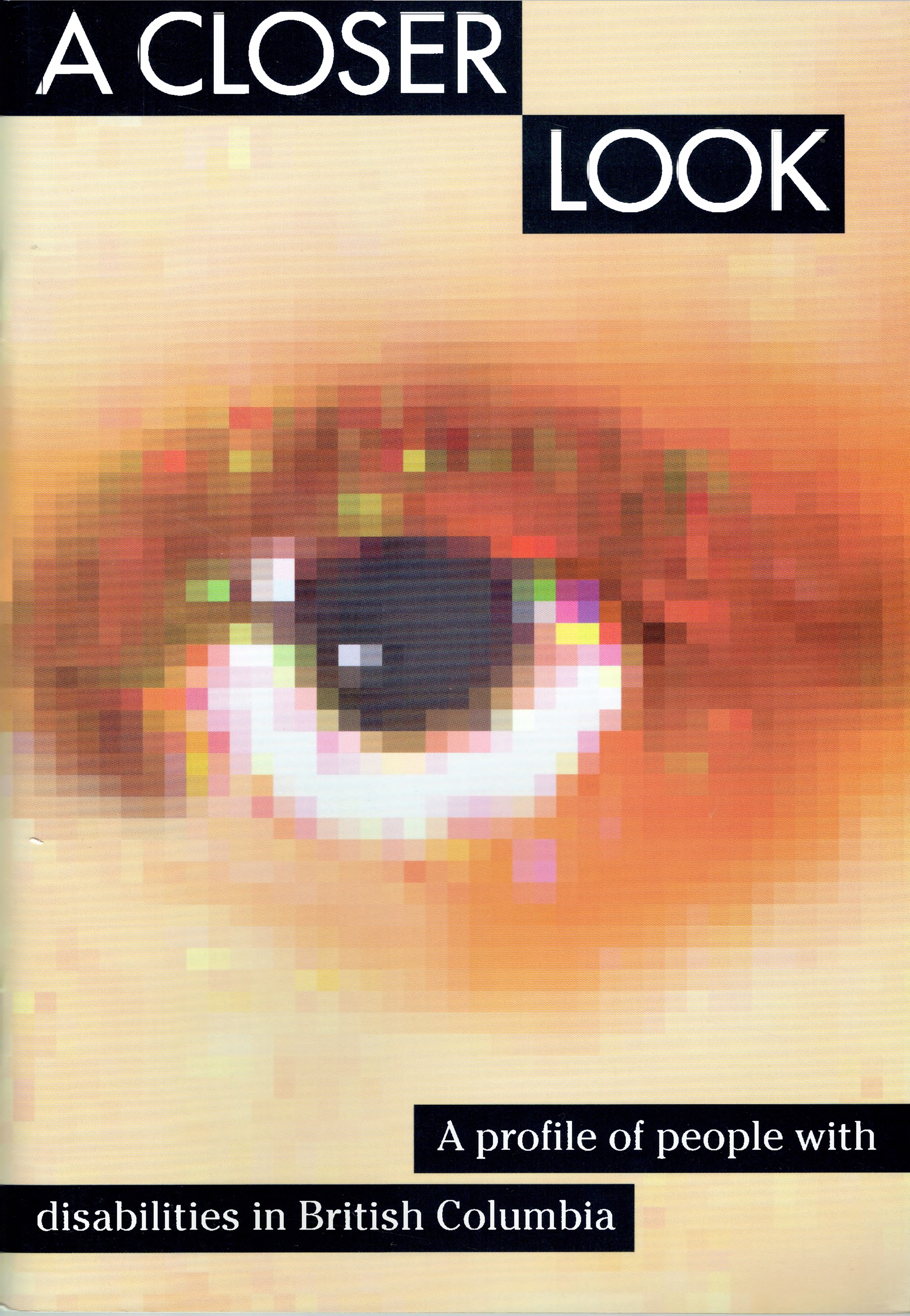
A CLOSER LOOK



A profile of people with disabilities in British Columbia

A CLOSER LOOK:

A Profile of People With Disabilities in British Columbia

April 1992

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ABOUT THIS BOOK

A Closer Look: A Profile of People with Disabilities in British Columbia presents highlights of the findings from the Health and Activity Limitation Survey (HALS). The HALS survey was conducted by Statistics Canada as part of the 1986 Census to provide an in-depth profile of people with disabilities in Canada.

A Closer Look focuses on demographic characteristics of people with disabilities in British Columbia. It outlines the conditions most often identified as limiting the activities of British Columbians and considers factors such as education, employment, and income which affect their livelihood and independence.

Preceding and following the measured facts are the personal accounts of several individuals who have disabilities. Hopefully these narratives and photographs will help render a human dimension to the statistical profile and contribute to a broader understanding of the conditions of daily living encountered by people with disabilities in British Columbia.

For its survey of the adult population, HALS relied on a concept of disability adapted from the World Health Organization (WHO) definition of disability. The WHO defines a disability as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

A different approach was used for determining disability in children under the age of 15. For children, disability was indicated by a positive response to a survey question dealing with one of three aspects affecting daily life: general limitations, chronic conditions, or use of a specified technical aid.

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"The more
people know
about the
difference,
the less
difference
it makes."

THE WILSON FAMILY

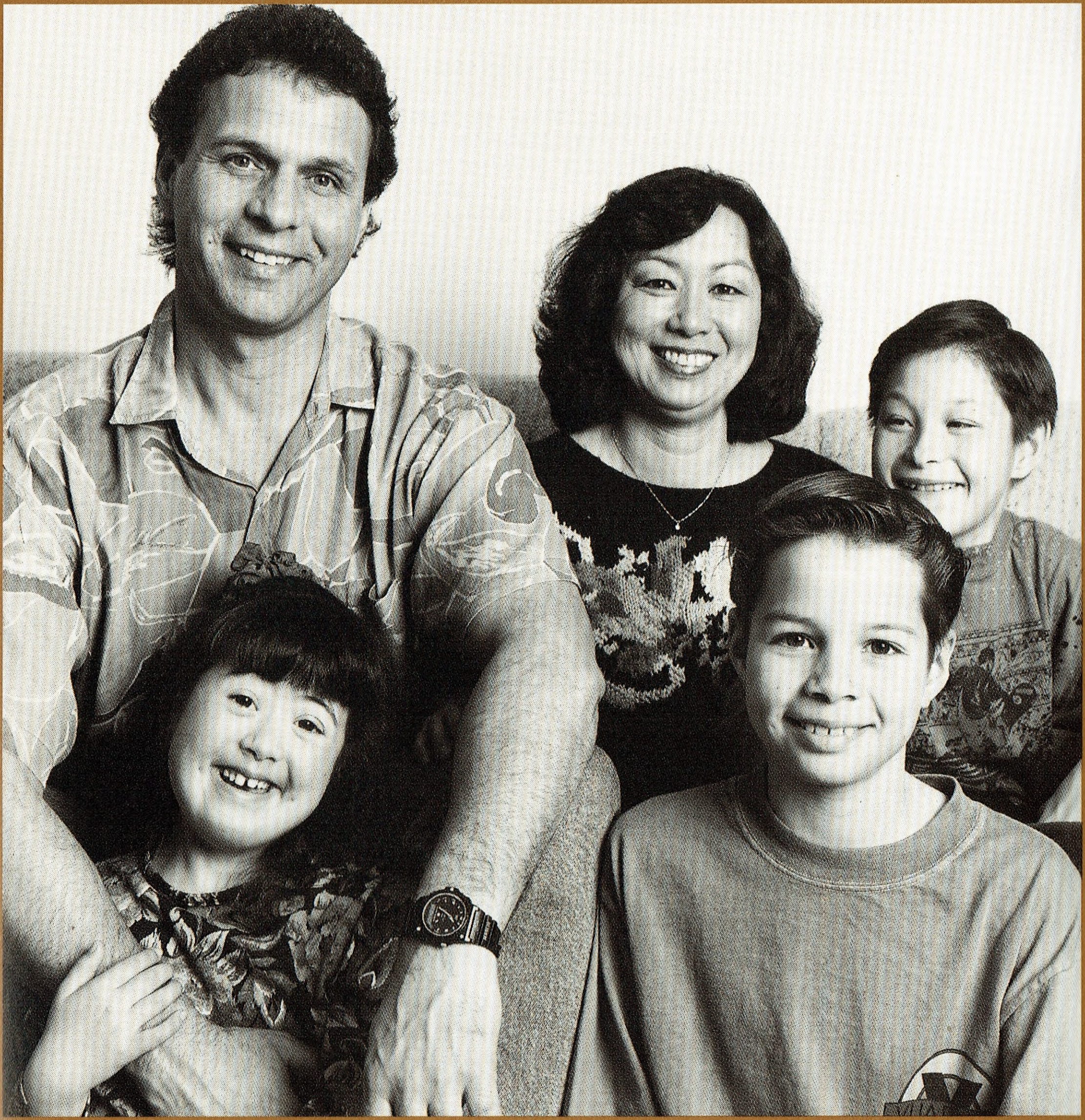
A weekday evening at the Wilson's home in Coquitlam is pretty typical of a young suburban family with three kids. Randy and Debbie Wilson both work and their three children are all in school. At night, their oldest son Brent, 14, plays with his computer. Todd, 10, comes home and tells his parents about his soccer practice. Roxanne, 9, is downstairs watching the Muppets on television. The settled, content atmosphere — a challenge to come by for any family — is particularly well-earned for the Wilsons who are bringing up two children with special needs.

