could hold a spoon or fork, and eat by herself. She could hold onto a swing with both hands. She could carry a lightweight bag for a short time. She could carry a glass or cutlery or a plate and place it on the dining room table. She could hold a pencil or marker and make independent strokes, if given a verbal prompt. Granted, it took intensive efforts for us to teach her to use her hand for each skill. Nevertheless this was possible.

Because of our experience and because most girls diagnosed with Rett Syndrome lived in institutions, Peter and I disregarded the gloomy prognosis. We were convinced that living in an institution not only hindered development but actually caused regression. We had also experienced that life was not as bleak as earlier predicted by the specialists who diagnosed Yvonne with severe retardation and autistic characteristics. Yvonne's experience demonstrated that though the girls lost the use of their hands, with time and effort they could use them again, at least to some extent.

Our conclusion was supported by Dr. Rett. "There are many different grades of severity [of Rett Syndrome]: it depends largely on what the parents do with the children." One approach that proved promising for the girls was music therapy. "Girls who had no purposeful use of their hands but whose hands had been placed on piano keys could bang on the keys and feel the vibration of the keyboard. They were then able to grip a hammer or pick up a ball from the floor or feed themselves."

Did the electric chord organ, which we bought for Yvonne stimulate her hands? We hadn't known of this benefit. We just knew that music calmed Yvonne and gave her enjoyment. When we returned from vacation, I would check into music therapy.

The Chisms also told us about Dr. Patrick MacLeod, a geneticist at Queen's University, who was studying Rett Syndrome. A few days later, we drove onto the Queen's campus and while Peter went into the Kingston Hospital to call Dr. MacLeod, Yvonne and I strolled the grounds of a nearby park.

Peter soon raced toward us. "Dr. MacLeod is anxious to see Yvonne. He can meet us at the library in two minutes."

"Two minutes?" I asked disbelieving. As we rushed through the park and crossed the street I numbly uttered, "I can't believe this. I hadn't even expected an appointment, much less at a moment's notice!"

Dr. MacLeod, wearing his white lab coat, met us out on the parking lot. Answering my startled expression he explained, "The meeting room is hard to find." Never before had we met a doctor with such interest and enthusiasm! I was dazed, wondering if what we were experiencing was real.

Dr. MacLeod asked questions about my pregnancy and the early years. Not once did he doubt our account of Yvonne's development. He took notes and asked us each about our family history. He spoke to Yvonne. He felt her thin arms and her curved back, but he did not put her through the usual medical examination. Still, Yvonne was apprehensive and wouldn't smile at him.

After a while Dr. MacLeod showed us slides of girls with Rett Syndrome in an institution. "If Yvonne has Rett Syndrome," he said, "she is the most healthy of the cases I've come across." We were speechless. Until now, doctors called Yvonne's condition severe. Now we heard words like "most healthy" and "mild."

Dr. MacLeod commented on Yvonne's understanding and her appropriate responses. He observed Yvonne when I showed her a picture of the toilet and asked if she needed to use it. She pointed, and then walked toward the door. He was also encouraged to see her pick up a tumbler of juice, which I took out of my purse, and drink on her own. She clearly impressed him.

At the end of a one-and-a-half hour visit, Dr. MacLeod said, "I'll send my report to Yvonne's pediatrician in Fredericton. I'll also send a copy to Dr. Peter Camfield, a neurologist in Halifax who works in this field." We asked if we could get a copy as well. "Of course," he said kindly, "it and the other literature should be waiting for you when you arrive home from vacation." He told us he was encouraged.

We in turn were encouraged; not only by his positive assessment of Yvonne's condition but also by his attitude. He was the only doctor, next to the family physician in Newfoundland, who believed our description of Yvonne's early development.

Although Yvonne didn't feel the visit with Dr. MacLeod was a highlight of our trip, we did. We were spirited and energetic as we left Kingston. Arriving at Killarney Provincial Park in Ontario, we even attempted a challenging four-kilometer hike on the Cranberry Bog Trail. In places, the trail went up and down, and over boulders and tree stumps. At times Peter carried Yvonne, fourteen years and sixty-three pounds, on his back when she was afraid to go down a steep slope. We panted and sweated and laughed. Yvonne was a good sport.

In Manitoba and Alberta we saw many friends and relatives. Yvonne was a seasoned traveller. She no longer rested, and preferred to sit in the front with us. She tolerated long travel days, like fifteen hours from Winnipeg to Calgary. She tolerated late supper meals, and I recalled the early years.

Then, supper had to be punctual at 5:30. Once, after I put the supper into the oven, I explained to Yvonne, "Supper is cooking," and went to wash my hair. She stood in the kitchen and cried until I returned. I opened the oven door and emphasized, "Supper will be ready when Daddy comes home at 5:30." But she only stopped crying when I finally took the dishes out. Yvonne wanted me in the kitchen preparing food at a precise time. She had an uncanny sense of time. If we planned a late supper, I gave her a second snack; still, at five o'clock, if I wasn't in the kitchen, she cried. It was as if she could read the clock!

As Yvonne got older, she became more accepting of changes in schedule. While travelling, we talked about stopping at McDonald's. Yvonne smiled and inhaled with anticipation. She understood when we explained, "You have to wait till we get to the next town." Yvonne remained patient, no matter how long it took, because she was confident of getting a McDonald's hamburger.

Near the end of our vacation we looked forward to being back home. I wanted to follow up with the pediatrician and request a referral for Yvonne to see Dr. Camfield. I wanted to look into a music therapy program, and I needed to complete arrangements for Yvonne's week at Green Hill Lake Camp. We missed Teresa and were anxious to see her. Peter and I were also eager to get back to work; plans were in the final stages for children to leave the Dr. William F. Roberts Hospital School, a provincial residential institution for children with behavioural disorders or a mental disability, in Saint John. Social Services would return children to their families or to foster homes in their home communities with the necessary supports.

Returning from vacation, I first contacted the Fredericton CAMR about Yvonne's summer support worker. Yvonne's summer companion was Caroline a psychology student at the University of New Brunswick. We were delighted because Caroline knew Yvonne from two years earlier, when she had worked to eliminate Yvonne's hand flicking during the noon meal at school. Caroline had a pleasant personality and Yvonne liked her. She was athletic; she was confident; she spoke softly and always wore a broad smile, laughing freely.

Caroline didn't have a car; she biked to our home. She and Yvonne then took the bus downtown and strolled along The Green. The long narrow park, shaded by huge elms and willows, curved with the Saint John River through the downtown. They often had their lunch on The Green or at Officers Square Park where they watched the Calithumpians, a local theatre group, perform before a lunch-time audience. They also hiked to Wilmot Park and Odell Park, and walked the trails through the woods or viewed the ducks and the fenced-in deer. On rainy days they ate their lunch at Caroline's apartment. Rain or shine, they walked daily. By the end of summer, Yvonne's skinny legs became strong and muscular. Her thin arms were strengthened from the almost daily exercise on a swing. She gained weight. She looked healthy and was happy.

This summer Yvonne went to Green Hill Lake Camp for the entire week. Teresa arranged to take a week off from Camp Medley, and spend it at Green Hill Lake; she could give Caroline a periodic break and enjoy some time with Yvonne.

Yvonne arrived home smiling and laughing. The arrangement had worked well. The girls in the cabin enjoyed having her and included her with enthusiasm in their activities and antics. After Yvonne was in bed, Teresa drew me aside and whispered, "If Yvonne won't lie down, just say 'Whoosh!' and she'll lie down."

"What?" I asked incredulously.

Teresa then told me the story. "It was late in the evening. Yvonne was lying on her stomach but she was up on her elbows and refused to put her head down. I pulled her arms back and said, 'Whoosh!' and she flopped down on her chest. At first the girls thought I was mean, but then Yvonne laughed. After that it became a game. Whenever I or any of the girls said, 'Whoosh!' she'd throw herself down and laugh."

I tried the approach at home. It worked like magic for a long time.

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The report from Dr. MacLeod arrived. I called the pediatrician immediately. He too received the report and with a note of enthusiasm said, "I've made a referral for a neurologist to see Yvonne at the special clinic in Fredericton. This clinic, with two neurologists—Dr. Camfield from Halifax and Dr. Meek from Saint John—and a geneticist meets twice a year at the Chalmers Hospital [in Fredericton]. Yvonne has an appointment to see Dr. Meek."

I had mixed feelings. I was grateful that we arrived home in time to get an appointment instead of waiting for several months, yet I was disappointed that Yvonne had an appointment with Dr. Meek. We had hoped to see Dr. Camfield who was knowledgeable about Rett Syndrome.

The day of the appointment arrived. The large waiting room was noisy. The receptionist was friendly and understanding; she recognized Yvonne's anxiety and asked, "Would you prefer to wait in a smaller room?" We had never experienced such understanding and personalized treatment. This receptionist proved it could be done.

What would Dr. Meek be like? The door soon opened and a man entered. Extending his hand he said, "Hi, I'm Dr. Camfield."

Perplexed I uttered, “Dr. Camfield? I understood we had an appointment with Dr. Meek.” Then, realizing our good fortune I swiftly added, “Of course we’re glad to meet with you.”

“Dr. Meek,” he replied, “is with another patient. We work as a team.”

Enthusiastically we informed Dr. Camfield about our visit with the Chisms in Montreal and Dr. MacLeod in Kingston. He listened, and asked questions. He examined Yvonne and showed a keen interest in her past development. I handed him a photo album which I had put together for this appointment. Pictures showed Yvonne as a baby up to fifteen months playing meaningfully. Later years showed the hand-rubbing, changes in facial expressions, and the wide gait walk. Recent pictures showed Yvonne carrying her lunch box, sitting on a swing holding on with both hands, standing on skis and holding the ski poles, stirring a pot on the stove, and holding onto a shopping cart in the grocery store.

I also showed him the pictures used for communication. He was intrigued by Yvonne’s ability to use her hands and by her level of understanding. I then told him about our frustrations at school: that the teacher was negative about Yvonne’s constant hand-flicking and had insisted that Yvonne see a behavioural psychologist.

Sitting back in his chair, Dr. Camfield listened and thoughtfully observed Yvonne. He rose abruptly and said he would be right back. He returned shortly and introduced us to Dr. Meek. Then we learned that Dr. Meek, too, was familiar with Rett Syndrome. Unexpectedly, in the past two months, we met three doctors who not only believed our account but who were genuinely supportive and interested in helping in any way they could.

Dr. Camfield helped by writing a “To Whom It May Concern” letter regarding his thoughts about an educational program for Yvonne. He emphasized increasing the range of her communication system by using an object board or picture board. He also stressed focusing on dressing skills. “I was impressed that she can stop rubbing her hands together easily if there is something to do with her hands. I do not think that a major behavioural effort should be undertaken to decrease the hand rubbing. Efforts would probably be best spent in concentrating on increasing hand function which, by itself, will decrease hand rubbing to some degree.”

Before school commenced, I asked Yvonne’s social worker about music therapy.

“I know Paul Lauzon,” she said, “he gives private sessions to a few clients in Saint John.”

"Saint John?" I asked, disappointed.

"Yes," she said, "but he lives in Fredericton. I'll make some inquiries and get back to you." She called back promptly, as she always did. She gave me Paul's phone number and some basic information, including his fee. "The sessions are expensive," she acknowledged, "but the department has agreed to cost-share the expense based on the therapeutic value."

I called Paul and he set an appointment. He lived on the north side, in an older but grand home, overlooking the Saint John River. He took us through the living room and opened the French doors into the adjoining room. This was the music room. A piano stood against the cream-coloured wall. A xylophone mounted on a stand stood on the polished hardwood floor near the window. He positioned a set of drums near the wall to the right.

