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ABSTRACT

This review of the literature on disabilities considers: (1) their effect on individuals, families, and society; (2) their causes; and (3) their prevention. Individual subsections address such aspects as defining disabilities; causes of disabilities at various stages of the life cycle; emotional, social, legal, and practical aspects of effects of disabilities; defining the prevention of disability; current primary, secondary, and tertiary prevention efforts; and the cost of prevention. The paper concludes with a rationale and description of a program to instruct students in grades 7 to 9 about prevention and amelioration of disabilities. This program has been designed to be taught as an independent course but can also be incorporated into a family life curriculum. Each grade's teaching module contains a unit of general information about disabilities, a unit to encourage positive attitudes toward people with disabilities, and a unit about methods for preventing disabilities. Appendices provide addresses for obtaining related instructional materials and cost figures for services to people with disabilities in Saskatchewan (Canada). (Contains 93 references.)  
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# R E S E A R C H I N B R I E F

## Prevention of Disabilities

SSTA RESEARCH CENTRE REPORT: #94-07a DATE: Oct 1994

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This report and the *Prevention of Disabilities Program for Grades 7-8-9* was developed for the SSTA Research Centre by Florence Lalonde as a summary of her graduate student project entitled *Prevention of Disabilities: A Grade 7-9 Program to Encourage the Prevention and Amelioration of Disabling Conditions*. This work is distributed in two parts:

- #94-07a *Prevention of Disabilities* (background paper)
- #94-07b *Prevention of Disabilities Program for Grades 7-8-9*

The purpose of this study was to examine disabilities and their prevention. The importance of prevention was demonstrated through examination of the causes and effects of disabilities and through study of the cost of services required by people with disabilities and their families. Current prevention efforts were studied and public education was found to be an effective way to prevent the occurrence of disabling or handicapping conditions and lessen the effects of existing handicaps. No instructional program was found that was devoted to teaching the general population of young adults about disabilities and their prevention. Therefore, a program is offered to instruct students in grades seven to nine about prevention and amelioration of handicaps.

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## Abstract

Prepared as part of a Master of Education program, the purpose of this study was two-fold. The first goal was to research disabilities: their effect on individuals, families, and society; their causes; and their prevention. The second goal was to develop a curriculum to teach disability prevention to students in grades seven, eight, and nine.

Numerous books and articles (eg. Corbett, Klien & Bregante, 1987; Day, 1985; Goffman, 1963; Hahn, 1981, 1988; Hanson, 1992; Makas, 1988) describe the pervasive effects of disabilities on all aspects of life for individuals and their families. The literature also details the cost to society of lost productivity and creativity, and reveals the tremendous expenditure required to provide the services needed to minimize the effects of disabilities. Saskatchewan alone has over 100,000 people, including 10,000 children under the age of 15, who have some type of disability, and over \$100,000,000 is spent each year to provide residential, therapeutic, medical, vocational, educational and developmental services. Efforts to reduce the incidence of disability and to lessen the effects of existing disabilities are essential for both humanitarian and economic reasons.

The author's literature review revealed that there are numerous known causes of disability, as well as many additional factors that increase the possibility of an individual becoming disabled at some point in life. These risk factors may interact with each other and with conditions in an individual's ecosystem in extremely complex ways. Some of these causal factors can be eliminated and others reduced by the use of currently available preventive methods.

There are many prevention efforts underway at the present time, but requests sent across Canada and throughout the United States failed to locate any program specifically providing information on the prevention of disabilities to the general population of young people in the 13-16 year old age group. The **Prevention of Disabilities Program** (POD Program) section of this project was developed to fill this need.

The grade seven, eight and nine POD program contains background information for teachers, complete teaching modules for each grade, and an extensive section of instructional resources. Each grade level module contains three units, one with general information about disability, one which emphasizes community involvement, and one which addresses a specific area of prevention. The topics are as follows:

- Grade 7 injury prevention;
- Grade 8 child care and child development;
- Grade 9 prevention before birth including an optional section on the controversial topics of birth control, abortion, and sterilization.

By ensuring that teen-aged students are informed about the causes, effects, and prevention of disabilities, the incidence of disability may be reduced in both this generation, and in the next.

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## Section 1

### INTRODUCTION

According to Statistics Canada (1990), more than 3.3 million Canadians are afflicted with handicaps which affect their personal, economic, and social lives. These people suffer from social stigma and discrimination in fields such as job opportunities, housing, and community access. The services provided for them by the government amount to a substantial financial commitment which society is morally obligated to provide.

Some handicaps, perhaps as many as 80% (Drash, 1992; Pope & Tarlov, 1991), can be prevented by the application of present-day knowledge. It is my belief that, within ethical limits, disabilities must be prevented whenever possible. Further, I believe that funds should be provided for this prevention, and that this would be a good investment from both humanitarian and monetary perspectives.