Brent is undiagnosed but is non-verbal, has a seizure disorder, and has gross and fine motor difficulties. He is also chronically ill with cyclical vomiting, a condition which makes Brent vomit several times an hour for as many days. The condition then subsides and may reoccur at any time. "That's the hardest thing for a mother. You always want your children to be healthy," explains Debbie. "When they are sick, the disability becomes secondary."

> *"We fought so hard to get Brent into the regular school system. I shudder to think what parents went though just 20 years ago."*

The Wilsons have made their children's disabilities secondary from day one, insisting Brent and his sister Roxanne, who has Down's syndrome, participate in all regular activities in and out of school. "We fought so hard to get Brent into the regular school system. I shudder to think what parents went through just 20 years ago," says Randy. "Many kids ended up in all these institutions that are getting shut down. There has to be mainstreaming. There is no other choice."

Debbie recalls signing up Roxanne for class and feeling obligated to explain her daughter's disability. Now she automatically assumes both her children will be allowed to join whatever



programme they wish. Brent, for instance, has just taken up skiing and is looking forward to having 10 friends from school over for pizza and a video. His talking laptop computer fascinates the kids in his Grade 7 class. About to face another major adjustment when he starts junior high, the Wilsons have arranged for Brent's classmates to visit the feeder schools and tell the students about their friend so they will know how to treat Brent come September: just like any other kid.

Randy and Debbie both admit it took a long time for them to become as positive as they are. No link exists between their children's disabilities, so they initially despaired when Roxanne was born. "But now she's often the spark that gets me going," adds Debbie, sounding like every mother on the planet.

"The real difference in having children with disabilities is the amount of work involved," Randy says. "Todd will plan his own future. But we will continue to be involved in the planning for Brent and Roxanne as they grow up." The Wilsons stress getting connected with the growing number of support groups and agencies available. Ideas, support, and information shared in these groups have led to the shift in attitudes towards children with disabilities. Going it alone, according to Debbie, "would have been a mistake for us. You have to admit we're not your usual family."

"It's not unusual to me," Randy laughs. "I haven't known any other."

MARIKA SPRANGERS

"Sometimes I feel that having a disability can be a gift. You don't take anything for granted. Lots of things are a challenge, so beating them gives me a real sense of triumph."

Born in 1966 with spina bifida, Marika Sprangers was mainstreamed into the Surrey school system after spending one year in a special school because children with disabilities were not integrated in the early 70's. As she moved through elementary to junior and senior high, her parents fought to have each school made accessible for her, but the other battles were her own. "There were people, both teachers and students who didn't appreciate me being there. I could ignore the attitudes of the teachers. It was a lot harder with the students. Some ignored me; some laughed at me and some gave me too much attention. It was all because of fear and ignorance but at 13, it was rough. Of course, there were a lot of really good friends, too." The good experiences clearly outweighed the bad; Marika doubts she would have achieved as much as she has outside the regular school system.

"Some ignored me, some laughed at me, and some gave me too much attention."

Other milestones were giving up the crutches for good when she was 12 and opting for the wheelchair — a move her doctor disapproved of but one Marika considers "one of the best I've ever made" — along with getting her driver's license. Now, living in a Vancouver housing co-op and working for the Kinsmen Rehabilitation Foundation, she credits her family with helping her find her independence, but admits that having moved on, she's not quite sure of her goals.

Common frustrations are inaccessible bathrooms and sidewalk ramps that allow her to cross the street only to find there's no ramp on the other side. But those things are easier to change than people's attitudes, which Marika sees as the biggest obstacle for all persons with disabilities. She regularly makes presentations to organizations and companies on disability awareness.

"I want the same things you want," she says, "Freedom, friends, a solid relationship, success. I'm used to having lots of things in my way, but the hardest thing to get past are the people who automatically assume I can't do something because of my disability."

Slowly chipping away at various obstacles, Marika has participated in swimming, javelin, discus, and racing. But because of potentially permanent shoulder damage from both sports and the regular, everyday strain of pushing a chair, Marika chose to end that career and took up coaching instead. While she's never walked a day in her life — except on crutches and leg braces — Marika feels that she has – and more. "When I meditate I can walk, run, dance, fly. My mind relaxes and I really can do those things. Maybe that's why I don't miss them in real life."

Still, regardless of how much she makes of her life, people have told her they don't know what they'd do if they were in her situation. "What's that supposed to mean?" asks Marika, gesturing to the room around her, but also the world outside; "Is this so bad?"

DENNIS KAYE

Dennis Kaye first noticed the twitch in his right arm while operating a freight boat in Kelsey Bay. He was 30 years old, had a young family, his own business, a home, and, as he soon found out, a disease that was slowly stealing muscle control while leaving his mind completely unaffected. He was diagnosed with amyotrophic lateral sclerosis (ALS) and told he would be dead in three years.

Seven years later, Dennis writes and produces videos, is in the midst of an autobiography, and motors around the house in an electric wheelchair with a bumper sticker that says "Warning: I Twitch At All Railway Crossings." Far from dead, Dennis has survived a disease that normally runs its course so quickly there is no time to adjust to one disability before another develops. "I am in every sense a big baby," explains Dennis. "My wife gets me up, dresses me, bathes me, shaves me, lifts my spirits and drops my drawers. People tend to forget that while I may be dying of ALS, Ruth is the one who has to live with it."

> *"Amyotrophic (A-my-o-trophic) lateral sclerosis is a fatal, rapidly progressing neuromuscular disease. It attacks the motorneurons that carry messages to the muscles resulting in weakness and wasting in arms, legs, mouth, throat and elsewhere."*

As the initial arm twitch spread across his body, affecting first his upper body and then his legs, Dennis gave up his freight business and received financing from the Department of Labour to start a video company. When he required the full time use of a wheelchair, Dennis was unable to go on location. Eventually his voice deteriorated and Ruth had to make the phone calls. ("My voice machine sounds like Darth Vader with a harelip.") Now, with limited control of his hands, he pecks away at the keyboard with a pointer strapped to his head

A regular contributor to CBC's Morningside, Dennis is an eloquent spokesman for ALS – also known as Lou Gehrig's disease. He says ALS killed more Canadians last year than multiple sclerosis, muscular dystrophy, cystic fibrosis, and Huntington's disease combined. He believes few people with ALS are speaking up because they die so quickly. "Ironic, eh?" Dennis wrote in a letter to Peter Gzowski: " A disease's very severity being the single biggest reason for its lack of publicity. One can hardly expect the victims, mostly elderly and dropping like flies, to have a unified voice."

The Kayes live on Quadra Island with their two daughters who have never known their father in any other condition. "They think I'm drunk," Dennis jokes, admitting he misses being able to do what other fathers can, such as attend a school picnic. Also a distant memory are the treasured moments alone on his boat.

Instead, Dennis sails along on a sense of humour, the antidote he believes has kept him alive far longer than most people diagnosed with ALS. "It may not be a cure but it's a damn site better than anything the specialists have come up with."

"I'll start by saying that A.L.S. is not for the faint of heart. In fact I only recommend it to those who truly enjoy a challenge. After a broken sleep, interrupted off and on by severe muscle cramps, I awaken to stare at my living room ceiling. We no longer sleep in our upstairs bedroom, as I am unable to maneouver the stairs safely. Often, the first thing I feel is my face on a wet pillow. Most nights I am unable to contain my saliva and this leads to the area around my head becoming saturated in drool. From both a physical and an emotional standpoint, I believe these first few moments of the day to be the most dangerous. Not only is muscular movement unpredictable, but it's the time I usually question the importance of getting up at all. Walking is a balancing act in every sense of the word and demands total concentration. Because my arms hang limp, I am unable to protect myself in a fall. The margin for error is minimal, so the slightest distraction can lead to a cracked rib or a broken nose. Once I've overcome the indignity of being washed and dressed I make the long trek to my office (it's in the next room) ...

While I stared at the ceiling recently it occurred to me that my condition is only an advance look at what most of us will experience sooner or later. I am being granted a physical preview of what is usually reserved for the elderly, while being denied the wisdom that another 50 years would bring."

Dennis Kaye

Excerpt from a letter to Morningside

TRACEY HOOPER

Tracey Hooper is writing her Masters degree at U.B.C., focusing on grassland ecosystems. She spends her winters in front of a computer crunching the numbers she collects during the summer in B.C's interior where she walks across the rangeland taking soil samples, observing birds, and collecting bugs. One of the reasons she chose to study grasslands can be traced back to a car accident on New Year's Eve, 1979.