Yvonne looked around with interest, and walked to the piano. I followed with a tissue in hand, afraid she might forget to swallow and perhaps ruin her chances of experiencing even one session. Paul was unconcerned. He watched Yvonne's reactions with interest. She stood behind the piano bench and gently scaled down the keys with her right index finger. Standing in a fixed position, she moved her arm, bringing her hand back to the high notes, striking down on each key.

Paul spoke to Yvonne with confidence and interest. Yvonne took an instant liking to him. He sat on the piano bench and played. Yvonne's body became alive with movement and laughter. She even sat beside him, much to my surprise. He continued playing. She played, striking the keys with more vigor. Paul sang. Yvonne hummed and laughed.

Subsequent sessions were equally stimulating. Paul encouraged Yvonne to try other instruments, but the piano was her favourite. Paul expressed delight over Yvonne's sense of rhythm as she struck the keys and moved her body. Was he suggesting she had innate musical talent? I dared to dream the teacher would allow Yvonne to use the piano at school. I wanted so much for Yvonne to develop her ability. Perhaps Paul could attend a meeting at the school.

Yvonne's second year in junior high got off to a fantastic start. She came home smiling, laughing, shaking her small navy gym bag which contained her food containers and the parent-teacher notebook. Her bright eyes expressed, "Open it! Open it!" Eagerly I unzipped the bag. I removed the empty containers and noticed only the notebook. Yvonne watched with breathless anticipation.

"This is what the teacher wrote," and I read aloud: "Yvonne made out very well in her new homeroom. She was there for the opening, lunch and beginning of afternoon sessions. She will need sneakers as her homeroom has gym tomorrow." Yvonne laughed heartily! "Yvonne!" I exclaimed, "You're with the regular Grade 8 students." She laughed all evening.

The next morning Yvonne pushed open the screen door, walked down the front step without help, and ran toward the mini school bus when it stopped in our driveway. To my further amazement, she stepped up before I caught up to her. The driver, familiar with Yvonne, looked surprised and remarked on her achievement. Yvonne, motivated by the excitement of being in a regular class, had, for the first time at fourteen years, done this independently!

Several months into the school year the gym teacher approached me as I arrived to pick Yvonne up for a therapy appointment. "Can I speak with you for a moment?" she asked. I felt the blood drain from my face. Will she say that Yvonne can't be in the class anymore? Bracing myself to hear the worst, I waited.

"I have to be honest," she began. My muscles tightened. She continued with a serious but kind expression, "I have to tell you that when I was first approached about having Yvonne in my class, I was afraid. I didn't know what to expect and I didn't know how I could help her. Now that I've gotten to know Yvonne, I find her a joy in my class." I was speechless. "I don't need the aide from the auxiliary class anymore; several students have volunteered to help Yvonne." My dream for Yvonne was becoming reality! Yvonne was accepted; her peers and teachers included her.

I found myself contemplating the differences in attitude between regular teachers and auxiliary class teachers. After assessing the current situation and our experiences, I concluded that teachers with special education, who have taught in segregated environments, adopted the attitude that they were the experts, they had all the answers. This explained why they resented participation from parents and from specialists or therapists outside their system.

Regular teachers, on the other hand, including the principal, admitted their limited knowledge and welcomed involvement from parents and other resource people. They showed no defensiveness. The segregated system focused on "control." The integrated system operated as a "partnership."

This year Yvonne's education marked the beginning of partnership with the principal and the homeroom, art and gym teachers. This, however, was only a partial partnership because Yvonne still spent most of her time in the auxiliary class. Here, as in the previous year, we had problems.

I didn't know what Yvonne did during class. To assist with the lack of communication regarding Yvonne's program, the director of auxiliary classes suggested I observe Yvonne at a time convenient to the teacher. The observations were useful and informative but also frustrating. On the positive side, I was glad Yvonne carried her own book from the auxiliary class to her homeroom. She sat quietly at her desk alongside thirty students. Occasionally she flipped the pages of her book during Sustained Silent Reading.

Back in the auxiliary class, the teacher-aide helped Yvonne, hand over hand, in printing sentences which the teacher wrote on the chalkboard. Yvonne smiled. Weeks later however Yvonne refused to hold a pencil or marker. Why the change?

I discovered the reason during an observation in art class. The aide kept a tight grip on Yvonne's hand and manipulated it back and forth while looking intently at a dried branch displayed at the front of the class. When Yvonne pulled her hand back, the aide tightened her grip. She didn't look at Yvonne and she didn't explain what they were drawing. She didn't notice Yvonne's grimace of pain. After class I spoke with the art teacher about my observation. "I'm not interested in the artistic abilities of the aide," I explained, "I'm interested in what Yvonne can do, even if she only makes a single independent stroke."

He nodded with understanding. "I purposely hadn't intervened," he said, "because the teacher-aide has special training. I will, however, take a more active role in directing her." Following his intervention, Yvonne again held a marker at home. She independently made long vertical lines, a series of short strokes, and a continuous series of ovals. At a later meeting I showed the art teacher some samples. He was genuinely interested. He showed me a book which deciphered the meanings of various drawings. The next day Yvonne returned home with a photocopied article from his book, with a note, "Feel free to contact me anytime."

On another visit I observed Yvonne during math in the auxiliary class. She was matching numbers one, two and three. She was also matching cardboard picture clocks: 7:00 with 7:00. I didn't know Yvonne could identify numbers.

The teacher-aide brought out an assortment of pictures, and asked Yvonne to match the muffin with the muffin and the car with the car. Yvonne smiled and made the correct match. Soon the auxiliary class teacher suggested to the aide, "Ask Yvonne to choose pictures that belong to a food group."

"That's a good idea!" she replied cheerfully, and laid out a variety of pictures. Just then the bell rang and the aide stopped the activity. It was only midmorning, yet the teacher-aide slouched back in her seat and moaned, "I'm exhausted!" Yvonne, on the other hand, smiled, hyperventilated and picked up the pictures. She wanted to carry on. I was suspicious that, because of my presence, Yvonne got more attention than usual and they likely did not work on these activities regularly.

Yvonne's classes were scheduled into forty-five minute time slots except Functional Skills; this was scheduled for a full afternoon twice a week. I didn't know what they did during Functional Skills and arranged an appointment to observe this class. First the auxiliary class teacher brought out Bingo cards. She called out the numbers and the teacher-aide helped Yvonne place plastic disks over the numbers. Yvonne kept withdrawing her hand and wouldn't focus on the task. When the activity finished, I asked the teacher, "Did I misunderstand? I thought this period was Functional Skills."

Miffed she retorted, "This is Functional Skills!" I raised my eyebrows. She elaborated, "Many parents enjoy Bingo, it's a big part of their life. They look forward to their kids going to Bingo with them." Bingo was not a part of our lifestyle. Her reasoning made no sense in Yvonne's case. Furthermore she did not list this activity on Yvonne's IEP. I didn't argue with her; however, I would address this at a planning meeting.

Following the Bingo activity, the auxiliary class teacher led her students down the hall toward the laundry room. The aide followed, carrying a large green garbage bag. She emptied the contents onto the floor: two bed sheets, pillow slips and a yellow blanket. I watched in disgust. The teacher requested each student to do one step of the laundry. Yvonne's task was to pour, hand over hand, the powdered detergent into the washer. Yvonne pulled back and cried as the powder and the scent drifted into the air.

Earlier I told the teacher that perfumes and detergents bothered Yvonne. Was this the teacher's deliberate attempt to get me to react? I bit my tongue, but I was already planning how to deal with the inappropriateness of doing laundry at school.

The principal soon called a meeting and we discussed Functional Skills. “I do not want Yvonne doing laundry at school,” I said firmly, “nor do I want her to learn to tuck in a bed sheet. These activities are appropriate in the home, not at school.”

The principal shook his head. “I’m confused. What you’re saying is different from what the director of the auxiliary classes is saying. She was talking about increasing functional skills. Yet you don’t want any of that.”

“Functional skills,” I explained, “have to be appropriate to the school environment. In the past, segregated schools focused on teaching laundry skills and personal hygiene.” I told him of a mother who was devastated when teachers at the Murray F. Humes School taught hair-washing as part of the skills program! “Do regular students do laundry or wash their hair at school? I think school is an appropriate place to learn about money. The teacher could teach Yvonne to sort coins; she could then help the secretary by sorting the canteen cash. She could also go to the grocery store and buy food items for the home ec class. They could then prepare and eat the food, thereby working on many skills in a natural way.”

While I was on a roll, I continued, “I would also like Yvonne to learn to use a calculator, typewriter and a computer. The teacher could help Yvonne write a letter to a friend in Newfoundland, or to her grandmothers in Manitoba; then, as part of a field trip Yvonne could go to the post office, buy a stamp and mail her letter. These, in my opinion, are functional skills and are meaningful and reinforcing to Yvonne.”

The auxiliary class teacher immediately shot down the idea of writing a letter. “That’s personal,” she said, “and should be done at home.”

The principal swiftly replied, “Okay, we’ll forget the letter. We’ll focus on learning about money and using the calculator.” After further discussion the meeting adjourned. I had intended to raise my frustration about the inconsistent approach to using Yvonne’s communication system. I realized, however, this was not the time to address it. Eleanor had moved and the new speech therapist who saw Yvonne primarily in the auxiliary class reinforced the teacher’s assessment that Yvonne had little understanding; worse yet, she even doubted Yvonne’s correct responses. I was devastated. Everything we had gained to this point was in danger of being lost. Yet I couldn’t raise my concern because the auxiliary class teacher would have the support of the speech therapist. I was again forced to prove that Yvonne understood.

Lying awake at night I brainstormed, what can I do to make the speech therapist see that Yvonne understands? How can I expand the use of pictures and how can I make them more meaningful for Yvonne?

Over the years I used pictures in different ways. Most recently I used an album. Earlier I mounted a piece of carpet on the wall and attached pictures with velcro. In this way Yvonne could remove the desired picture. Then I made a calendar so Yvonne could anticipate upcoming events. None of these methods, however, were adequate. Yvonne needed pictures she could carry with her and pictures to identify every subject of each day.

I remembered seeing a communication kit, Talking Pictures, but the black and white line drawings were meaningless to Yvonne. However, I liked their idea of each picture being encased in plastic and held together by a metal ring. I got an idea. Swiftly but silently I got out of bed; I couldn't wait until morning. In the darkness I groped in the dresser drawer until I felt the plastic luggage tag. In the kitchen, I cut out a picture of a toilet from the Sears catalogue, glued it onto business card-sized paper and slipped it into the plastic holder. Yvonne could carry this with her, and the picture would be protected.

A food flyer soon lay in shreds as I cut out pictures of fruit, vegetables, cereal and meat. Yvonne could use these to help find the actual item in a grocery store. She could carry in her pocket several plastic-covered pictures on a ring. Maybe she could learn to flip them and find a picture of her choice.

The following day I drove to the airport to buy one hundred luggage tags but they weren't for sale. After explaining why I needed the tags, the attendant donated them. I made up a wide assortment of pictures, including food and utensils used in the home economics class.

Then I discussed my thoughts with the teacher. Characteristically she was not excited. However, she went along with the idea. To my surprise, she said she would find the subject pictures for each day. She would then ask the aide to help Yvonne remove the appropriate picture after each class. Finally Yvonne would know which subjects she had each day.

Later the speech therapist became involved and suggested pinning the subject pictures on the bulletin board in the classroom. Then, when the bell rang, Yvonne would remove the subject picture. This worked well when Yvonne was in the auxiliary class, but not when she went to regular classes because the system wasn't portable. I had to be careful, however, not to be critical; I didn't want to risk losing the cooperation we were developing.