One effective way to reduce not only the incidence of disability within the province, but also the effects disabilities have on individual lives, is through public education. The school is an appropriate place for this learning to occur, but there is no program in place in Saskatchewan schools which is devoted to the topic of disability prevention. The program presented here is designed to fill this void and inform Grade 7, 8, and 9 students about the prevention of handicaps.



Before attempting to influence any condition or situation, it is necessary to analyze it and understand it as fully as possible. Therefore, sections two and three of this paper examine handicaps, and describe existing prevention efforts. Section four contains the Prevention of Handicaps curriculum. It includes a teacher information section, unit outlines, lesson plans, and a section with suggested resources and sources of additional information.

## Section 2

### DISABILITIES OR HANDICAPS

This section has three goals: to define disabilities, to examine some of the causes of disabilities, and to explore the effects disabilities have on those afflicted.

#### Defining Disability

In order to describe disabilities, I will define them, discuss the terminology, and examine the relevant statistics.

#### Definitions

A disability is "the expression of a physical or mental limitation in a social context - the gap between a person's capabilities and the demands of the environment." (Pope & Tarlov, 1991, page 1).

Disability is not a single condition but a continuum which stretches from mild to severe and profound. According to the American Committee on a National Agenda for the Prevention of Disabilities (Pope & Tarlov, 1991), this continuum starts with a pathology. This professionally diagnosed condition may weaken or damage the patient's structures or functions, and result in an impairment. If this impairment limits a person's ability to perform a normal activity, there is a functional limitation. A functional

limitation, combined with a community situation that restricts the person's ability to live a normal life, produces a disability. A person with a pathology does not necessarily pass through all these stages and become disabled; the progression may be halted, or even reversed by medical procedures or environmental adaptations.

According to Pope (1992), "disability in this model, then, corresponds to what has often been referred to as handicap. However, handicap is a term that many people with disabilities and their advocates consider to be pejorative" (page 349). In view of this, the term "handicap" is used very little in this paper; however, when used, it is considered to be synonymous with "disability".

### Terminology Associated with Disabilities.

The field of disabilities, like all specific areas of interest, has its own terminology which changes with time, scientific discovery, and social change. We realize that time has changed acceptable professional terminology whenever we read a book which uses such outdated terms as "idiot" or "cripple". Medical discoveries constantly add new terms to the field. Clinicians feel a need for medical labels, but when these labels are applied in the community and the classroom, they may cause discrimination and stigma (Adelman, 1992; Darling, 1989; Lilly, 1992). As a result, there is a "push" by advocacy groups to change the terminology used in referring to disabilities (de Balcazar, Bradford & Fawcett, 1988/1990; Goffman, 1963; Meyerson, 1988/1990).

"Mental retardation" is a controversial term because it has highly negative stereotypic connotations. However, professionals must ensure that

the terms they use are clearly understood by the public; some of the common alternatives may not be perceived as equivalent. For example, parents told that their child is "developmentally delayed" may expect the problem to be completely resolved, eventually. They could be emotionally devastated when they finally realize that the child is mentally retarded. Throughout this paper I have used the term "mental retardation" because it seems to have the clearest meaning of all the alternatives; I have also used "intellectual impairment" as an alternate, for it seems to me to correspond well to other descriptors, such as visual impairment, which are in common usage.

### Statistics

In this section, I will explore the demographics of disability in Saskatchewan. I will define incidence and prevalence, describe the number of people who are disabled, and consider what disabilities they suffer.

#### Prevalence and Incidence of Disabilities

Prevalence and incidence are ways of measuring the size of a target group within the general population. The incidence rate of a condition is the number of new cases to occur within a given time. For example, the incidence of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) in Canada is 1 or 2 births per 1000, or 400 to 500 new cases each year (Donovan, 1992). The prevalence rate, on the other hand, is the number of cases in the entire population. When Donovan (1992) stated that "tens of thousands of Canadian adults are estimated to have FAS/FAE" (page 1), she

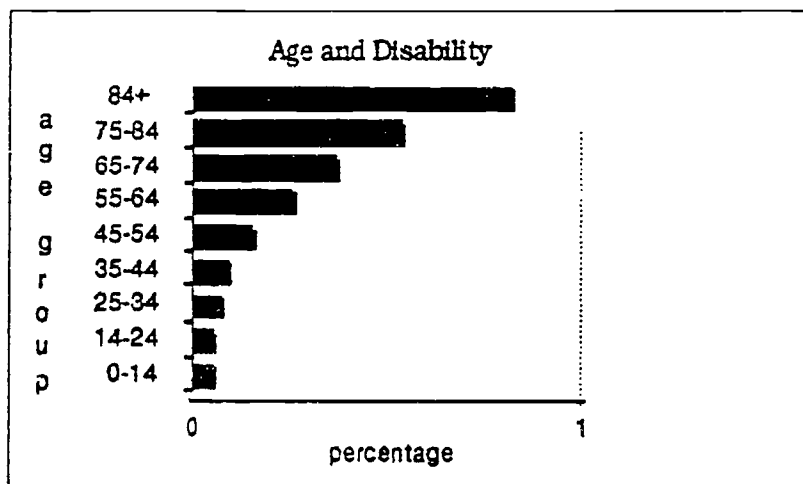
was giving the estimated prevalence.