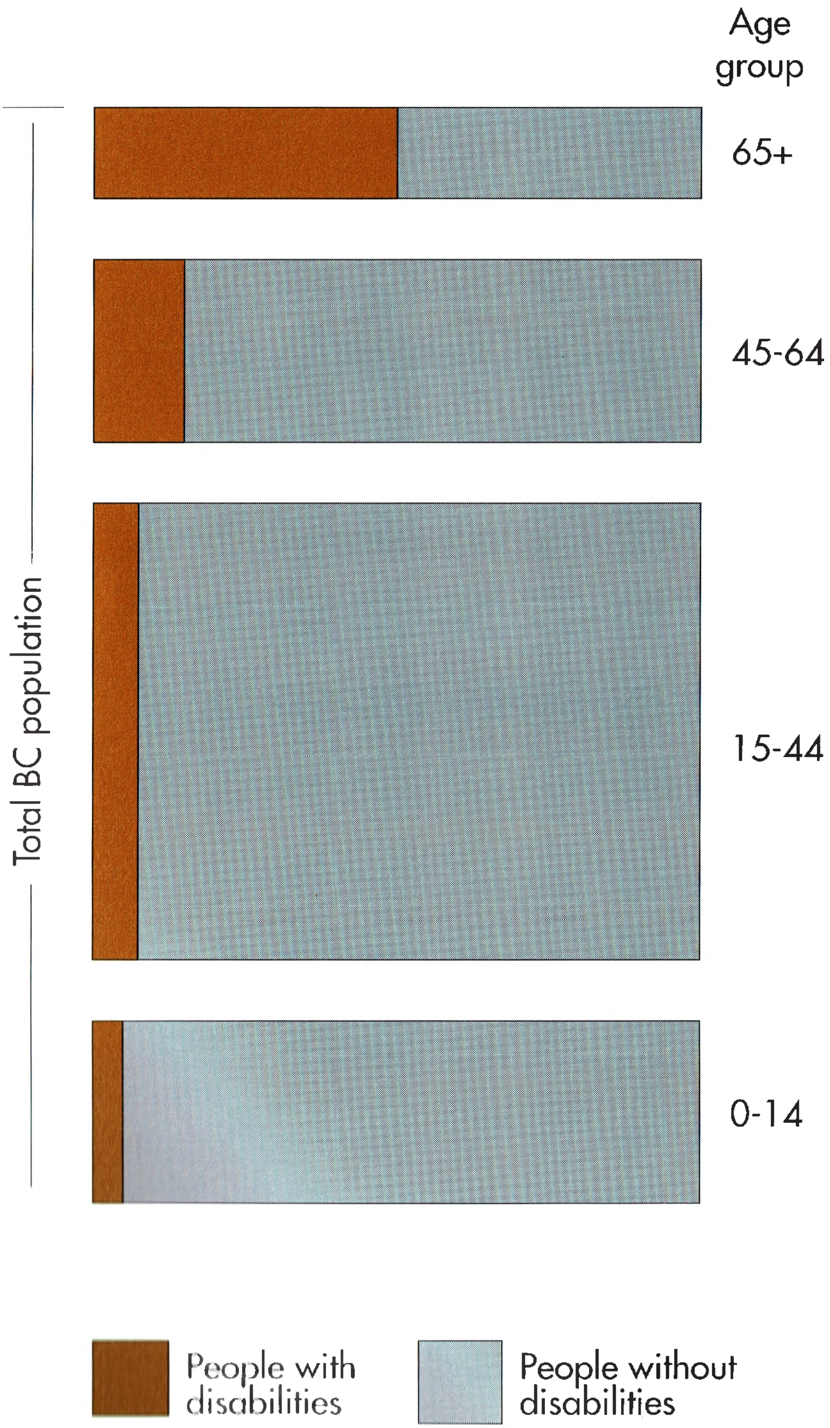
Tracey and five friends were driving down a mountain in Salmon Arm following a day of skiing when the car went off the road and rolled down an embankment. Tracey's neck was so seriously broken that one nurse told her the only other people she'd seen with similar injuries were in the morgue. Today, Tracey has impaired motor function on her right side and limited sensory functioning on the left, not enough of a disability to stop her from pursuing a degree in biology. Getting around with the aid of a cane would be a serious obstacle to doing research in old growth forests or on a boat, but is only a minor nuisance in the grasslands.

"I often feel that two lives have been lived in one body."

It's a long way from the hospital ward where Tracey remembers learning how to walk again. "One fellow had just been told he would be a quadriplegic for life. He could see me practise walking as I went up and down the hall and whenever I passed his door he would ask 'How's it going?' I was getting better every day and he would never walk again. How do you answer a question like that?"

Tracey doesn't feel she shares a particular bond with people who are disabled. "I don't want to be defined by my disability. Most of the time I don't even consider myself disabled." With that attitude providing momentum, Tracey has completed a tour of China, re-learned how to swim, and taken up Tai Chi.

PROPORTION OF PEOPLE WITH DISABILITIES, BY AGE



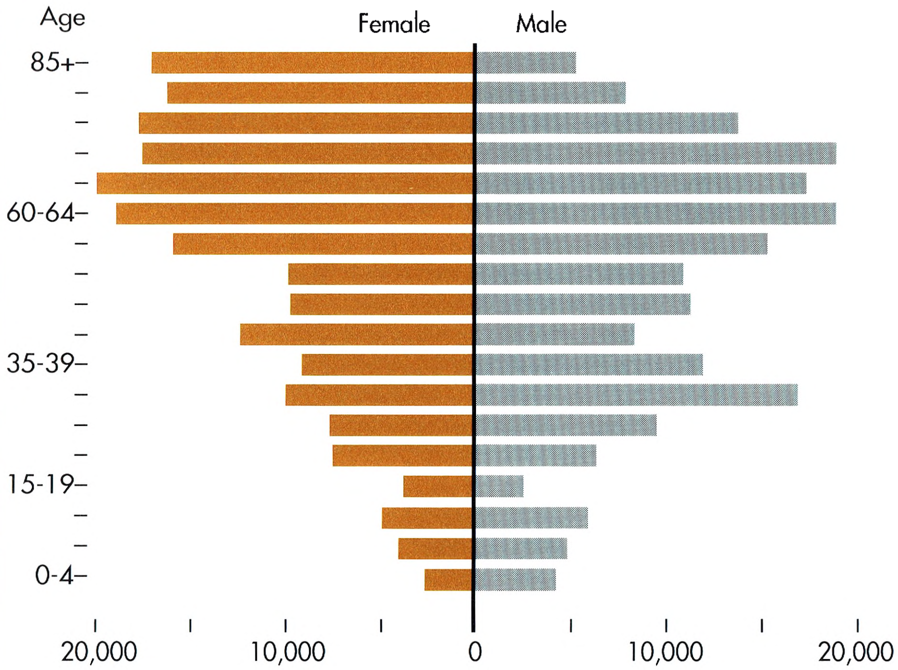
1 ON THE FACE OF IT: AN OVERVIEW OF PEOPLE WITH DISABILITIES

In 1986, 395,000 people with disabilities lived in British Columbia, or one out of every seven people in the province. Of this population, 27,000 were children under the age of 15; adults between the ages of 16 and 64 numbered 217,000; and 151,500 were seniors 65 years or older.

The proportion of the population with a disability increased with age. About one in every 20 children under the age of 15 in British Columbia had a disability, but that proportion rose to over one in 10 adult British Columbians between the age of 15 and 64 and nearly half of seniors over the age of 65.

One out of every seven people in British Columbia had a disability.

One out of every two seniors over the age of 65 had a disability.



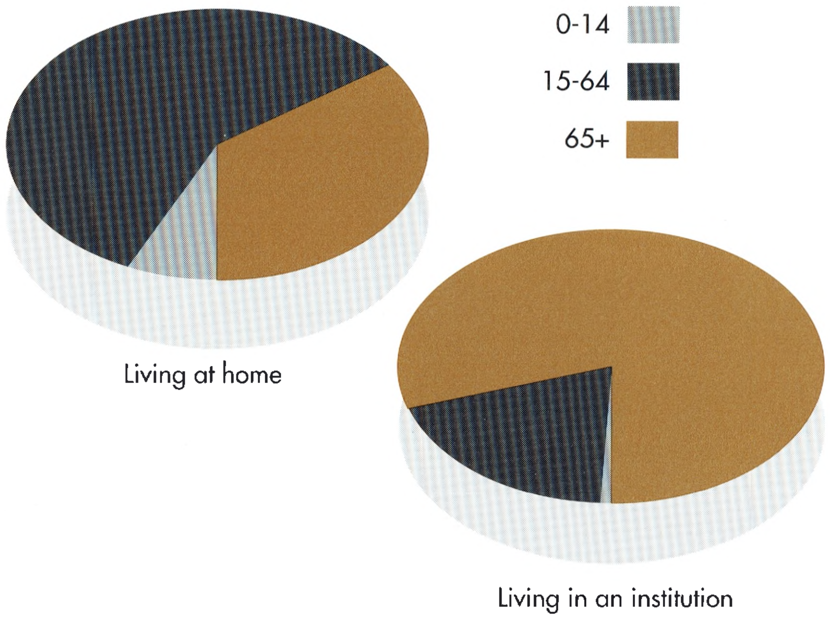
Boys have a higher disability rate than girls.

Among children, boys had a higher disability rate than girls. One out of every 20 boys had a disability compared to one out of every 25 girls.

As they grow older, females have a higher disability rate than males.

The ratio between disability rates for males and females continued to hold for adults in the 15 to 34 age range. However, the relative proportion of women to men with disabilities increased in later years. The disability rate for females, aged 35 to 64, was about the same as the rate for males. But females aged 65 or older had a slightly higher disability rate than males. The much greater numbers of women than men aged 65 and over with disabilities reflects the longer life expectancy of women in the population as a whole.