Yvonne enjoyed school and each year looked forward to going back. Each year though she experienced episodes of undue stress. We too lived with constant tension. Repeatedly the teachers forced us to prove that Yvonne understood. We had to be ever cautious in what we said and how we said it. We wanted an open and honest relationship, but this was difficult when teachers were negative or used an authoritative approach. Each year we hoped the next school year would be better, but each year we ended up looking forward to holiday breaks.

We particularly appreciated the spring break. We would get together with other MCC service workers for an annual retreat. Here we could relax, share, reflect, meditate and regain our energy. During our years with MCC we enjoyed experiences that otherwise weren't possible for us. Our lives were enriched by the people we got to know and the places we got to see. The annual retreats took place in either New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland, Labrador or Quebec. Sometimes we could drive but other times we had to fly. We no longer dreaded plane trips as we once had, because we found a solution for Yvonne's crying during takeoff and landing.

As the plane raced down the runway, I popped a raisin into Yvonne's mouth and instructed, "Bite! Bite! That's good. Chew more!" When Yvonne swallowed, I popped another raisin into her mouth with the same instruction. I continued the procedure until we reached a cruising altitude. Constant chewing and swallowing prevented Yvonne's ears from popping and hurting. When the pilot began the descent, I used the same approach with the same success. Yvonne, who once cried uncontrollably in the plane, now enjoyed the experience.

Retreats were memorable, especially the one in Northwest River, Labrador. Among other experiences, Yvonne had a ride in a komatik across the frozen north land and even participated in ice-fishing for smelt. Peter and I had opportunities to interact with the Innu people, and gained a better understanding and appreciation of people from a different culture.

After a five-day retreat we returned home physically, spiritually and mentally energized. We were ready to face the challenges with renewed strength.

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Throughout 1985 Peter and I met families whose children lived at the Dr. William F. Roberts Hospital School in Saint John. We helped them, together with Social Services, develop appropriate plans for their sons and daughters to come back to their home communities. Most parents and staff at the institution, however, opposed the planned closure. The minister of the Department of Social Services, Nancy Clark Teed, nevertheless was committed to keeping children in their communities. Despite fierce opposition, she took a courageous stand fully supported by CAMR-NB and the national CAMR, and the doors of this institution officially closed on November 27, 1985.

Many service plans were good, but some left parents feeling let down and even bitter, because the service system ultimately wielded its power. In one instance, we helped a family who wanted to renovate their home so their son could return. However, while we were on vacation, two social workers visited the family and showed them a video of a group home in British Columbia. The social workers tried to persuade the parents that a group home was a "good place" and they should agree to their new plan.

The mother asked us to help. "We don't want him in a group home, we want him home with us." She talked about the painful day, years ago, when doctors insisted that the Roberts Hospital School was the best place for their son. "He's so unhappy," the mother declared, "he's lost everything we taught him while he lived at home. We love him and want to make it up to him. We can do it if government gives us the support." I agreed to call the social worker.

"The government," said the social worker, "is not prepared to cover the cost of renovations to their home." After months of planning and positive responses, this news was devastating. I knew that government paid for extensive home renovations for foster families and so I challenged the social worker. Calmly she replied, "We don't think that this family can manage, even with support."

Flabbergasted by the abrupt change in attitude, I asked for an explanation. "We don't think the family is interested in their son," she said flatly. "The files show they stopped visiting him at the Roberts Hospital School."

"Just a minute!" I snapped back. "Do you know why the family quit visiting him? The staff had requested the family not to visit because he got upset each time they left. They told the parents it took days to calm him down after each visit and that it was better for him if they didn't come at all. Now, Social Services is holding this against them!"

Unfortunately, this wasn't an isolated incident. We knew other families who after contacting a lawyer to access their children's files at the institution, discovered the same accusation: "Parents were not interested. Parents quit visiting." The files didn't mention the gifts nor the clothes which the parents sent to the institution regularly. These parents sadly remarked to us, "We had assumed they got them, now we wonder."

Working with this family brought several facts to light. Social workers had powers that could be used to either help a family or, as in this case, rule against a family. Because of the social worker's recommendation, the son didn't return home. Furthermore, this social worker was involved in developing plans for a group home in another community, and this family's son became the required fourth occupant.

Parents have shown time after time that they want to be responsible for their son or daughter. They can't do it alone, however, nor should they. Government and the community at large need to share this responsibility fairly.

Following the closure of the children's institution in New Brunswick, the Newfoundland government became more serious about closing Exon House, the remaining children's institution in St. John's. Social Services, in discussion with the national CAMR and CAMR Newfoundland and Labrador Division, agreed to work jointly to return the residents from Exon House to their home communities. CAMR then approached MCC about getting service workers for this project.

MCC asked if Peter and I were interested. How could we turn down such an opportunity? "This is ironic," I said to Peter. "Exon House, the institution where a psychiatrist once pressured us to admit Yvonne. Now they're asking us to help bring residents out."

I then recalled the psychiatrist's comment, "I don't want you to become professional parents." Little did he realize that the lack of support unwittingly drove us to be just that.

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We made plans to move back to Newfoundland. We decided to keep our house, however. Teresa would stay and continue her studies at UNB. Chris and Carol Bayly, a young couple from UNB whom Teresa knew through our church, would rent the main floor.

Our friends, Bob and Eeva, hearing about our plans to return to St. John's, offered to rent their house; they had just moved into a newly built home. We told

Chris Campbell, the MCC director in Newfoundland and Labrador, who ultimately made the housing arrangement.

We had many questions on the personal level. How would Yvonne react to moving back to St. John's and adjust to living in Bob and Eeva's house? How would she react to most of our belongings staying in Fredericton? More importantly, how would she react when she realized that Teresa wouldn't be coming with us? And how would she react to going to school in St. John's?

Carefully I explained everything to Yvonne. She listened and studied my face. She seemed to accept what I was telling her, including my firm assertion, "Yvonne, you will not go to the Developmental Centre. You will go to a regular school, to regular classes!"

Chapter 14

The Association for Community Living

"Welcome home!" boomed a Newfoundland friend, and we did indeed feel that we were home again. Much had changed, however, during our three-year absence. In October 1985 the national CAMR changed its name to the Canadian Association for Community Living (CACL), to more appropriately reflect the principles of normalization. Provincial and local associations followed suit. May 3, 1986, the Newfoundland provincial association became the Newfoundland Association for Community Living (NACL).

The People First organization, whose members were labelled "mentally handicapped," had pressured CAMR to change its name. They didn't want a stigmatizing term, and they didn't want CAMR promoting themselves as an advocacy association for the mentally retarded. Others, also favouring integration, lobbied for the name change, while those supporting segregation lobbied and voted against it. Their main argument was that the new name did not identify the clientele and people in the community would not understand who the association represented. Those favouring integration reasoned that the new name reflected the vision of having people with disabilities living and participating in the community.

For years we noticed that Yvonne accepted hearing "CAMR," but became upset at the word "retarded." This sounded harsh and suggested, "can't, unable, doesn't, won't ever." Did Yvonne sense this as well? We struck this word from our vocabulary, yet were dismayed that we had to use it in our involvement with the association.

At this time the National Institute on Mental Retardation (NIMR) also changed its name—to the G. Allan Roeher Institute. Dr. Roeher, a strong advocate for community living died in 1983 in an airplane fire while returning to Toronto from the United States where he promoted his vision of community living for people with disabilities.

The Newfoundland Association for Community Living hired Joe Cawthorpe as part-time executive director. Bill Duggan, coordinator of the Atlantic Training Institute, a subsidiary organization created by NACL, worked in the same office. He was responsible for teaching the nine-month training program in community-based services. Pauline Steinmann, an MCC service worker, shared the office space and coordinated the newly developed Citizen Advocacy program. Moya (Walsh) Clarke, the faithful, efficient secretary and office manager, rearranged the office to accommodate two extra people.

This time our two-year assignment with MCC had a different focus. Besides working with NACL to develop plans to bring residents out of Exon House, Peter and I were responsible for administering the MCC programs in Newfoundland. We met with various agencies, became familiar with the existing MCC projects, and discussed the development of new ones.

Most of the first year, however, was devoted to Yvonne's education. When we arrived in St. John's on August 15, 1986, Joe said seriously, "If you don't accomplish anything else except to get Yvonne integrated, I want you to know that your assignment here was a success."

"Joe! That's not why we came here!" Then, softening my approach I said, "Of course we'll work to get Yvonne integrated, but you know our primary purpose for coming back."

"I'm serious," he said, and repeated emphatically, "even if you don't get anyone out of Exon House, but if you get Yvonne integrated, your assignment will have been successful because you'll have opened up doors for others."

After he left the room I stormed defiantly, "Why would he say even if we don't get anyone out of Exon House? That was why we came here and that's what we intend to do!" Joe, however, was right. That first year, NACL was unable to be directly involved with plans around individuals living in Exon House. Bringing people out of the institution was a highly political issue, and they gave NACL one reason after another for the delay in contacting families. While we waited for the go-ahead, we became submerged in the education system.

I called the Integrated school board regarding Yvonne's placement immediately upon our arrival in August. Earlier in February, I wrote Bill who contacted the three school boards in St. John's on our behalf. I had sent copies of Yvonne's educational program from Fredericton, her report cards, and letters from both the principal and the teacher. In our letter we stated our goals for Yvonne: 1) to develop an appropriate communication system, 2) to build social relationships with non-handicapped peers, and 3) to develop the use of her left hand.

Although we wanted Yvonne to use her left hand, we realized that she might never dress independently nor take care of her personal hygiene. This was no longer important. Since we met Judith Snow at a national conference and heard about her experiences, we gained a different perspective on the meaning of "quality of life."

Judith had described her life, receiving total care in an institution. She fought with the help of friends to get out and obtain the necessary supports to live in the community. Judith could speak and had partial use of her right hand, enough to control her electric wheelchair. Other than that, she was dependent on others for her basic needs. Life in the institution had no meaning for her, but now in the community, surrounded by a group of friends, that gave true meaning to her life.

In spite of her physical limitations Judith had intellectual abilities and had gained a master's degree from a Canadian university. Although we did not expect Yvonne to achieve high academic learning, Peter often told Yvonne that someday she would be a writer and tell her own story, and I told her, "Someday you'll make it into the movies, you're such a character with your many expressions." At these comments, Yvonne's eyes brightened and she burst into exuberant laughter. Although we fantasized about her "career," we did not fantasize about the importance of developing friendships. After all, friendship and companionship are crucial for a quality of life. How and where are friendships developed?

Children develop friendships at school where they spend most of their day. Since Yvonne was fifteen years old, it made sense for her to attend a junior high school. Of course she needed support, but in our view it could be provided in a regular class. In our letter to Bill we had stated, “We are prepared for Yvonne to pilot a program in a regular class if necessary, and we’ll do all we can to help.”

Bill had spoken with the special education coordinator and the deputy superintendent of the Integrated school board. He received a verbal commitment from both to try our suggestion of a pilot approach if the principal and staff agreed. Our hope, however, to have Yvonne attend Macdonald Drive Junior High, where she would know Krista and Joanne who lived in the neighbourhood where we once lived, was not an option. Instead, the school board recommended Macpherson Junior High.

In mid-August we learned that Ginna’s son had graduated from Macpherson in June and the staff were receptive and supportive. I remembered how Ginna had paved the way in the past. Now her son, who required only minimal support, influenced attitudes enabling Yvonne to attend Macpherson Junior High.

To our dismay, however, a week before the opening of school, the school board informed us they had no funds to provide individual support to Yvonne in a regular class. They told us they allocated funds for special education to TMH classes (Trainable Mentally Handicapped).

I requested a meeting with the assistant superintendent responsible for special education. I explained, “In Fredericton, Yvonne was home-based in a regular class and participated in several regular courses. Yvonne’s learning and behaviour improved. Students volunteered to help her. When Yvonne becomes familiar with her environment and develops some friendships, she might not need a full-time teacher-aide.”