### Prevalence of disabilities within Saskatchewan.

According to Statistics Canada (1990) the prevalence rate for disability is 13% of the population which means that approximately 3.3 million people in Canada are disabled. Of that national group, Saskatchewan has over 137,000 people who have some type of disability.

The prevalence of disability within the Canadian population rises with age, as indicated by figure 2.1.

Figure 2.1



### Severity and types of disability within Saskatchewan.

Disabilities among the population of Saskatchewan have been categorized by the severity of the condition (Statistics Canada, 1990). These figures are summarized in table 2.1 on page 7.

Table 2.1

Severity of Disabilities in Saskatchewan  
total number = 127,020

Age	Disability level		
	mild	moderate	severe
0 - 4	2,025	265	195
5 - 9	2,270	960	260
10 - 14	3,080	865	385
15 - 64	35,820	21,630	8,740
65 and over	16,155	21,380	12,990
total	59,350	45,100	22,570

The frequency of various conditions which affect children and adults in Saskatchewan is detailed in table 2.2 and table 2.3 (Statistics Canada, 1990).

Table 2.2

Characteristics of Disabled Children Living in Saskatchewan

wheelchair use .....	240
walking aid required .....	110
special footwear required .....	720
health conditions or diseases .....	3,035
cerebral palsy .....	340
serious arthritis or rheumatism .....	100
psychiatric problem .....	1,515
mental handicap .....	1,580
learning disability .....	2,550
missing arms, legs, fingers or toes .....	230
paralysis of any kind .....	255
visual problem (not correctable) .....	1,135
hearing problem .....	1,460
speaking problem .....	1,115

Table 23

## Characteristics of Disabled Adults Living in Saskatchewan

Impairment	Age Group	
	15 - 64	65 and over
mobility	39,095	38,090
agility	33,260	32,060
vision	7,850	12,155
hearing	15,200	21,820
speaking	3,440	2,740
other	16,165	13,445
unspecified	6,620	1,025

The figures given above do not consider that some individuals suffer from multiple handicaps. Despite the wide variety of disabling conditions listed, the only areas of disability considered in this paper are: sensory impairments, physical disabilities, and mental retardation.

In the sections above, I have defined disability, discussed acceptable terminology, and examined the number of people affected by disabilities. In the next two sections, I will consider common causes of disabilities, and the effect that disabilities have on the lives of those afflicted.

### Causes of Disabilities

There are two main reasons that professionals strive to find the causes of disabilities: first, the identification of a specific cause can help in treating the condition, and second identification of the cause of a disability may help prevent the occurrence of such disabilities in future generations.

There are thousands of known causes of disabilities (Ince, 1987), but

in a great number of cases the exact cause of the impairment is never known. Several factors may combine to create a disability (Bennett, 1981; Fotheringham, Hambley & Haddad-Curran, 1983), but for the purpose of this discussion I will consider causal factors individually. I have chosen two major categories to classify the known causes of disabilities: biomedical or constitutional, and socio-cultural/environmental.

Biomedical or constitutional causes have a basis in the body of the individual; there is a biological aspect to the condition. Most severe and multiple handicaps include conditions which fall into this category. Congenital disabilities, those present at birth, are constitutional conditions (Nagler, 1990).

Socio-cultural and environmental causes of disabilities are those which originate outside the individual's body. This includes not only those causes which stem from the social, cultural, and physical environments, but also those causes which result from the individual's life-style and behavior. These factors are hard to isolate for two reasons. First, they are very complex, and second, they do not inevitably result in impairment. For example, risks among people of low socio-economic class can run through generations because the cycle of poverty creates conditions which contribute to the incidence of disabilities (Kopp & Kaler, 1989). In spite of these conditions, the majority of poor children do not develop disabilities (Fotheringham et al., 1983; Santrock & Yussen, 1989). Since there is no direct cause and effect correlation between the associated socio-cultural and environmental conditions and disabilities, the conditions are generally called "risk factors". Those exposed to them are considered "at risk" for developing a disability.

Disabilities can originate at any stage of life: prenatal, perinatal, infancy, early childhood, adolescence, adulthood and old age.