HOUSEHOLD STATUS

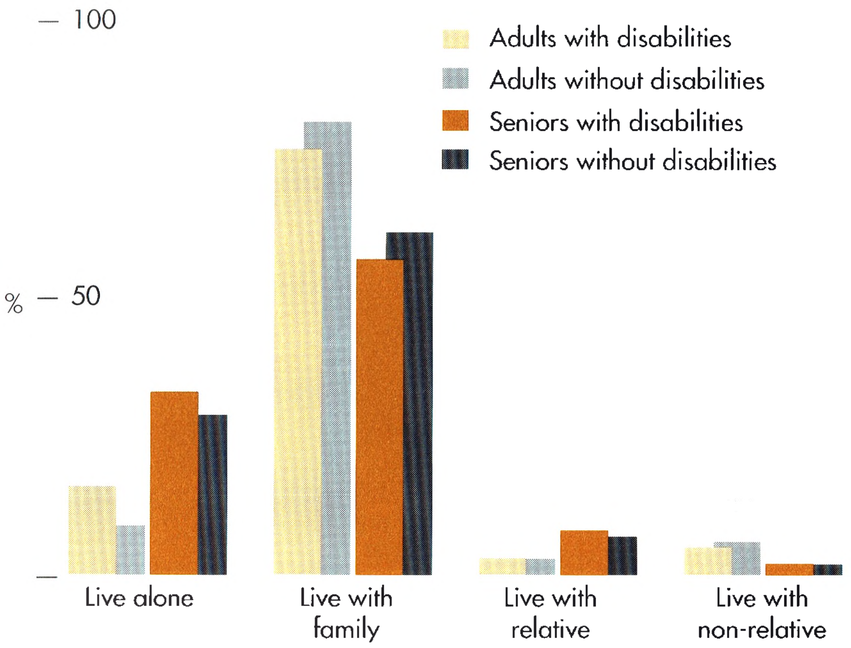


The relative proportion of people with disabilities who lived in institutions rose particularly after age 75. While only 4% of people aged 65 to 74 with disabilities lived in health-related institutions, the numbers increased to 18% of those aged 75 to 84 and 40% for people with disabilities 85 years of age and over.

Ninety-nine percent of children and 97% of adults with disabilities lived in households. In total, 7% of people with disabilities lived in health-related institutions, while 93% lived in households.

As seniors age, they are more and more likely to live in a health-related institution.

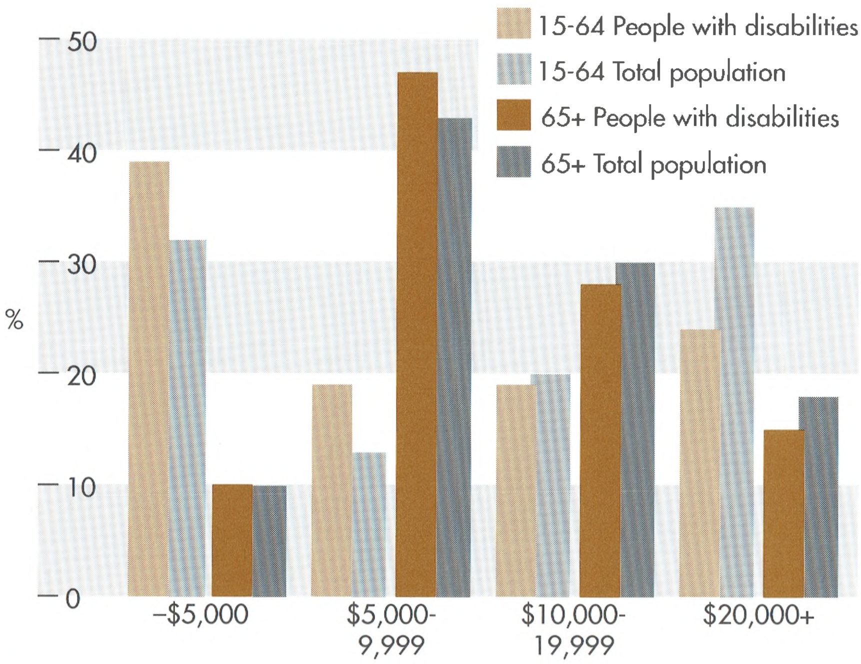
LIVING ARRANGEMENTS



One out of every six adults who had a disability and lived at home, lived alone. Of the seniors with disabilities who lived in a household, one in three lived alone.

Almost two thirds of adults with disabilities were married. A total of about 15% were either separated, divorced, or widowed; while one in five had never married. Approximately 55% of seniors with disabilities residing in households were married. One out of three seniors were widowed. Just under 6% of seniors had never been married.

INCOME



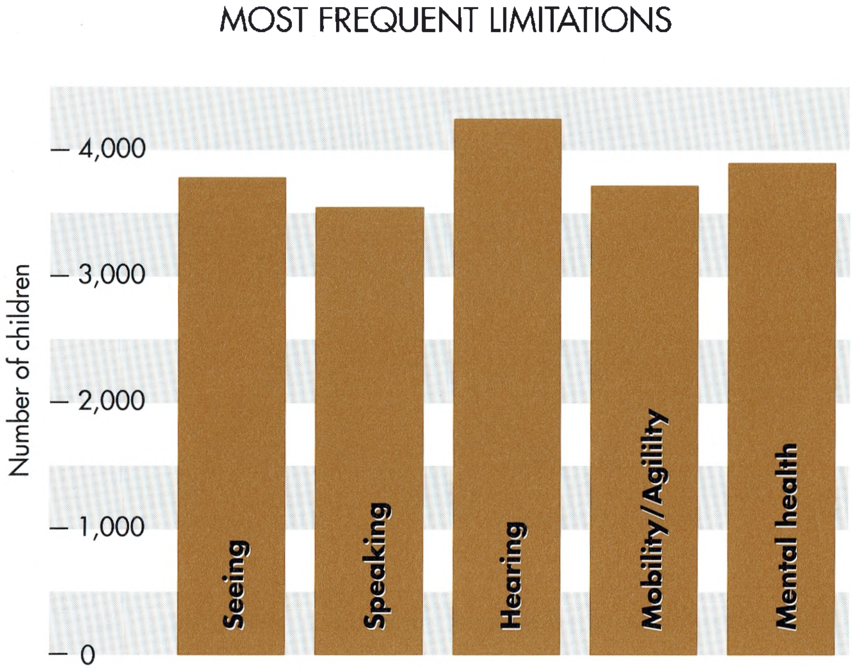
Thirty-nine percent of adults with disabilities received less than $5,000 in total income in 1986. This compares with 32% of the general population in British Columbia aged 15 to 64. Forty-seven percent of seniors with a disability and 43% of seniors in the general population received a total income of between $5,000 and $9,999 in 1986.

The poverty rate, based on total household income for adults with disabilities, was 28%, or twice the rate for the comparable general population. Among seniors with disabilities, the poverty rate was 24%, two percentage points above the rate for seniors without disabilities.

The proportion of adults who received a total income of $20,000 or more in 1986 was 24% for people with disabilities as compared to 35% for the general population. Fifteen percent of seniors with disabilities and 18% of the total senior population received an income of $20,000 or greater.

More people with disabilities live in poverty than people in the general population.

2 SUNDAY'S CHILD: DISABILITIES AFFECTING CHILDREN



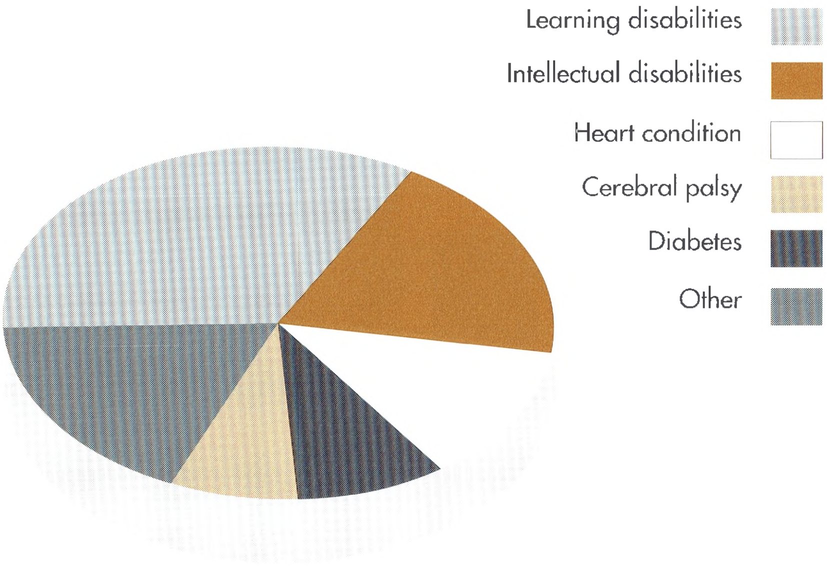
The HALS survey identified children with a disability according to one of three criteria: the presence of a general limitation, a chronic condition, or the use of a specified technical aid. The survey reported on general limitations affecting hearing, vision, speech, mental health, and other limitations.

About one in six children in British Columbia who had a disability had a hearing problem. Nearly one out of seven had a vision problem which could not be corrected by glasses or contact lenses.

Mental health and speaking disabilities were assessed only for children over the age of five. Nearly one out of five children between the ages of five and 14 with a disability had a mental health problem. More than one out of six children had trouble speaking and being understood because of a condition or health problem.

Nearly one out of five children with a disability had a mental health disability.

CHRONIC CONDITIONS



Nearly one child in four who had a disability, had a learning disability.

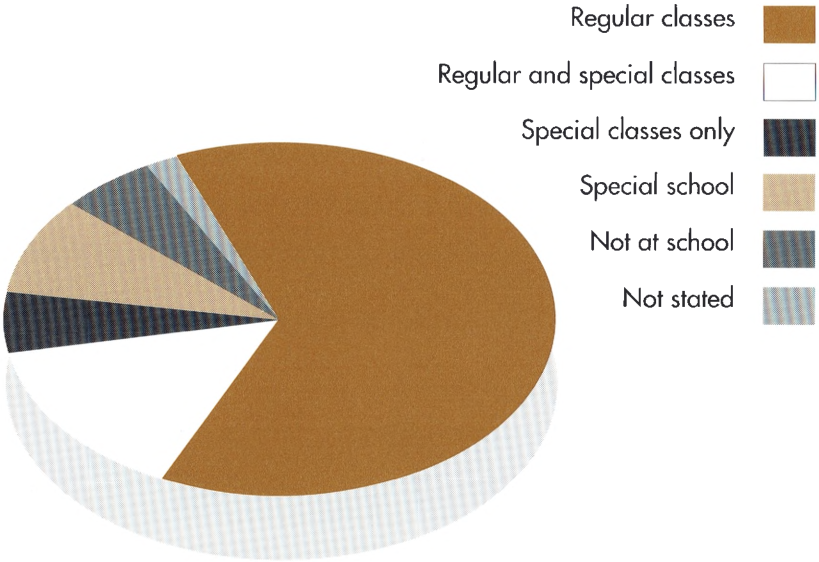
Learning disabilities, intellectual disabilities, heart condition or disease, diabetes, and cerebral palsy were the most prevalent chronic conditions for children. Nearly one in four children with disabilities had a learning disability and nearly one in seven had an intellectual impairment.