The assistant superintendent tapped a pencil on his desk and told us point-blank, “You will not get any resources at Macpherson.” His tone suggested he would see to it! His comment and attitude astonished us.

We soon discovered that people at the school board were trying to weasel out of the verbal agreement. Sadly, negative attitudes toward integration, which the influential director of special education fostered more than three years ago, were still thriving. Nevertheless, in my mind Yvonne was going to Macpherson. They gave Bill a verbal commitment, and with the support of NACL, we would hold the school board to it.

Joe, Bill, Peter and I discussed strategies. We placed many phone calls and held meetings with the school board and the Department of Social Services. In the end, NACL provided the one-on-one support for Yvonne. Bill arranged for a student from the Atlantic Training Institute to be the aide. The student would benefit from the intensive practical experience, which incidentally formed a major part of the training course. This, however, meant disruption to Yvonne's schedule when the student had to attend classes herself. Realizing this, Bill arranged for a former student from the course to provide backup support. The Department of Social Services agreed to cover this cost.

Bill introduced us to the student: Karen Seward. She was a top student in his class but still I was anxious. What if she and Yvonne didn't hit it off? I worried for nothing. Karen was youthful, bubbly and excited about her role. Yvonne smiled and her face glowed when we explained that Karen would help her in a regular class at Macpherson.

I called the board office about visiting the school, but I couldn't reach the assistant superintendent nor the special education coordinator. Finally I called the principal of Macpherson. "I was hoping Yvonne could have an orientation before school starts." The principal asked us to wait; he wanted the special education coordinator to be present.

Tuesday, the day before school began, I finally reached the special education coordinator at 8:30 in the morning. "I'm going to a meeting," she said hastily, "I'll call you back. But first, I need to know the exact location of your house on Thorburn Road." I told her, assuming it related to transportation for Yvonne. However, someone had questioned whether we lived in the right zone for Yvonne to attend Macpherson.

I was furious at these last minute delaying tactics, but managed to remain civil and answered the coordinator's questions. She replied softly, "I now know precisely where you live. Yvonne is zoned for Macpherson. I'll have to call you back."

I kept the phone line clear. Finally, at 3:00 the coordinator called. "The assistant superintendent would like you to come to the board office."

"What? We've waited all day to set a time to visit the school and we've told Yvonne this! It'll upset her if we now bring her to the board office!"

The coordinator said casually, "Although Yvonne is zoned for Macpherson, we have other programs. I.J. Samson School has classes for the handicapped, there is no backup at Macpherson."

"We were told," I fired back, "by the deputy superintendent and yourself that Yvonne would be attending Macpherson, and we've had a support person since 9:00 this morning waiting to visit the school!"

"You have a support person?" she asked surprised. "I'll have to call you back."

She called back within minutes. Again she acknowledged, "Yvonne is zoned for Macpherson. The assistant superintendent is calling Macpherson right now to register her. We still want to meet with you. Would tomorrow at 1:45 be all right?"

"Yes," I said coolly, "that'll be fine."

The next morning Peter and I drove Yvonne to Macpherson Junior High. We met Karen at the front door. The four of us walked into an unfamiliar building. This was not how I had envisioned Yvonne's first day at a new school! Students crowded the office. We added to the confusion. The staff, however, was friendly and soon assigned Yvonne to a Grade 8 class. Peter and I left, leaving the responsibility entirely with Karen. We could only hope that the one-and-a-half days of interaction and instruction regarding Yvonne's routine were enough to help Karen.

At the NACL office we organized our workspace. Then we left for the meeting at the school board office. We expected to discuss the curriculum. Instead the assistant superintendent said, "Yvonne is not zoned for Macpherson. We made an error yesterday." Slowly I released my inhaled breath and concentrated to contain my anger. He, on the other hand, continued nonchalantly, "Yvonne should attend I.J.Samson Junior High. They have been working on integration for three years."

Peter interrupted, "Is Yvonne zoned for I.J.Samson?"

"No," he replied, "Yvonne is zoned for Bishop Abraham but I wouldn't put her there."

"Why not?"

He wouldn't say. He insisted we visit I.J.Samson Junior High. We knew this school had several segregated classes and little integration. This would be a backward step for Yvonne. We told him we could not accept it.

We had a long discussion. Authoritatively he said, “We will do an assessment, with your permission, and the assessment will show the most appropriate program for Yvonne is at I.J.Samson. To change that, you will have to appeal to the board.”

I felt angry and sad that he didn’t understand what this would do to Yvonne. I wrote down what he said. He didn’t seem to care; he was so sure of himself.

Calmly Peter said, “We will agree to an assessment if the purpose is to develop an appropriate program but not if it’s to determine placement.”

We would not sign the form to give permission for an assessment until the placement was secure. Knowing that Yvonne was not zoned for I.J.Samson, we went along with the charade to visit this school. We would ask questions and observe everything as I had done at Pine Grove years earlier.

We left the meeting in silence. “I will keep detailed notes on each meeting and each phone call. If there needs to be an appeal we will be prepared.” My determination was mixed with feelings of frustration. Why do parents have to go through such needless hassles and stress? Why is the administration bent on denying Yvonne this opportunity for integration?

We drove to Macpherson School and waited nervously on the crowded parking lot, unsure of what to expect at the end of Yvonne’s first day. Soon the bell rang and students thronged out of the building. We spotted Karen and Yvonne among them. Yvonne was smiling! Peter and I sighed with relief. Jumping out of the car we exclaimed, “Yvonne! How was your first day at school?” Yvonne breathed heavily and smiled, and Karen filled us in.

Karen was as energetic at the end of the day as she had been at the start. Excitedly she said, “Yvonne met two friends, Annette and Jennifer, who knew her before you went to New Brunswick.” Karen also told us, with some concern, “Yvonne scratched her upper back most of the day and ate very little of her lunch.”

This did not surprise us. These were symptoms of stress. We were thankful it wasn’t worse. Yvonne could have cried or hit herself, and that could have been reason enough for the school board to remove her. We were proud of Yvonne and of Karen who helped Yvonne handle this uncertain and stressful day. This day was a turning point in Yvonne’s life. Never again would she be in a segregated class.

That’s not to say that we didn’t have ongoing struggles. Even while Yvonne was registered at Macpherson and attended classes with Karen’s support, we and the assistant superintendent continued our intensive tug-of-war. The school board administration was just as determined to remove Yvonne from Macpherson as we were to have her stay.

The principal was caught in the middle. He spoke with us daily and was open and honest. “I have to tell you that administratively I would not ask to have Yvonne. Nevertheless, if the school board asks me to take Yvonne, the school will do everything it can.” That statement was sufficient for us. We increased the pressure on the school board to live up to its commitment.

Until they settled the placement issue, however, the school couldn’t plan the curriculum. Therefore it was up to us to give Karen as much practical help as possible. We advised her to teach Yvonne to remain seated and listen quietly while the teacher was speaking. Later, when the students did their desk work, we suggested Karen help Yvonne do something related to that subject. We met daily after school and discussed the day and the subjects.

For math class, we sent in duplicate numbers, one to four. Karen could teach Yvonne to identify the numbers, match them, and enter them on her calculator. For English class we sent in the words YES and NO; we hoped Yvonne could learn to distinguish them. Someday, we dreamed, she might even answer questions related to the topics discussed in class. We now disregarded the advice of the former New Brunswick speech therapist who suggested not using words; she had claimed that mixing words and pictures would be confusing to Yvonne.

In social studies, students were learning about agriculture in Australia. I sent in pictures related to the topic plus scissors, glue and a notebook. Karen then helped Yvonne work on the same assignment by using pictures.

Despite the underlying stress Yvonne was happier, more confident and more communicative. To our surprise, Karen claimed that Yvonne pointed to the words YES and NO appropriately, only two days after introducing them. I was skeptical. Karen nevertheless was adamant, not only about this but about Yvonne’s overall understanding.

“During science class the teacher told a joke,” she said, “and Yvonne was the first to laugh! The kids were amazed that she understood. Later the teacher told the students they could pick their own lab partners, and Shelly asked if Yvonne could be her partner.”

Karen's enthusiasm and her belief in Yvonne were key factors in the initial success at the school. By the end of the first week, Yvonne was entrenched in life at Macpherson. Still we had meetings, made phone calls and wrote letters regarding her placement. To speed up the process we hand delivered our letters to the board office and school, and volunteered to deliver theirs.

Finally, on September 29, in a three-page letter, the assistant superintendent wrote, "After considering these letters and after discussions with the principal we are now prepared to continue Yvonne's placement at Macpherson and begin to develop a program that is more meaningful than what she is presently receiving." Finally we could spend our time constructively and concentrate on developing Yvonne's educational program.

The Newfoundland Association for Community Living again helped us. They arranged to use Emerson Coish from Labrador to help develop a program for Yvonne. The school board had already brought the Coishs to St. John's to provide training for special education teachers.

Even so, the school board still insisted that their educational psychologist assess Yvonne. Since this was to set specific objectives for Yvonne's overall educational plan, we gave permission. The school board also requested that we take Yvonne to a medical doctor at the Children's Rehabilitation Centre to get referrals for physiotherapy and occupational therapy at the school. As well, they requested a communication assessment by Jane Green through the Diagnostic and Remedial Unit at Memorial University.

We followed through on these assessments. Peter and I attended all planning meetings at the school. We discussed the course content, and modifications or special equipment necessary for Yvonne, with the principal, each subject teacher and the appropriate therapists. Peter volunteered to design the individual education plan (IEP) forms. We wanted to limit the demands on the teachers, as the individual planning process was a new experience for the school.

Initially all teachers had questions, concerns, doubts and even fears about Yvonne's participation in their classes. The home economics teacher worried that Yvonne might burn herself in the cooking class. I told her, "Yvonne's favourite room at home is the kitchen." I explained how I involved Yvonne with food preparations. "Yvonne is cautious and never burns herself. Once though, in the auxiliary class a year ago, Yvonne received a serious burn on the back of her left hand. The teacher-aide claimed Yvonne placed her hand under the scalding water.

However, anyone who knows Yvonne knows that bringing her left hand under the tap is difficult, and even then she will pull back at the slightest increase in water temperature." We acknowledged that accidents happen. We only expect that Yvonne get the same medical treatment as anyone else.

Hearing this, the home economics teacher was reassured and accepted Yvonne in her class. Before long, this teacher came up with adaptations and even gave suggestions which were helpful at home.

This teacher taught sewing in the second semester. She talked about Yvonne using a machine with Karen's help. This time I was apprehensive. Yet I wanted Yvonne to participate. The students were making gym bags from denim; I knew Yvonne would be proud to have one like the rest of them. I had to trust Karen's judgment as she assisted Yvonne. Later Karen told me how several students wanted to help Yvonne pin and cut the fabric. My heart raced! Still, I realized I had to allow Yvonne to take risks with others in charge. Such experiences provided scope not only for Yvonne, but also for those with her.

Yvonne enjoyed all her classes. At home I worked with her on assignments. We looked through the National Geographic, bought at a secondhand bookstore for pictures appropriate for social studies, art and home economics. Yvonne made a poster depicting "A Good School Lunch" for home economics. I found pictures of foods typical of her lunch at school. Hand over hand, I helped her cut out pictures of a sandwich, muffin, crackers, cheese, raisins, grapes and orange juice. "Yvonne," I said, "point to where you want it on the poster." I then helped her apply the glue and place it on the spot. It was important that Yvonne realize this was her work and she too would pass in an assignment.

The English teacher came up with the idea of "thought webs." He instructed Karen to ask Yvonne to point to all the pictures which make her think of a certain word or topic, and to number the pictures as Yvonne chose them. The word "party" was selected for the first thought web. When Yvonne arrived home from school, I eagerly looked into her English notebook. I could hardly believe the pictures that she had chosen: cheese and crackers, chips, hamburger, presents, people, music, camera, earrings, balloons, chocolates and nuts.