Of children who had a disability, one third used an assistive device. Medically prescribed footwear, hearing aids, braces (other than for teeth) and crutches or other walking aids were the most commonly reported devices. One out of 10 children with a disability used medically prescribed footwear; one in 15 used a hearing aid; one in 22 used braces; and one in 25 used crutches or other walking aids.

One child in seven had an intellectual impairment.

Over one third of children aged five to 14 who had disabilities regularly took medication due to a condition or health problem. One in three children between the ages of 10 and 14 with disabilities was prevented from taking part in physical activities due to the condition or health problem.

SCHOOL ATTENDANCE



Nine out of ten children with a disability between the ages of five and 14 attended school, with two thirds attending regular school classes. One in five children attended special classes. Almost three quarters of the children attending special classes also attended some regular classes. One in 10 school children who had a disability attended a special school.

Fifty-seven percent of the children attending special classes were enroled in a physical or communication therapy class. Forty-four percent were taking classes in daily living skills. Three quarters of the children attended special classes in academic subjects.

Of those who were not attending school, one in four had attended school prior to the survey and three quarters had never attended school.

Of the children with disabilities who had attended school at some time, one in three needed extra time to achieve their level of education.

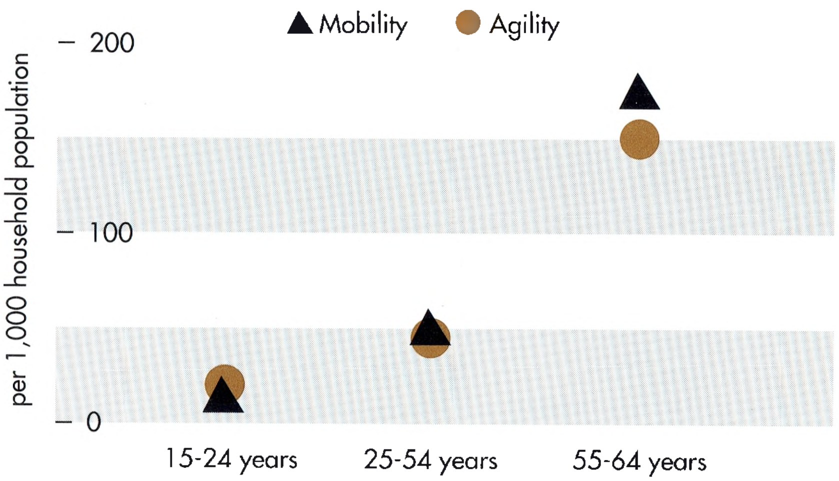
"Tell me, I'll forget. Show me, I may remember. But involve me, and I will remember."

Nine out of ten children with a disability attended school, with the majority going to regular classes.

Local public transportation was available for more than two thirds of children with disabilities between the ages of five and 14. But one in six children for whom public transportation was available had trouble using it. One in every nine children with a disability between the ages of five and 14 needed a special bus or van for local trips. Special bus or van service was only available for half of those children needing it.

3 FROM DAY TO DAY: ADULTS AND DISABILITIES

MOBILITY AND AGILITY

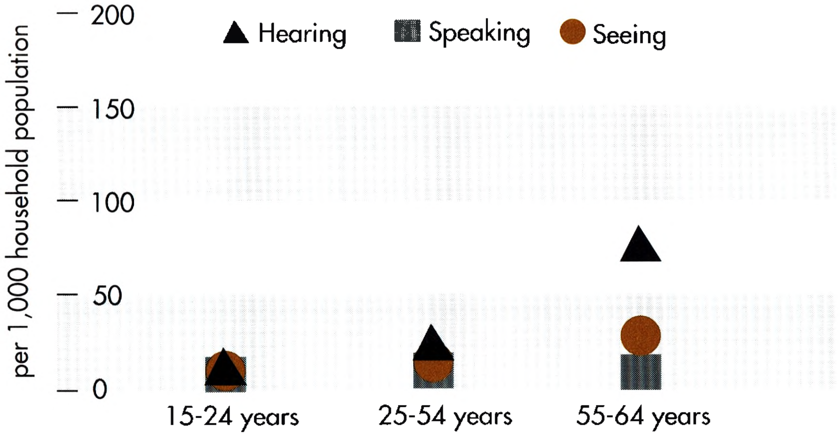


The most common disability among adults was a mobility limitation. HALS defines a person with a mobility limitation as limited in the ability to walk, move from room to room, carry an object for 10 metres, or stand for long periods. Nearly six out of 10 adults in British Columbia who were disabled and who lived in households had limited mobility.

More than half the adults with disabilities were limited in the ability to bend, dress or undress themselves, get in and out of bed, cut toenails, use fingers to grasp or handle objects, reach, or cut their own food.

Mobility limitations were the most common disability for adults.

HEARING, SEEING, SPEAKING



Hearing disabilities were more prevalent than seeing or speaking disabilities.

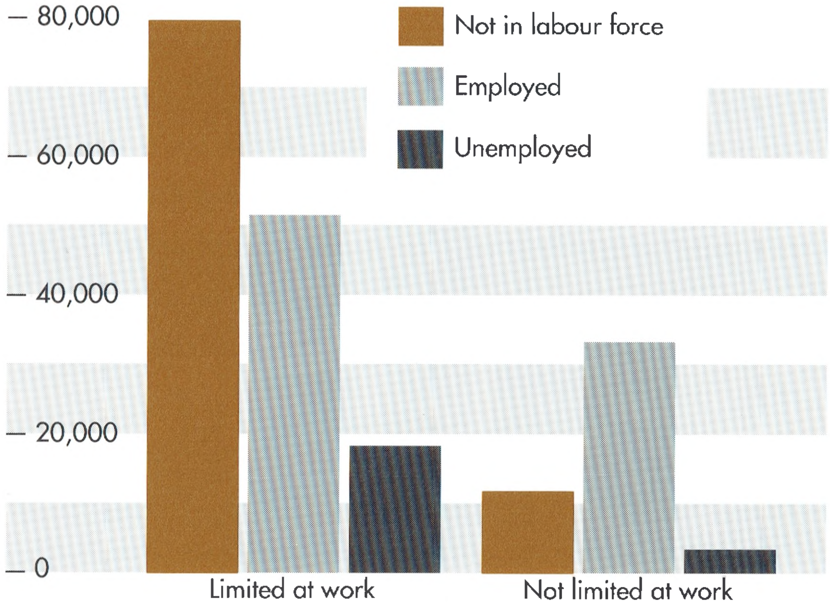
HALS defines a person with a hearing disability as being limited in the ability to hear what is being said in conversation with one other person or in a group conversation with three or more persons, even when wearing a hearing aid. One quarter of adults with disabilities had a hearing problem.

A person with a seeing disability is defined as limited in the ability to read ordinary newsprint or to see someone from four metres, even when wearing glasses. Twelve percent of adults had a vision problem which could not be corrected by glasses or contact lenses.

About six percent of adults who were disabled were limited in their ability to speak and be understood.

Two in seven adults with a disability were limited because of a learning disability or because of a mental, emotional or mental health disability, or because of developmental delay.

PARTICIPATION IN THE LABOUR FORCE



Fifty percent of people with a disability were in the labour force.

One out of every two adults who had a disability was active in the labour force. People with disabilities comprised about 7% of the provincial labour force. Of those active in the labour force, 80% were employed and 20% were unemployed. One in eight employed persons with a disability was self-employed.

Two thirds of labour force participants with disabilities had a disability which limited the kind or amount of work they could do. The unemployment rate for labour force participants who were limited at work was 25%, or two and a half times the rate for those who had a disability but were not limited at work by it. About half of unemployed persons reported barriers related to their condition that made it difficult for them to find work.

The unemployment rate for people with disabilities in the labour force was more than twice that of the general population.

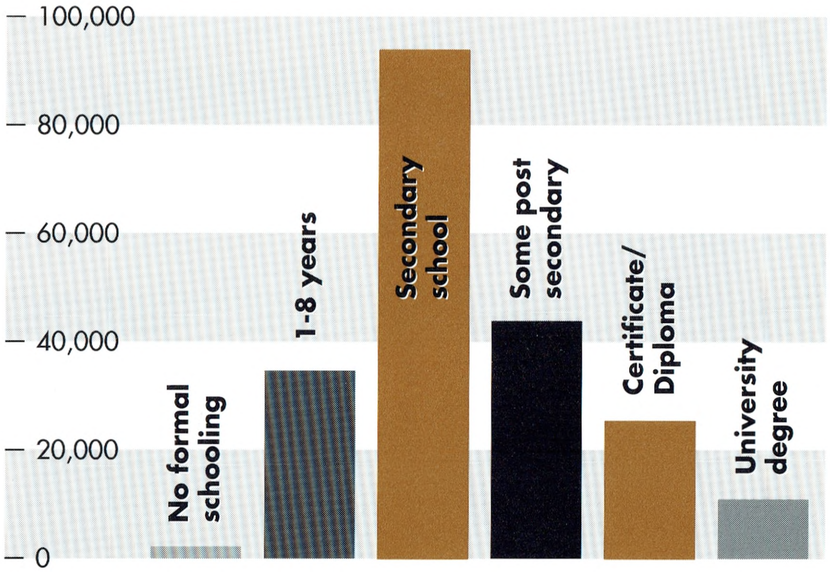
Three quarters of employed persons who reported that they were limited at work by a disability worked full time, while four fifths of those who were not limited at work worked full time – the same proportion of full time employment as among people who didn't have a disability.

Fifty-eight percent of the approximately 100,000 adults with disabilities who were not in the labour force reported that they were completely prevented from working because of a disability. About one in 10 of those people not in the labour force were not limited in the kind or amount of work that they were able to perform.

Half of those adults with a mobility disability were completely prevented from working because of their disability. Only one quarter of those with a hearing disability were completely prevented from working.

On-the-job training was offered by employers to one third of employed persons with disabilities. Thirteen percent of employees with a disability were limited or prevented by their condition from taking an available job training course.

EDUCATION

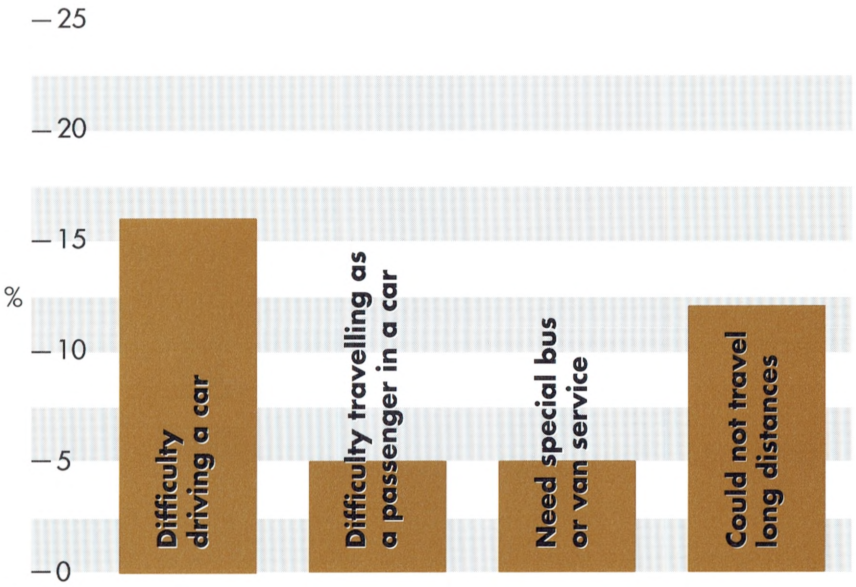


Five percent of adults with disabilities had a university degree while 12% had completed a post secondary certificate or diploma. Attendance at secondary school was the highest educational level attained by 44% of adults with disabilities. Seventeen percent had completed less than nine years of schooling.

For one in five adults with disabilities, a limiting condition was present before completion of their education. Over one third of those for whom the condition was present had their education interrupted for long periods. One quarter had to change schools because of their condition. One in five had to take fewer courses at school, college or university. Thirty percent of those who had a condition prior to completion of their education had to discontinue their education.

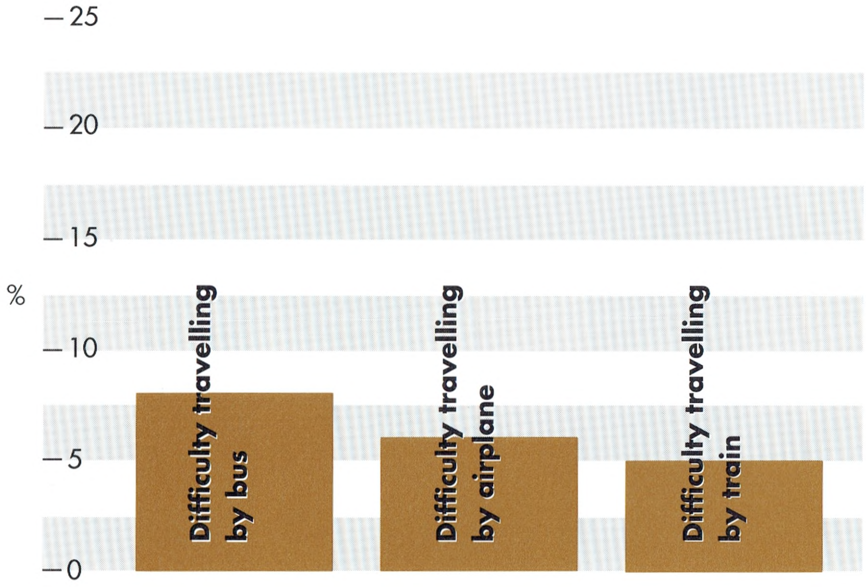
A person's disability affected school attendance, the number of courses taken, and the continuity of education.

TRAVEL – LOCAL



One in 20 adults with a disability was unable to leave his or her household due to the condition. Sixteen percent had difficulty driving a car, while 5% had difficulty travelling as a passenger in an automobile. Of the 5% of adults with a disability who needed special bus or van service, 40% did not have that service available.

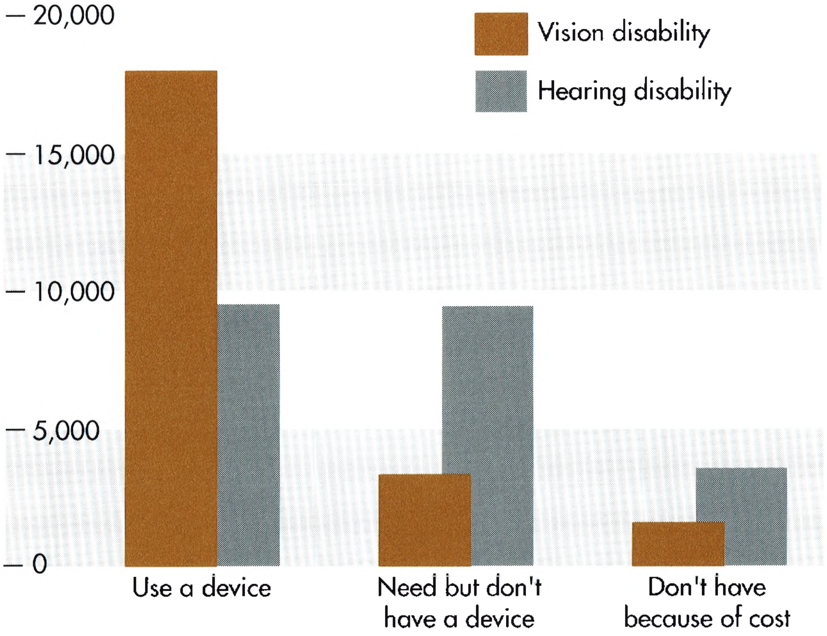
Long distance travel was not possible for one eighth of the adults with a disability. About half were prevented from taking long distance trips because the transport service was not suitable for their condition. One in seven who could travel long distances needed to be accompanied on the trip.



One in 10 adults with disabilities who could take long distance trips had difficulty travelling by airplane, bus or train. Bus travel posed a difficulty for about 8%. Airplane travel was difficult for about one in 17 adults with disabilities who could travel. One in 20 adults had trouble travelling by train. Ninety-five percent of adults with a disability frequently participated in activities outside their residence. Nevertheless, about 43% wanted to take part in more activities.

Forty-five percent of adults who would like to take part in more activities were limited by their physical condition and a similar number were restricted from taking part because the costs were too high.

ASSISTIVE DEVICES



Assistive devices were used by 17% of adults with a disability.

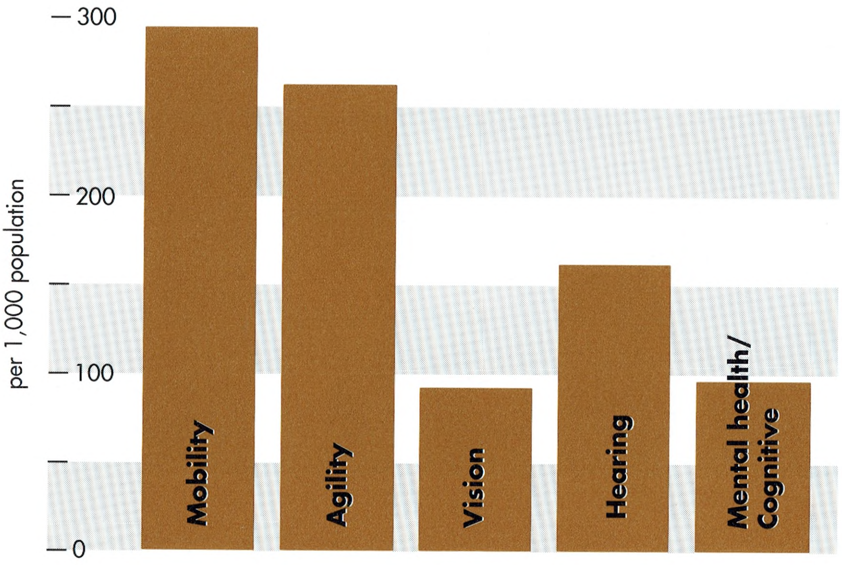
An equal percentage needed, but did not have, an assistive device for hearing.

Seventeen percent of adults who had a hearing disability used either a hearing aid, a volume control telephone, or both. A further 17% needed but did not have a special aid for hearing. Cost was the main reason for not having a hearing assistive device for 37% of adults who needed, but did not have one.