This impressed the teacher too. He then suggested to Karen to list the pictures which Yvonne did not choose. The next thought web was "school." For this topic Yvonne chose notebook, boy and girl, sewing machine, computer, pencil, calculator, Pierre Trudeau (representing a male teacher?), correction fluid, guitar, crayons, book, volleyball, library, people, glue, scotch tape and basketball. She did not choose barbecue, camera, skiing, kettle, tent, sleeping bag and picture frame. Again, we were amazed at Yvonne's comprehension.

Yvonne particularly enjoyed math class. Numbers fascinated her. During that first year she identified numbers one to ten. She learned to transfer number recognition to her surrounding environment. At the airport she heard flight numbers and gate numbers, and laughed loudly. Numbers now had a meaning. She even chose to use the elevator over the stairs because she wanted to push a button with a number on it. In church, numbers referred to a specific song in the hymnbook. Yvonne realized that numbers were everywhere!

We soon bought a digital clock for Yvonne's bedroom. She often awoke at night and now I could explain, "Yvonne, it's only 3:10. You have to sleep more. Look, three o'clock. Then comes four, then five, then six, then seven. At seven o'clock you get up." She laughed and looked at her illuminated clock. Smiling, she put her head down and went back to sleep. Understanding time, and seeing the numbers was reassuring to her.

Yvonne's participation at Macpherson was a life-changing experience for her. She was responsive and alive with excitement. She was physically healthy, and her digestive system worked well. She no longer required antacids for an upset stomach and her earlier problems with constipation disappeared.

One day Karen told us about the upcoming school dance. Yvonne listened but looked serious and puzzled. "Yvonne," I explained, "a dance is like the sock-hop —" Her face brightened; she understood. I looked back at Karen, silently asking if she would take Yvonne.

Karen exploded, "Of course I'm taking Yvonne to the dance. I wouldn't miss that for anything!"

Anticipating the event was as exciting as the dance itself. A few days before the dance Karen laughed, "You should have seen Yvonne. During lunch the girls were all talking about what they would wear to the dance and about boys, make-up, and jewelery. They included Yvonne in their conversation. Yvonne was sitting at her desk, surrounded by her friends. She was smiling and laughing. I just stood on the sidelines and watched. It was like watching a scene in the movies!"

Karen had a gift of understanding just when to help Yvonne and when to back off and let Yvonne be with her peers. Later Karen wrote an article where intuitively she expressed, “Yvonne needed friends who were experiencing the joys and pains of growing up. She needed positive role models.” Karen’s understanding approach helped Yvonne gain confidence and built up her self-esteem.

Yvonne looked charming on her first night out without Mom and Dad. She wore black pants, and a long-sleeved white blouse with a black and fuchsia vest; this was topped with a single long string of fuchsia beads with matching clip-on earrings. Because the other girls wore nail polish, Karen claimed Yvonne should as well. With painted fingernails to match her outfit, Yvonne raised her hand to eye level, waved her hand vigorously in front of her face and laughed. We drove Yvonne to school and met Karen at the front door.

Later in the evening, we drove back to school to pick up Yvonne and Karen. Waiting on the parking lot, we were apprehensive. Soon Yvonne and Karen emerged. Yvonne looked tired but happy.

Karen, bubbling with excitement, told us about the evening. “The music was deafening but Yvonne laughed, especially when she heard Bruce Springsteen and Corey Hart. Those are her favourite tapes during gym class. And then a boy came up and danced with Yvonne!” Karen was excited for Yvonne and delighted in sharing every positive experience.

Chapter 15

Integrated at Last

“I now see Yvonne walking down the hall with her head up, smiling!” the principal said proudly. He was pleased that Macpherson School helped make a difference in Yvonne. He took a growing interest in her and spoke to her daily.

The principal participated in all planning meetings and before long, he and Peter, having the same computer programs, discussed and worked together on the format of Yvonne’s IEP. The team approach of home and school working together without a power struggle was something we always dreamed about. Soon the principal acknowledged, “The school is ready and prepared to assume full responsibility for Yvonne’s educational plan as it does for any other student.”

Before long, we heard from various sources that the principal was publicly promoting integration based on the experience in his school. This was gratifying for us and the many families across the province who had the same vision but faced obstacles. Joe had been right when he said, "Success in integrating Yvonne will open up doors for others."

The Association for Community Living was delighted that Yvonne was integrated. They cautioned us, however, that integration was "fragile." A breakdown of support or a lack of commitment on anyone's part could create a major setback for integration. They told us to stay involved and publicize the benefits to Yvonne and the regular students.

The story about John has particular significance. He was "bully of the class" and often found himself expelled because of his behaviour. As an April Fool joke, he covered the teacher's chair with chalk dust. The teacher noticed, however, and waited until he left the room, then switched her chair with his. When John returned and was about to sit, the teacher called out to him, yet it was too late. He sat. The class laughed hysterically; the joke was on John. Yvonne, however, cried. Throughout the day when students or staff retold this incident, Yvonne cried; she was sensitive to people laughing at others.

The following day, when we dropped Yvonne off at school where Karen waited, a tall, broad-shouldered guy stepped up to Yvonne. He helped her at her elbow. She looked up at him and smiled. Together they walked up the steps. Karen looked at us, shrugged her shoulders and followed them. Our curiosity had to wait until the end of the day.

"Who was that this morning?" I asked when we arrived at school.

"That was John," Karen replied.

"John, the guy with the April Fool joke?" Smiling, she nodded.

In the days that followed, Karen told us how John was helping Yvonne. "You know," she said, "the kids in the class have even commented he is less of a bully."

"You'll never guess what happened today!" Karen exclaimed a week later. "We were in the health room watching this movie when there was a loud rap on the door. The teacher went out and came back in; there was a lot of commotion. They couldn't find John. A month ago they expelled him from all health classes for the rest of the year because of his behaviour but he wasn't where he was supposed to be. It turned out," Karen chuckled, "he was in the health room all along. He was so quiet the teacher didn't know he was there!"

Success stories were important and the Canadian Association for Community Living asked Karen to write an article for entourage, a national publication, about her role as integration facilitator. Her article appeared in the Summer 1987 issue. The cover featured Yvonne smiling and interacting with another student. The headline proclaimed, "Success with Integration in Newfoundland."

In her article, Karen relayed several vignettes. "Jeff used Yvonne's cards to ask if he could share her markers. She pointed to YES. Jeff then pointed to her word 'Thank you.' Yvonne laughed loudly. She was happy that somebody was using her communication system." In another, Karen wrote, "During lunch Trevor said he always thought that people like Yvonne were different and couldn't learn anything. He has since changed his mind. He said she is just like everyone else and she's cool."

Peter and I submitted a companion article from a parent's perspective. Both the provincial and national Associations for Community Living advised us to publicize the success and to give credit to the school board. "Give credit to the school board?" I asked incredulously. "That would be hypocritical!"

We were told, "No matter what has taken place, in the end the school board did the right thing and that's what counts. Besides, the more positive publicity given to them, the more likely they will integrate other children. How can a school board say 'no' to other families when the integration of Yvonne was successful?"

We understood the politics involved. Yet, disliking such politics, we chose our words carefully. We commended the school board for taking the courageous step of total integration and not falling into the "readiness" trap. "Children are always ready," we wrote, "they just need the appropriate supports." We emphasized this point because many educators claimed a child needs to be "ready" for integration. We always argued against this misconception. If a child with a disability lives with a family and participates in community activities, is that not integration? It only follows that the child should have equal access to the neighbourhood school. Further in our article, we stated, "that while the school board played the major role in getting Yvonne into school, the credit for making it a success belongs to Karen, the principal, the teachers and the students at Macpherson."

For political reasons, we gave only fleeting credit to the Association for Community Living. Yet Yvonne experienced integration only because of the steadfast commitment and support from people with the provincial, national and local associations. The Association for Community Living had supported Yvonne, not only for her sake, but also to prove to educators they could integrate students with very challenging needs. Educators could not dispute this success.

Although we saw that integration was better for Yvonne, we realized that Yvonne herself, through her school photographs, best described her educational experiences. We made slides from her school pictures from Macpherson and the two previous years, and used them in our presentations at provincial and national ACL conferences. Later we showed these slides at an international symposium hosted by the Canadian Rett Syndrome Association in Toronto in May 1988, where we participated on the education panel.

Yvonne did not usually attend conferences with us, but we made an exception for the Rett Syndrome conference. We thought meeting Yvonne might give encouragement to other parents. Because the discovery of Rett Syndrome in North America was recent, and since Yvonne was one of the oldest girls diagnosed with Rett Syndrome living at home, her presence might dispel the earlier gloomy prognosis.

Many other parents also brought their girls to this conference, some with the hope of meeting personally with Dr. Andreas Rett. Yvonne sat through most of the presentations. Once we made a hasty exit after she cried out; a speaker had used the word "retarded." In the foyer I explained the context in which the speaker used the term. Yvonne looked at me skeptically. Finally I persuaded her to return to the conference room. Her hard hand-flicking told me she was still uneasy.

Later, while Peter and I spoke on the education panel, a helper took Yvonne outdoors. We didn't tell Yvonne that we were speaking, fearing she'd get upset. We realized Yvonne became tense when we talked about her and we needed to respect her feelings. Nevertheless, we wanted to share what she was experiencing.

Our presentation differed from the others. We focused on the child's perspective, not the clinician or educator's view. The three pictures of Yvonne provided a vivid perspective. I explained the circumstances of each picture and interpreted Yvonne's feelings. In the first slide from 1984-85, in an auxiliary class Yvonne was totally segregated. Her expression looked painful. She could be pleading, "Please believe in me!" In the second slide of 1985-86, Yvonne was integrated in some classes. Her set jaw, tightly clenched hand and downward look suggested a combination of frustration and determination. She could be saying, “I want to be fully integrated!” In the third slide of 1986-87, Yvonne was in a regular Grade 8 class at Macpherson. Her bright eyes and dimpled smile tell the story.

Someone from the audience asked, “Is it fair to use two ordinary pictures with a posed picture to promote integration, just because you believe in integration?”

“I’m glad you asked,” I responded, “because it gives me another opportunity to emphasize that these are school pictures. We weren’t involved. In the third slide, where Yvonne is looking up and smiling, it was Kelly, a classmate and friend of Yvonne, who got her to look up at the camera. This picture tells us how Yvonne feels about integration.”

I also focused on the importance of developing an appropriate communication system and described our experiences. In St. John’s we had the valuable assistance of Jane Green, an augmentative communication consultant at Memorial University, who helped us develop a communication system that worked for Yvonne.

Jane taught Bliss Symbols and wanted to use this system with Yvonne, but we expressed our concern that symbols would be too abstract; Yvonne had more success with pictures. Jane respected our assessment and declared, “If pictures work for Yvonne, then let’s not change it. We’ll stick with pictures, but maybe we could use symbols for concepts that are hard to portray.” This made sense, and together we developed a communication board using pictures, symbols and a few words.

Then we had to figure out how Yvonne could carry the board. Jane brought a purse designed by a student for a young child which, unfolded, displayed an assortment of symbols. Using this idea, I made a purse from denim that from the outside was age-appropriate. Unfolded it displayed Yvonne’s communication board. On the front I sewed a flap with a velcro closure. Yvonne could open the flap and point to her YES and NO words even while she wore the purse hanging from a strap over her shoulder. The back of the purse had a pocket for her comb, tissue, and “menu” and “activity” booklets.

We developed Yvonne’s menu booklet after an incident on vacation. It was a hot day and we stopped for an ice-cream cone. Thirty-two flavors peered at us through the glass case. We called them out to Yvonne and watched for her reaction. She seemed indifferent. We played it safe and bought her vanilla. I held it to her mouth.

She licked, then turned aside. Thinking she felt slighted at having a plain cone, I said, “Here, Yvonne. Try mine. It’s chocolate fudge.” Again she turned away.

“Yvonne! You’ll like mine,” Teresa held her cone toward Yvonne. “It’s Heavenly Hash.” Yvonne turned aside.

How could she not like ice cream? This was not the first time that among the three of us, we ate four cones. I remarked, “Maybe Yvonne doesn’t like ice cream. Maybe she’d rather have a hamburger.” Instantly Yvonne turned toward me and smiled. “Yvonne, do you want a hamburger?” Her expression left no doubt.

Clearly, Yvonne needed a method to make choices. I bought a business card holder to make a “menu” booklet. Expanding on my earlier idea I took food pictures and organized them beginning with beverages and snack foods, to breakfast, lunch and supper meals, and desserts.

I also made an “activity” booklet with pictures of a shopping cart, swing, car, park, picnic table, swimming pool, chord organ, book and so on. The idea was for Yvonne to choose what she wanted to do.

Realizing that pictures and people were important to Yvonne, I bought ten mini albums and placed pictures of friends and relatives from across Canada into the appropriate albums according to the province. On the covers I glued a map of each province. These “people” albums had a threefold purpose. When people moved to another province, I changed their pictures accordingly and explained it to Yvonne. This helped her realize we weren’t the only ones who moved and moving was often a natural part of life. Selected albums came with us on our trips; this helped Yvonne understand who we were visiting. The maps helped her learn about the geography of our country and where the people lived.

Communicating with Yvonne is as crucial for her as for anyone. We hoped that by sharing these experiences at the Rett Syndrome conference, parents might get ideas to develop a communication system that would work for their daughters. We were not presenting a blueprint but were showing what was possible. “A communication system,” I stressed, “needs to be developed according to the need of the individual.”

On the final evening of the conference, Yvonne, dressed in black pants, a soft green blouse and wearing her new cream-coloured communication purse, accompanied us to the closing banquet. Sitting at a round table for eight near the head table with a place card announcing “Yvonne Penner,” Yvonne looked proud.

The formal atmosphere brought out her best manners and she left an impression on several parents of younger girls. They voiced their pleasure at having met her and told us she was an encouragement to them.

As we waited for the food to be served, I buttered a roll for Yvonne and broke it into a few small pieces. Yvonne took a bite and laid the rest on her plate. So normal. I smiled, remembering the grey-haired committee member who, several years earlier, was aghast that we took Yvonne to McDonald's. Would she believe this scene if she saw it?

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The June 1987 year-end planning meeting was a memorable one. I had anticipated a positive meeting and took my camera as I wanted to remember the people who believed in Yvonne and worked as a team to increase her participation at Macpherson Junior High. Yvonne sat with us. She flicked her purse, and a pile of papers within her reach. For the most part, she looked down and appeared not to be listening. The principal asked each teacher to briefly summarize Yvonne's involvement in their class and give recommendations for improvement for next year.

Yvonne's sudden burst of laughter following one teacher's comment was evidence that she was listening intently and understood. The teachers' laughter then rippled along the table. Yvonne smirked. She knew they in turn had understood. Planning meetings had become fun and we no longer kept them secret from Yvonne. We now gave her a choice of attending or going to a friend's home. Most often she chose to attend. She wanted to know what we were saying about her and what was being planning.

The group, consisting of the principal, teachers, therapists, the social worker and the school board special education coordinator, unanimously agreed that in September Yvonne should go with her classmates into a Grade 9 class, with the support of a full-time teacher-aide. Everyone also agreed they should hire Karen to provide continuity of support.

This was a problem, however; Karen didn't qualify under the present system of employing teacher-aides. Every school which needed an aide submitted a request to the school board. The school board then passed on this request with a priority listing from among all the schools in the district to the Department of Education. The Department of Social Services then provided the Department of Education a number of allocations for hiring teacher-aides through the Employment

Opportunities Program. In short, eligibility for employment was determined not by the Department of Education, but by the Department of Social Services to reduce the number of people on social assistance. The duration of employment, was restricted to forty weeks.

Parents objected to this method of hiring teacher-aides. In 1980 the Parents for Developmental Progress, whose children attended the Developmental Centre, stressed the importance of continuity of staff. At that time they hired teacher-aides for only a twenty-week period (after which they qualified for unemployment insurance). The children, having just begun to feel comfortable and secure with an aide, were forced to adapt to a new aide halfway through the school year. The following year, however, they hired teacher-aides for the full school year.

Still parents were dissatisfied and advocated for more permanence. They contended that children needed security and yearly staff changes often resulted in developmental setbacks. Eventually the Division of Special Services hired teacher-aides annually but only for the Developmental Centre. Teacher-aides in regular schools were still hired through the Employment Opportunities Program for up to forty weeks. The following year they were ineligible for employment because they were then on unemployment insurance, not social assistance.

"How can we keep Karen on?" the principal asked insistently.

The special education coordinator quietly replied, "Unfortunately the school board has no mechanism to hire Karen." She motioned to the social worker, "Can you do anything?"

The social worker sighed. "I don't like the present system either, but it's in Yvonne's best interest for Karen to return next year. We have to come up with something." All eyes focused on her expectantly. "I could make a case to get funding through the Special Child Welfare Allowance Program but I'm going to need your help."

"What can we do?" the principal interjected.

"I'll need several letters. One from you," she said, looking at him, "to express the need for a full-time aide and the reason for requesting Karen; and one from Jane who developed Yvonne's communication system. Jane will need to express her concern that a new person could set Yvonne back by several months." The social worker asked us, as parents, to request funds through the Special Child Welfare

Allowance: “Outline the benefits to Yvonne of this past year and stress the importance of having Karen continue.”

Peter and I left the meeting satisfied, but drove home in silence as we were both composing a letter in our minds. At home we put our thoughts on paper, compared notes, and wrote the letter.

The principal and Jane Green promptly wrote their letters and gave us copies although we hadn’t asked. This was a clear indication we were working together. Their positive attitude and swift response were reason enough to feel relaxed about September. School closed and we left St. John’s elated for our four-week vacation.

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Our first major stop was Fredericton. We were eager to see Teresa. We hadn’t seen her since Christmas when she flew to St. John’s. The Baylys now made us feel welcome, in our own home, and we joined them for meals. We slept in the spare bedroom in the basement. Yvonne accepted the arrangement surprisingly well. She understood that after our vacation we were going back to Newfoundland, and she would again attend Macpherson Junior High.

But first, we drove west. I had brought Yvonne’s numbers along and we made a game of counting down the kilometers to the next picnic site or campground. Yvonne laughed when I held up the number. “When we get to Manitoba,” I said to Peter, “you should attach a piece of wood to the dash and screw in ten cup-screws so I can hang up the numbers. Then, when we call out a number, Yvonne can take it off herself.”

Peter planned how he would make it. “I’ll use velcro fasteners which aren’t hazardous.” Yvonne laughed.

We arrived in Manitoba, and as usual we did not have time to visit all our friends and relatives. In our busy schedule we forgot our plan for mounting Yvonne’s numbers. Driving homeward along Lake Superior Yvonne became sad and cried. We asked her questions but couldn’t figure out the problem. Yvonne then leaned forward and pointed to the dash. Peter said, “Yvonne! You’re telling us we forgot about your numbers.” She looked at him and sighed. She was glad he understood.

We continued east, then detoured south to St. Catharines and explained to Yvonne that she would see a doctor about her back. Late in spring a doctor in Newfoundland advised surgery to straighten Yvonne’s spine. At first this surgeon implied negligence on our part. We felt guilty. Yet no one had suggested surgery before.

Briefly he outlined the procedure. He spoke of placing a rod in Yvonne's back requiring two operations, one through her chest and the other on her back. He gave no guarantee, however, that the rod would hold; Yvonne had too much of a forward posture. The procedure alarmed us. "What if the surgery robs Yvonne of her ability to walk? How can we look into her eyes and tell her the surgery was meant to help her?"

The surgeon looked thoughtful and nodded, "It would be most tragic to take away the wide range of activities that she can participate in at this time."

We had another worry and asked the doctor, "Could the curvature result in a life-threatening respiratory problem?" He did not think so. "Could we try another method to straighten her spine? Someone told us about a doctor in St. Catharines —" He agreed to make a referral.

Yvonne accepted the appointment in St. Catharines well. This doctor talked about surgery only as a last resort. He outlined two other alternatives: electrical stimulation and the gravity lumbar reduction therapy program. The first approach consisted of a small battery unit with electrodes attached to the upper back. The current pulsated at intervals to stimulate the muscles in the back. The second approach involved suspension from a frame while wearing a specially designed padded vest. We took the information back to Newfoundland for discussion with the physician.

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We arrived home on July 20 and eagerly sifted through the mail, searching for the letter from the Department of Social Services which would confirm the funding for Karen in September. The letter was there but we were disappointed.

The letter, signed by both the social worker and the supervisor, stated, "Before an official response to your request for Karen to continue in September 1987 as Yvonne's teacher-aide can be made, we would like you to put in a written request to the school board for this. They in turn will contact the director of Special Services, Department of Education. We need a letter from the Department of Education either approving the request or outlining reasons why they cannot approve such a request. This is essential before we can officially respond to your request."

We were exasperated. Why couldn't they work this out among the Department of Social Services, the school board and the Department of Education? They all knew the circumstances. Why did they put the responsibility on us parents? We wrote the letter, however, knowing that otherwise they wouldn't hire Karen.

School only opened September 9; we still had seven weeks of summer and Yvonne needed to be involved in outside activities. If she sat around the house, she became upset and resorted to negative behaviours. The Department of Social Services, concerned about developmental setbacks, again provided funding for summertime support. This year the social worker arranged for us to hire and supervise the support worker. We preferred this approach because we didn't want Yvonne in a segregated summer program.

I explained to Yvonne, "Mom will find you a friend who can take you to the park or hiking or swimming." At first Yvonne smiled, then she looked serious. I knew she worried who the friend would be.

I called student employment and arranged for six interviews in our home. Yvonne joined us in the living room. After the second student left, Yvonne cried loudly. This student did not come across as a friend. She would "take care of" Yvonne. Yvonne recognized this attitude and didn't like it. "Yvonne," I said, "she's not the right friend for you. We'll find someone else. You let me know who you want for a friend." In the next interviews I changed my approach. I made it more clear that Yvonne needed a friend and guided the discussion around Yvonne's personal needs more sensitively.

Yvonne found the interviews stressful. Her reaction, however, was valuable. Twice she pointed NO after the student left. She reserved her YES decision until after the sixth interview. She chose Charlotte Edwards. Charlotte became a friend not only during the summer but throughout the year.

Meanwhile, at the end of July, an official from the Department of Social Services told me the school board was planning to fill the teacher-aide position at Macpherson through the Employment Opportunities Program. He advised me to track down the principal and tell him, "Stick to the agreed upon plan; the special funding for Karen will be there." Evidently someone was trying to sabotage Yvonne's integrated schooling!

Our lives seemed destined to be embroiled in politics. Assessing the situation I saw we had a choice: continue to play the political game, or submit to the philosophy of those in the segregated system.

With steeled determination, I placed phone calls and requested meetings with the Departments of Social Services and Education and the school board. I would go to the ministers of the Departments of Social Services and Education and even the premier, if necessary. With support and advice from Joe and Bill, I worked my way up the ladder. Peter dealt with everything at the office and home, enabling me to pursue the bureaucrats.