Seventy-two percent of adults who had a seeing disability reported the use of a vision aid. Thirteen percent needed, but did not have, vision aids. For 47% of those who didn't have a needed vision aid, lack of affordability was the main reason.

Mobility aids were used by 23% of adults who had a mobility disability. The most common type of mobility aid was a cane, used by one in 10 adults. Wheelchairs were used by one in 20 adults who had a mobility limitation.

MOST FREQUENT CONDITIONS



Three quarters of seniors with a disability had a mobility limitation. Two thirds of seniors who had disabilities had limited agility. Mobility aids were used by 36% of the seniors who had a mobility disability. The most common type of mobility aid was a cane, used by about one quarter of seniors with a mobility disability. Wheelchairs were used by 7% of seniors.

Forty-three percent of seniors had difficulty hearing. Forty percent of the seniors who had a hearing disability used either a hearing aid, a volume control telephone, or both. More than one in five seniors with hearing disabilities needed, but did not have, a special aid for hearing. Cost was the main reason for not having a hearing device for 29% of those who needed, but did not have one.

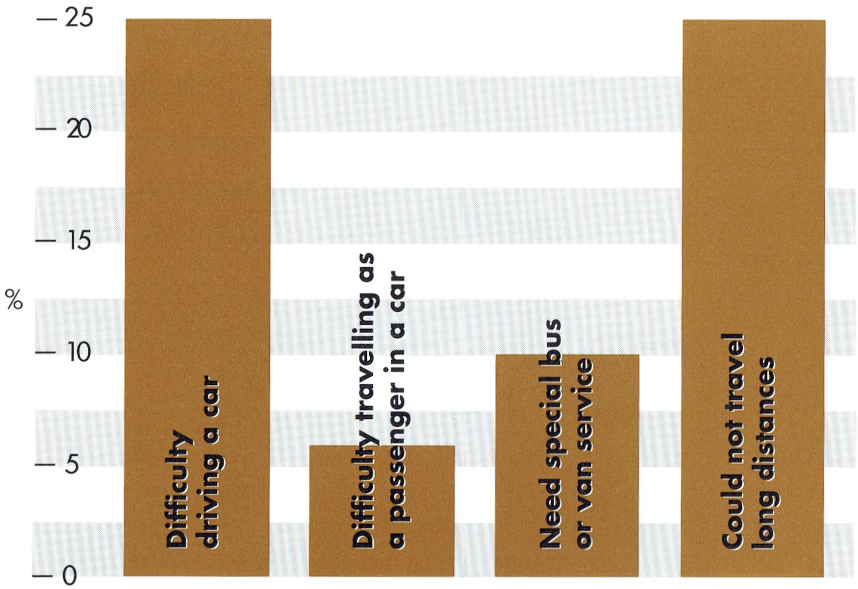
Mobility limitations were the single greatest disability for seniors in British Columbia.

Seven percent of seniors with a disability used a wheelchair.

Nearly one out of four seniors had a vision problem. Eighty-four percent of seniors who had a seeing disability reported the use of a vision aid. Of the seniors with seeing disabilities, 16% needed, but did not have, vision aids. Lack of affordability was the main reason for 31% of those who needed, but did not have, vision aids.

Only 4% of seniors were limited in their ability to speak and be understood. One quarter of seniors with a disability were limited because of a learning disability or because of a mental, emotional or mental health disability, or because of developmental delay.

TRAVEL



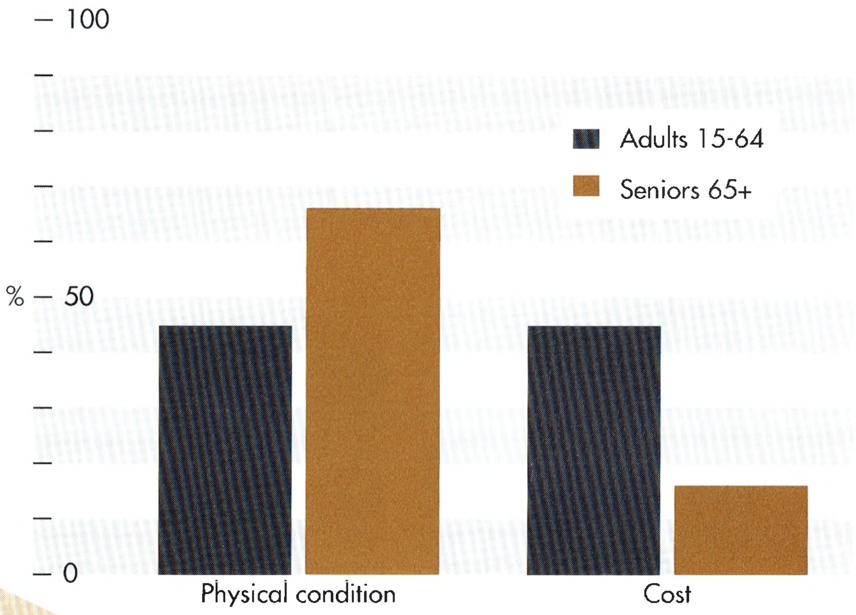
About 10% of seniors who had a disability were unable to leave their residence because of their condition. One quarter had difficulty driving a car, while 6% had difficulty travelling as a passenger in an automobile. Of the 10% of seniors with a disability who needed special bus or van service, one quarter did not have that service available.

Long distance travel was not possible for one out of four seniors. About half the seniors who could not take long distance trips were prevented from doing so because the transport service was not suitable for their condition. One fifth of seniors with disabilities who could travel long distances needed to be accompanied on the trip.

One in 10 seniors with disabilities who could take long distance trips had difficulty travelling by airplane, bus or train. Bus travel posed a difficulty for about 8% of seniors. Airplane travel and train travel were difficult for about one in 20 seniors with disabilities who could travel.

One out of four seniors with a disability could not travel long distances.

BARRIERS TO ACTIVITY



For seniors with a disability, physical limitation was a more considerable barrier to participation than the cost of the activity.

Eighty-five percent of seniors who had a disability frequently participated in activities outside their residence. About 30% wanted to take part in more activities. For seniors, physical limitation was a more considerable barrier to participation than costs. Two thirds of those who would like to take part in more activities were limited by their physical condition while one in six was restricted by the cost.

About 50% of seniors with disabilities received help with heavy household chores. One half of the seniors who received help with heavy chores received help from family members. Other major areas where seniors with disabilities received help from others included everyday housework (33%) and shopping (29%).

Forty percent of seniors who had a disability had been hospitalized at least once in the 12 months prior to the survey. Seventy-seven percent had visited a medical doctor at least once in the three months prior to the survey.

DARLYNNE HILDEBRANDT

Darlynne Hildebrandt knew something was wrong with her pregnancy long before she went into labour while driving by herself down the Malahat highway. She had bloated from 125 to 205 pounds and not once had she felt her baby kick. Even though it was her first pregnancy, Darlynne recalls a "sixth sense" from the beginning that the child would be born with some disability.

"I knew my life was going to focus on looking after her until she died."

She saw her daughter Chelsy for the first time in critical care, a moment Darlynne says was the most significant in her life. "When I looked at Chelsy it was as if I were watching a film running by at a zillion frames a second. And what it showed me was a child who was severely mentally handicapped and her dying. I knew my life was going to focus on looking after her until she died."

Chelsy was 10 weeks premature but was discharged only 13 days after birth. Distraught to find the medical team was treating her child as solely premature and ignoring her belief other things were not right, Darlynne kept a detailed log of Chelsy's painful, atypical progress. She couldn't keep any food down, was unresponsive, and screamed constantly. When she had her first seizure at two months, testing began.

Because it's difficult to diagnose an infant, doctors were reluctant to label Chelsy's problems. Already convinced of the severity of her daughter's handicaps, Darlynne wanted to take the next step. "I had processed what was happening and wanted to discuss how to provide for Chelsy before she died. I wanted to know what I could do to make whatever time she had a quality experience."

Medical and technological support was practically unlimited. But when Darlynne and Chelsy's father preferred to give their daughter the support of a family, they found they were on their own. Practically living in her pyjamas, Darlynne was up feeding Chelsy every hour or attending to nearly constant seizures. They never went out as a family; one parent shopped while the other monitored their daughter. Darlynne recalls feeling like a prisoner in her own home. She was even busier when her healthy son was born and admits she often felt like tossing in the towel. "I was so angry at that time. The technology was there to intervene and keep Chelsy alive, but as soon as she was discharged, we were ignored – as if our family's needs would go away once we were out of sight."

One evening, surrounded by doctors, three year old Chelsy responded to her mother's voice by lifting herself up and turning her head, something she'd never done in front of other people. For Darlynne, determined to show that her daughter would respond to love above all else, it was a proud and poignant moment. Chelsy died that night of pneumonia.

"She gave me unconditional love. I gave it to her and she gave it back. Her life wasn't in vain. My husband and I learned, others learned. I felt caught between two worlds; one that would celebrate my healthy son, the other world scorned and punished my daughter for not being perfect. We have to recognize that all people count and ensure that all children — not just some — are welcomed, safe, and cherished. It's a responsibility we all have."

"Three years ago I bought my daughter a fifty dollar hand-crocheted cloth for Christmas, on sale for half price. You might say a person on low income shouldn't buy such expensive presents when they can't provide for themselves. But you have the joy of Christmas — of having a gift loved — and I want the same. I don't want to put on my children's head the burden that I am abnormally poor. They have no idea I do without.

My children worry about me having schizophrenia. They were 19 and 20 when I became ill and they went through hell putting me in the hospital. Even then, they didn't discover that I had schizophrenia. They and I went through three more years of torture until a welfare worker, bless her, put me back in the hospital. The second time, with proper diagnosis, I was placed on medication. Luckily, I can function perfectly well on medication.