I couldn't reach the special education coordinator at the board office; I finally reached her at home. She still supported the request for Karen but couldn't write a letter until August 17; she was leaving on vacation that afternoon. Thinking this was too late, I called the superintendent of the school board. He was unaware of the situation. I explained and requested a meeting. "We don't need to meet," he said, "I don't see any problem, especially where everybody agreed it should be the same aide."

"Social Services requires a letter to this effect," I said, with a sense of urgency.

"I will ask the special education coordinator to write it when she returns from vacation," he said.

Three weeks later I called the special education coordinator. She assured me she would write the letter the following day. To be certain that she would and that the letter would get there on time, I said, "Because of time pressure, could you please call me when the letter is ready? I'll be glad to deliver it to the director of Mental Retardation Services." She said she would, and she did.

A few days before school was to begin, the principal told me they could not hire Karen. I called the social worker. She suggested I call her supervisor, who assured me this was all a misunderstanding. "However," she said, "if the school board hired someone through Employment Opportunities, for the teacher-aide position at Macpherson, they can use that person in another school." Nonetheless I was uneasy and called the assistant superintendent.

He listened and said flatly, "We won't give up the Macpherson position through Employment Opportunities until we know for sure that Karen will be there."

"But it's all arranged!" I contradicted.

He replied stiffly, “We have nothing in writing what Social Services is prepared to do regarding insurance, liability, benefits and so on. When we get that we’ll see how we can work it out administratively.”

I called the Department of Social Services. This time the coordinator of Mental Retardation Services offered to write the letter to the school board. I picked up and delivered the letter. She gave me a copy dated September 2.

On September 8, the day before school started, I got a call in the morning. The coordinator of Mental Retardation Services sounded genuinely upset. “I’ve just been advised that all salaried positions through the Special Child Welfare Allowance are now discontinued.” I was speechless. Vaguely I heard her suggest, “Call Noel.” He was the director of Mental Retardation Services and was very helpful to families.

Noel was shaken by the news, and referring to the new policy, said, “I’m working on changing it yet.”

“There isn’t time, Noel!” I replied anxiously. “I’ll need to go see the deputy minister.”

“Don’t just go down,” he cautioned me, “call him and ask for an appointment.”

The deputy minister scheduled an appointment for 2:00 that afternoon. I phoned several friends to ask if they could stay with Yvonne; Charlotte had the day off. Peter was at the office but I had the car. I had no choice; I took Yvonne with me.

I dared to think that Yvonne’s presence might be a positive factor. It was. The deputy minister looked at her compassionately as I relayed her school experience and the recommendation for September. Then I passed him the September 2 letter from the coordinator of Mental Retardation Services which confirmed to the school board the funding for Karen.

The deputy minister frowned. He waved the letter and muttered, “This shouldn’t have happened.” He wanted to look into it and promised to call me.

I arrived home to a ringing phone. The principal, gravely disappointed, said, “The assistant superintendent called this morning. They have rescinded the special funding.”

“I’m not giving up yet,” and I told him about my meeting with the deputy minister. “There are still two steps on the political ladder.”

“Good,” he replied sincerely. “Keep me informed.”

I hung up and the phone rang again. This was Bernadette, the president of NACL. She spoke forcefully and worked tirelessly in support of integration. She too struggled to get her daughter integrated. This September her daughter would finally attend a regular class. Today, however, Bernadette was upset. Her daughter was promised a teacher-aide through the Employment Opportunities Program, but now they told her she would get a “support worker.” A support worker could only help in areas of physical need, not classroom instruction, and was hired for only twenty weeks. I empathized with her. I promised to call Bill and we’d see what we could do to help.

Bernadette and I shared our feelings of frustration. Integration was provincial policy, yet some people in the Department of Education opposed integration. These people purposely made things difficult and complicated, trying to show that integration was more work than it was worth. Individual parents, parent groups, local associations and the provincial association were forced to spend valuable time and energy to solve these problems and change attitudes. Integration by now should be accepted and we should be spending our time discussing curriculum development.

After a lengthy call with Bernadette, the phone rang again. My head buzzed from the intensive day.

“I’m calling for the deputy minister.” It was Noel. “The D.M. changed his mind.” Dazed I questioned if I heard him correctly. “The funding will be there,” Noel affirmed. “That’s the kind of man he is. If he believes in something, he’ll support it.”

It was nearly five o’clock. Shaking from exhaustion, I called the principal at home. He was relieved and delighted at the news. Then I called Karen. She too was relieved, and, as the reality sank in, she sang out, “I’ll see you in the morning, with bells on!”

“Will we ever see the day,” I remarked to Peter, “when Yvonne will be part of a school system where we don’t have the hassles and mad scramble?”

The next morning we drove Yvonne to school and waited in the car until Karen appeared. I opened the car door for Yvonne. She stepped out without help and ran toward the steps leading into the school. Karen welcomed her enthusiastically and both disappeared into the building.

Smiling, Peter and I drove to the office where everyone—Moya, Bill, Pauline and Fraser, the president of the St. John's local association—expressed their joy that Yvonne had Karen as a teacher-aide. That joy, however, was short-lived. That afternoon at 1:00, Karen called. She was upset. "Yesterday," she snapped, "I had no job. Today I have two jobs."

"What are you talking about?" I asked, bewildered.

She explained that her husband just called the school with an urgent message from the Department of Social Services. "I'm supposed to get back to Bell Island to sign some papers. I've got a job at St. Augustine's School. I should have been there today."

"Karen, there's some mistake," I replied without alarm.

Karen remained upset and confused. "I didn't even apply for the job!" Wanting to calm her so Yvonne wouldn't become upset, I told her I would check into it, meanwhile she should stay with Yvonne and take her to classes.

After several calls, I discovered the problem. The school board had told the Department of Social Services on Bell Island they had filled the position at Macpherson, through Employment Opportunities, and that they didn't need Karen; therefore, the school on Bell Island could have her. I was furious! "Somebody," I wrote on my note pad by the telephone, "really wants Karen out of Macpherson. The program has been too successful."

The turmoil and confusion were finally straightened out after three intensive days. Karen was definitely hired for Yvonne at Macpherson.

*****

We wrote letters of thanks to those who aided in getting support for Yvonne. In our letter to the deputy minister of Social Services we added, "We realize the present system of providing teacher-aides in integrated school programs is inadequate and needs to be improved. We would be very interested in helping to work toward those improvements." In our letter to the chairman of the school board, we took the opportunity to request a meeting to discuss the employment of teacher-aides.

The chairman of the school board agreed to meet with us. We brought along two families who had called us for help in getting their sons into regular classes. The school board had told them, "The resources are not there." One family refused to send their son to school, as they did not want him in the Developmental

Centre. The parents explained how the interdepartmental committee had bragged about the wealth of resources available at the centre, yet resources couldn't be transferred to the regular system. Increasingly parents were demanding that this change.

Meanwhile Yvonne's second year at Macpherson was unsettled. During the first few days she was aware of the discussions over Karen's position. She had also been aware that Karen was under pressure from her family to accept the position on Bell Island, which would avoid the transportation hassles with the twenty-minute ferry crossing every day. Though Karen neither applied nor qualified for that job, this incident created a strain in the relationship between Yvonne and Karen. The assistant superintendent was largely responsible for the unnecessary tension.

Soon Karen needed time off for medical appointments. If Peggy the substitute couldn't come, Yvonne had to stay home because the school board had no mechanism to provide substitute teacher-aides. Many days the weather prevented Karen from arriving at school on time or at all. The spring of 1988 was exceptionally windy and the saltwater shoreline was packed with ice. The ferry was often tied at the dock or worse yet, stranded, unable to break through the ice in the channel between Bell Island and the mainland.

On windy nights I heard Yvonne tug on her bedroom curtain and cry. She couldn't sleep, and I knew she worried whether the wind would prevent Karen from making the crossing.

Some days when Karen was in school she worried if she could make the crossing back home. She called the ferry terminal from school; Yvonne was aware of this and became tense.

One sunny but windy afternoon, Yvonne had her usual after-school snack at the dining room table and I began supper preparations in the adjoining kitchen. She cried. When I reached the table, she quit. I went back to the kitchen; she cried. I went to her; she stopped. I couldn't figure it out. The next time I watched from the kitchen. She cried when she looked toward the window.

I walked over to her, knelt beside her, and found her line of vision through the window. "Yvonne," I asked, "are you looking at the flag?" She looked at me, smiled briefly, then cried loudly. Finally I understood. "Yvonne," I said sympathetically, "you're looking at the flag. It's windy outside. You're worried if Karen will make it to school tomorrow."

For the next few minutes Yvonne cried her heart out. I hugged her in silence and let her release the built-up tension. When her crying subsided, I promised, “Yvonne, I will get something worked out. I know you want to be in school every day, just like the other kids.”

When Peter came home, I said, “Do you remember a couple of weeks ago when you looked out of the dining room window and remarked, “It’s neat we’ve got a flag across the street; we can always tell the direction of the wind.’”

“Yes, I remember.”

“Yvonne must have heard you,” I said, and relayed the incident. How often did Yvonne listen to our conversation and later use what she heard to tell us something?

Yvonne’s distress drove me into action. The next morning I called the principal; he agreed to meet. “Yvonne needs stability,” I said. “If Karen is absent, Yvonne shouldn’t have to stay home.”

He checked Yvonne’s attendance record and was surprised by the number of absences. He agreed that Yvonne was seldom ill, that she enjoyed school, and that she was upset. “This can’t go on,” he admitted. Later we spoke with Karen; I offered her our spare bedroom if she wanted to stay in town during inclement weather. We had a long discussion. Karen wanted to work with Yvonne but, in the end, chose not to stay in town and reluctantly agreed to be replaced.

Social Services agreed to use the special funds to hire Charlotte, Yvonne’s summer companion from the previous year, as the teacher-aide for the remainder of this year. Charlotte had kept up her friendship with Yvonne, taking her swimming every Monday night; therefore the transition from Karen to Charlotte was smooth.

All students in the Grade 9 classes, including Yvonne, received an orientation to the high school program. The teacher gave each student a computerized course selection form. Some students were zoned to attend Bishops Field, while others would attend Prince of Wales Collegiate. Yvonne was zoned for PWC.

Before the course selections were completed, the principal called me at the NACL office. Since he seldom called the office, I was apprehensive. “I had to tell you myself,” he said excitedly, “how proud we are of Yvonne!”

“Why? What happened?”

"The principal of PWC wanted to meet Yvonne and she responded appropriately to everything he asked her!" With mock exasperation, he continued, "Yvonne wouldn't have done that for me!"

My mind reeled and my heart raced as I imagined what might have happened if Yvonne failed to respond to this stranger. She might have been denied access to PWC. Did Yvonne have a premonition how crucial this impromptu meeting was? I knew Yvonne disliked being tested and if people asked her, "Can you show me…on your communication board?" she usually refused to point. People then doubted her understanding. This time, however, Yvonne hadn't objected and she hadn't held back. The principal of PWC was pleased and the principal of Macpherson was very proud of her.

"Listen to this," I told Peter later in the day, "Yvonne is registered for PWC. She impressed the principal and he wants to meet with us to secure a full-time teacher-aide. Here's the irony—his wife, I just found out, is the principal of the Developmental Centre who is hoarding the resources in the segregated system."

Yvonne, however, did not attend PWC because we decided to move back to New Brunswick. Our two-year term with MCC in Newfoundland ended, and we accepted another two-year assignment back in Fredericton with the Fredericton Association for Community Living to develop an advocacy program for young adults.

Before returning to Fredericton, Yvonne anticipated a major event in her life. She would graduate along with her classmates from Macpherson Junior High. For this occasion we bought Yvonne a long lavender dress with short puffed sleeves, which suited her beautifully. The bodice and back were loosely folded and connected to the long slim skirt at hip level. The seamstress at Bowrings cut off the extra length and made two long side slits for easier walking. She made a large bow from the excess fabric and attached it at waist level on the back. The bow detracted from Yvonne's curved back and complemented the smaller bow on the hip at the front.

Yvonne looked elegant on the night of graduation. For the first time she wore dangling rhinestone earrings given to her by friends Russ and Kathryn. They too were proud of Yvonne. Before leaving the house I wanted a picture of Yvonne but she was impatient. I took my camera to the ceremony. Arriving at school, Yvonne's friends surrounded her. "Yvonne! You look beautiful! Your dress is gorgeous!"

Yvonne beamed at them and laughed with delight. I removed my camera from its case. Just then a girl who had a learning disability walked up to Yvonne and I heard her gravely say, "She hits her nose. Sometimes she hits her nose! Why?"

The magic was gone.

Yvonne cried. Frustrated she hit her nose. I tried to calm Yvonne. Another student steered the girl away. The principal appeared and spoke to Yvonne. She brightened.

"May I take a picture of you with Yvonne?" I asked.

"Sure," he said with a smile. "You make sure I get a print."

"You will," I promised. Before I could take the picture, the girl reappeared. She wouldn't leave Yvonne's side. She wanted to be in the picture too. The principal was in a hurry. I snapped the picture.

This photo with the girl clinging to Yvonne's arm clearly shows why Yvonne often became upset when she was with people who were labelled "handicapped." They often asked in front of Yvonne, "What's wrong with her? Is she sick? Why does she do that?" Some hovered over her. Some would cling to her and say, "I'll help, I'll take care of you."

Yvonne resented such comments and actions. She wanted to be accepted for who she was. She wanted to be treated as an equal. I believe she recognized the limitations in other people and resented their assistance which caused her to feel even more incapable and inferior. Yvonne's feelings and actions were contrary to some educators' belief that people with disabilities prefer to be with "their own kind."

Fortunately not all educators thought this. Some recognized the negative consequences of "being with their own kind." The Canadian Association for Community Living's publication Community Living 2000, A Time of Change, A Time of Challenge stressed, "Students with special needs, including those with very challenging needs, learn best when they learn alongside and from other children who are not handicapped. When they are only with other students with handicaps, what they learn best is to be handicapped."

Believing this and wanting to build on what we already achieved, I vowed that Yvonne would never be in a segregated class again. As we prepared to return to Fredericton I wrote to the principal of Fredericton's only high school, with nearly

3,000 students, to register Yvonne for the regular Grade 10 courses for the coming September. I enclosed a copy of Yvonne's course selections from St. John's and a letter of support from the principal of Macpherson Junior High. I wrote to the school board in Fredericton regarding classroom support for Yvonne. Then, in case we needed advocacy support, I wrote to both the local and provincial Associations for Community Living.

* * * * *

We moved back to Fredericton at the end of June, 1988. In mid-August I tried repeatedly to contact the principal of FHS regarding classroom support for Yvonne. The school secretary eventually instructed me to register Yvonne at the school board office, and then meet with the counsellor to select her courses.

Based on Yvonne's selections from Newfoundland, we registered Yvonne for English, Maritime studies, math, health and physical education, biology and music. A few days later the practical-program department head challenged the validity of Yvonne's registration and insisted she be registered with the auxiliary classes. Her registration in the regular classes was not because of a progressive integration policy, but because of the procedure which the secretary had advised. Nevertheless, we maintained that her registration should stand, and, as in the past, offered to work together to make integration a positive experience for everyone.

To our relief the principal and school board superintendent agreed to this—on the condition that it be a demonstration project and involve three other students, Vicki, Jocelyn and Kara, all with multiple disabilities. The demonstration project would show that students with very challenging needs could participate, with support and adaptations, in the regular acedemic curriculum alongside their peers.

Yvonne particularly enjoyed Maritime studies and hospitality and tourism. Yvonne's teacher-aide, Eileen, became her close friend and helped her with school work by using pictures, as in Newfoundland. Most parents remained actively involved, and developed a good working relationship with the teachers at the high school.

Before the end of the year the project was evaluated by Gordon Porter, a highly respected educator both provincially and nationally. Among six major recommendations, his first stated: "The integration program should continue but the term 'demonstration project' be dropped."

Two years later all students from the auxiliary classes had the opportunity to register for regular courses at this high school. Even so, parents continually faced challenges because a handful of people, still in the segregated system, felt threatened by integration.

Meanwhile, integration became a major issue for the New Brunswick Teachers Association in their 1989 contract negotiations. This led to a province-wide controversy, prompting the New Brunswick government to hold public hearings. A legislature subcommittee heard an unprecedented 250 presentations.

We, too, presented a brief in which we stated, “Being a part of the community is a basic human right which is not debateable and which citizens with disabilities should not be required to justify. We are looking forward to a future when discrimination against people with disabilities will no longer be an issue for public debate....”

The government acknowledged the overwhelming support for integration from parents, teachers, professionals and the public, and renewed its commitment to this policy.

Yvonne attended high school for four years, until she was 21. But due to recent allergies, she did not attend the graduation ceremony. Nonetheless, Vicki, Jocelyn and Kara, who proudly received their diplomas along with the other graduates, were proof that other families, too, were striving for integration.

Yvonne’s picture in the 1992 yearbook, among 748 graduates, is a lasting reminder how she always wanted to belong, and how happy she was when her peers accepted and included her.

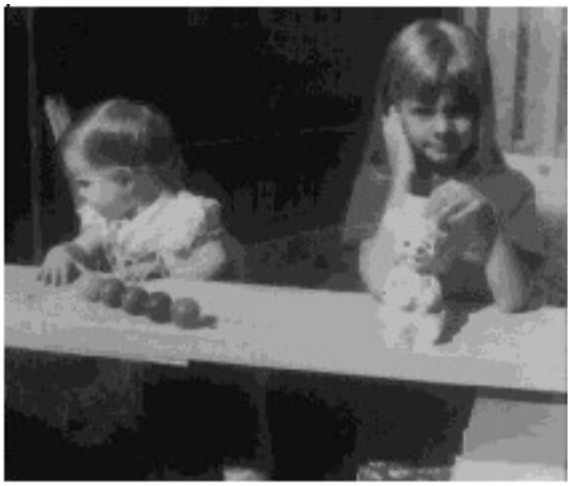
Chapter 16

The Story in Pictures

Yvonne (left) at 9 months, with her cousin Glenda, 7 months.

Yvonne, 1 year, with her sister Teresa, 5.

Yvonne, 15 months, enjoying sand and water play.



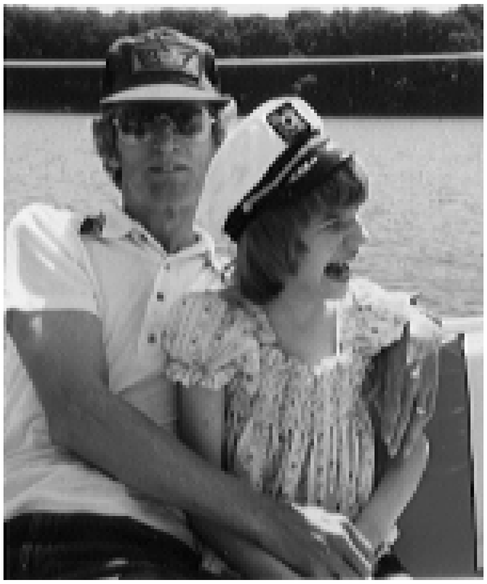
Yvonne, 16 months, with Teresa, watching movement in the grass.

Yvonne, almost 3, walked on her knees for 10 months.

Yvonne, 3 years, 3 months, walked for the first time, at Castle Hill, Nfld.

Yvonne, 4, started rubbing her hands and nodding.

Yvonne, 11, with Irma, 1982.



Yvonne, 12, with Peter; sailing in the Thousand Islands, Kingston, Ontario, 1983.

Yvonne at 13 years; leaving for Green Hill Lake Camp, N.B., 1984.

School pictures, 1984–1986:

Yvonne, 13, in an auxiliary class, with no integration.

Yvonne, 14, in an auxiliary class, partially integrated.

Yvonne, 15, in a Grade 8 class, totally integrated.

Yvonne, 15, at her first school dance, Macpherson Junior High, St. John's, Newfoundland, 1986.

Teresa's wedding day, with Yvonne, 17, August 12, 1988, Fredericton, N.B.

Yvonne, 21, yearbook photo, FHS graduation, 1992, Fredericton, N.B.

Epilogue

Since graduation from school, five years ago, Yvonne continues to live at home, and has a most valuable daytime companion, funded through Health and Community Services. Venessa has been with Yvonne for almost three years and is a trusted and dedicated friend. Yvonne is eager to go out every day, Monday through Friday. She enjoys visiting, walking in the parks and malls, and shopping for gifts for family and friends at special occasions. I marvel, each time, at the gifts she choses.

Because Yvonne developed serious allergies, in her final years at school, Venessa watches out for environmental irritants and also makes sure Yvonne eats only the specially prepared food they've taken along from home. Despite Yvonne's overall limitations, she is happy and feels secure. Living at home, and participating in the community with her friend, she is experiencing a quality of life.

In the summer 1996 we took our first vacation in twenty-five years, without Yvonne. This was possible only because Venessa, in whom we had full confidence, offered to be with her. As well, Yvonne preferred to stay home, mostly because she found long-distance trips too hard on her back. She experienced a wonderful four weeks with Venessa, Nina, Lori and Teresa.

Yvonne always looks forward to visits with her sister Teresa, brother-in-law Chris, and nieces Rebecca and Janet, who live a two-hour drive from Fredericton. Yvonne still enjoys short trips, and camping. She especially enjoys our rustic cabin in the woods.

Yvonne's future, however, is threatened. The New Brunswick government recently introduced a new policy regarding long-term care which would place many young adults with physical and mental disabilities into nursing homes. History is repeating itself; once again government is more willing to fund segregated facilities than small community residences.

Alarmed by the new policy, families and advocates across New Brunswick appealed to government. Due to enormous public response, the government delayed its implementation, but, at the time of this writing, still intends to keep the policy.

As parents of a daughter with a developmental disability we have realized that we must always remain vigilant, and may continually need to advocate for Yvonne's rights, and those of others.

As a family we are greatly encouraged though, when the public takes a stand to protect the rights of its citizens who are unable to speak for themselves. If, as a caring community, we continue to support one another and take a stand for justice, then our citizens with disabilities will be assured that they are valued, and belong.

IP, April 1997

Special Thanks

Over the years we have had the opportunity to interact with countless people in the medical profession, social services, the education system and volunteer organizations. Many of these people deserve special recognition and our sincere thanks for their positive involvement in Yvonne's life:

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David Malcolm
Maxine McKiel
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I would also like to acknowledge the many families in New Brunswick, Newfoundland and Labrador, who welcomed us into their homes as, together, we worked toward our common goal.

Abbreviations

ACL	Association for Community Living
ADM	Assistant Deputy Minister

AMR	Association for the Mentally Retarded
CACL	Canadian Association for Community Living (formerly CAMR)
CAMR	Canadian Association for the Mentally Retarded (renamed CACL in 1985)
DHSP	Direct Home Services Program
DM	Deputy Minister
FACL	Fredericton Association for Community Living
FHS	Fredericton High School
IEP	Individual Education Plan
MCC	Mennonite Central Committee
MLA	Member of the Legislative Assembly
NACL	Newfoundland Association for Community Living
NBACL	New Brunswick Association for Community Living
NIMR	National Institute on Mental Retardation (later G. Allan Roeher Institute)
PDP	Parents for Developmental Progress
PWC	Prince of Wales Collegiate
SNAG	Special Needs Action Group
TMH	Trainable Mentally Handicapped
TMR	Trainable Mentally Retarded
UNB	University of New Brunswick