My children defend me to family members who have no idea what schizophrenia is. I've seen my family half a dozen times in 11 years and you can hardly say, "Hi, I'm sane now!" My children are forever saying, "Mom's perfectly fine, go visit her." But the pressure is there. My daughter cried and told me she worried when her doctor told her that her son had a chance of getting schizophrenia. I don't want her to have the added worry of really knowing that I'm this poor. So, I try for a traditional Christmas."

client, Strathcona Mental Health Team
Excerpt from "My Journal on Being Poor"

"I'm well educated so I'm relatively bright and can figure out the system. But I know many others can't and are having a lot of trouble.

The key is finding proper housing. There are housing problems in Vancouver, Nelson, Kamloops – but it's especially a problem for the mentally ill. Their behavior appears bizarre to the norm, so people don't want them around. Social housing provides a good base; it's the critical issue."

Nora Thorson has earned two university degrees while experiencing the highs and lows of manic depresssion – now called bi-polar affective disorder.

"Sometimes people are afraid of me because they know I've got schizophrenia, but that's totally unreasonable. I've never hurt anybody.

I would go out of my way to rescue somebody but I would never hurt them."

David Dawson is a student at B.C.I.T. and plans to become an independent software developer.

CHRIS POND

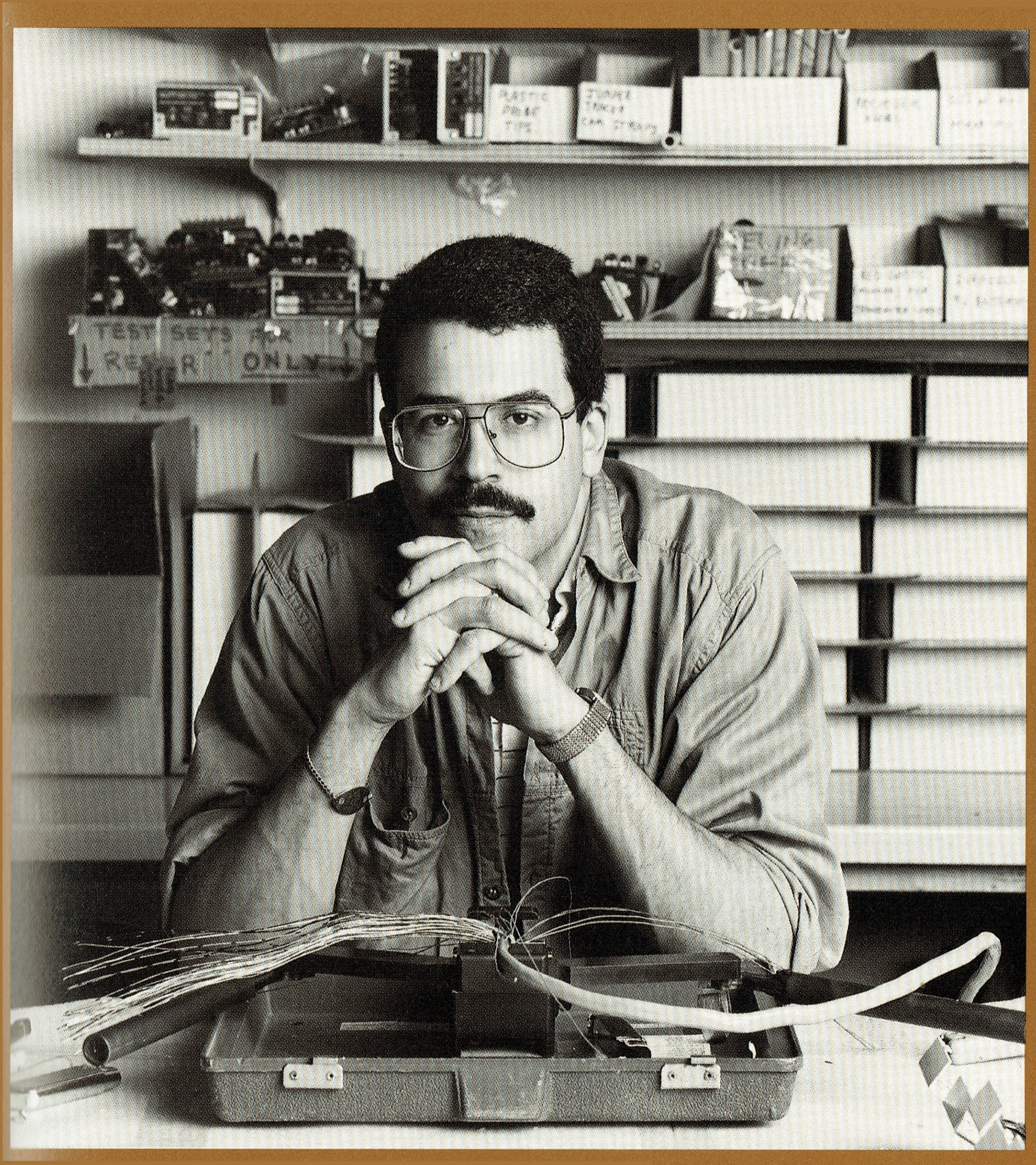
Taking a moment from his busy schedule to indulge in a little philosophy, Chris Pond shares an outlook so positive it could part the clouds: "Life is there for everyone. If there's an obstacle you go to it and go over it. There's nothing we can't do." After pausing a moment for effect he adds: "Some of us just need a little more time."

It took a long time before Chris learned why his school report cards were a parade of D's and the kids called him "retard". At 13 he was diagnosed as having attention deficit disorder – a learning disability which makes thinking about two things at once difficult and anything more nearly impossible. In a school system that places enormous value on concentration, somebody with an attention deficit can feel worthless. In his third attempt at Grade 10, Chris called it quits.

"At 26 ... Chris has a job installing phones for a communications firm, runs a company that offers software training, and is actively involved in several support groups for people with learning disabilities."

"That last year was a complete waste of time. But then I ended up stuck in a bad job and I wasn't going anywhere. My girlfriend felt the same so we decided to get married and come to Vancouver to change jobs, change careers, and restart our lives."

Now 26 years old, Chris has a job installing phones for a communications firm, runs a company that offers software training, and is actively involved in several support groups for people with learning disabilities. The key to his turnaround is control. By carefully managing his environment, Chris can do one thing at a time. He admits his daytimer is like a bible. "If I start to freak out because I've got a thousand things to do, I check my book. It tells me I only have one thing to do right now. That structure is important."


PLASTIC PROBE TIPS
TEST SETS FOR
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So is the support he's received from his wife, his religion, and an attention deficit support group which stresses the value of having a routine. When the routine is broken and the frustration returns, Chris goes for a run, because "when you are jogging, that's all you have to think about."

At work, however, escaping isn't always that easy. He gave up a sales position with a company when he acknowledged it meant juggling too many things at once. Installing phones has its challenges too, but Chris manages by memorizing complex wiring procedures in a way that makes sense to him — not as it's written in the manual.

Chris is the Vice President for the Vancouver Association for the Learning Disabled and sets nothing less than "social change" as his goal, concentrating on reforming the school system that caused him so much grief before he quit. "The proper programmes have to be chased down and set up. We need a lot of support, a fair amount of vocational training, and not so much school work."

Too much to ask for? Not to Chris Pond, who wrote the poem "What You And I See" to encourage others with similar disabilities to move ahead with their lives:

The Walls and Barriers that are put in front of us

Are put there artificially by outside people

They will seem insurmountable

Until we close our eyes.

KAY STOVOLD

A typical week for Kay Stovold begins with the phone ringing around 8:30 Monday morning and quickly develops into a series of meetings in and around Vancouver, several visits offering counselling services, and a few hours volunteering for a service group. At 81 and living with the effects of arthritis and osteoporosis, she's never been busier.

The two degenerative conditions — common amongst Kay's peers — began to seriously affect her only a few years ago. She now wears a back brace and has had one knee replaced. Unable to walk a full block or stand for long without experiencing pain, she has maintained a full lifestyle by admitting she can't do everything she once could. "I used to just hop on a bus and get wherever I wanted," says Kay, who never learned how to drive and now relies on her husband, Len, and others to get around. "I was very independent, so asking for help didn't come easily to me. But I learned to tell people if they wanted me to be somewhere I might need help to get there."

> *"I was very independent, so asking for help didn't come easily to me."*

Following the advice of her doctor to keep moving, Kay keeps a wheelchair in the trunk of the car to be used only as a last resort. Grocery shopping is possible with the support of a shopping cart, but large department stores are difficult. "I can make it to one department but then I'm pretty well stuck there."

Appointed by the Ministry of Social Services to provide counselling to other seniors, Kay has found having a disability is occasionally an asset. "It gives me a shared experience with them, so they don't hesitate to relate their problems to me. If they don't have a specific disability, often they are concerned they will face one soon. Depression itself is a disability."

Kay focuses her efforts on reaching out to isolated seniors and encouraging them to take responsibility for their own health. The first step is to acknowledge they could use some support and take advantage of social clubs and service groups that can help reintegrate them into the community. "Aging is a time of losses — family, friends. People begin to tell themselves they don't have much to live for."

Kay readily admits she misses things she used to enjoy, such as walks in Stanley Park, and the ability to watch birds through binoculars. But by staying involved, she has lessened the impact of her disabilities. "It's difficult for those who are not disabled to understand the anger and frustration that comes with it," she explains, acknowledging her respect for those who have successfully overcome significant obstacles. "I'm amazed at what some disabled people have accomplished."