## Prenatal Causes of Disabilities

The prenatal period extends from conception to the time of birth. Disabling conditions can occur at any point in the developmental process between those two events. Some prenatal biomedical causes of disability involve the basic building blocks of life: the genes and chromosomes which the person inherits. Other handicaps result from the prenatal environment within the womb (Kopp & Kaler, 1989). These causes can be considered separately, but it should be realized that heredity and prenatal environment work together to produce the infant.

### Chromosomal Causes of Disability

Most of us have 46 chromosomes (23 pairs) in almost every one of our cells. A woman's ova and a man's sperm cells usually have only one of each pair, or 23 chromosomes. When an ovum and a sperm cell unite, they produce a complete cell with 46 chromosomes. Of the 23 sets of chromosomes, 22 pairs are similar, but the other pair is very different. These are the X and Y chromosomes which determine the sex of the child. Two Xs combine to produce a female, while an XY combination produces a male.

Chromosomal abnormalities can involve the loss, gain, or exchange of genetic material from a chromosome pair. Such abnormalities often cause miscarriages, but may occasionally result in a baby with some kind of disability (Bennett, 1981).

Down Syndrome, a congenital condition which usually includes health problems and mental retardation, is caused by an abnormality of the chromosomes. The twenty-first chromosome set is a triplet instead of a

pair, hence the other name of this syndrome, Trisomy 21. Down Syndrome is associated with the mother's age. The incidence rate is high when mothers are extremely young, low for mothers in early adulthood, and increases with the mother's age after 35.

### Genetic Causes of Disability

Chromosomes are made up of genes which, alone or in combination, govern all our inherited characteristics. Some disabilities are caused by specific genes that create damaging biomedical conditions. There are over 3,000 different genetic causes of disability (Ince, 1987).

Just as we can inherit our eye colour or a dimple from one of our parents, so we can inherit certain types of disabilities (Bennett, 1981). There are definite patterns of inheritance which govern whether or not various traits affect us. An example of a genetic defect is Sickle Cell Disease, a blood disorder caused by recessive genes. Children only have the disorder if they receive the gene from both parents. If the gene is paired with a normal one, the individual does not have the condition, but can pass it on to his or her descendants. These individuals are called "carriers". About one in every 10 blacks in the U.S. carry the gene for sickle cell disease (Ince, 1987).

### Prenatal Environmental Causes of Disability

The prenatal environment is almost always a safe and nourishing one for a developing baby, but there are some environmental influences which can damage a fetus. These influences include external agents, infections, toxins, and maternal health (Bennett, 1981; Fotheringham et al., 1983;

Ince, 1987; Shurtleff & Shurtleff, 1981).

External agents which can cause prenatal damage include injury and radiation. Seatbelts done up across the mother's abdomen can injure the baby in an accident. Any violent blow to the mother's abdomen can also hurt her child. Radiation such as X-rays can affect the fetus.

Some infections that the mother suffers can damage the infant when the disease organisms cross the placental barrier. Rubella or German Measles can cause severe disabilities, including blindness and mental retardation. Syphilis and Acquired Immune Deficiency Syndrome (AIDS) can not only affect the fetus in-utero, but also may infect the baby during birth.

Many prescription and non-prescription drugs can cross the placenta and adversely affect the developing child. Street drugs such as heroin and cocaine can cause decreased central nervous system function and addiction in the fetus. A wide range of prescription medications such as hormones, anticonvulsants, antibiotics, and tranquilizers are known to affect the baby. It is suspected that other drugs may also have negative effects.

Alcohol crosses the placenta easily and stays in the baby's system longer than it does in the mother's (FAS Symposium, 1993). Alcohol can create a spectrum of effects on the baby. These may include any or all of the following: various degrees of mental retardation, physical abnormalities, hyperactivity, autistic tendencies, and failure to thrive. There are many identified variables that influence the degree to which a mother's alcohol consumption affects the fetus. Some of these variables are: the amount of alcohol consumed, the stage of development of the fetus, whether the mother had been "binge drinking" or drinking on a regular basis, and the mother's general health, nutrition level, and metabolism.

Maternal health and nutrition affects the developing child.

Deficiencies in iron, vitamins, and calorie intake can place the baby at risk. Illness of the mother, especially long-term illness, can also affect the child. Good prenatal medical care reduces these risks and increases the likelihood of having a healthy infant.

The age of the mother is another factor associated with an increased risk of impairment. Teen-age mothers, especially those under 15 years of age, have a greater risk of having babies with low birth weight (March of Dimes, 1989, 1992). Babies who are full term, but unusually small, are more likely to have a disability than are larger, more robust infants (Fotheringham et al, 1983; Levy, Perhats, Nash-Johnson & Welter, 1992; McDonough, 1985).

#### Perinatal Causes of Disability

The perinatal period is the time immediately before and after birth. Disabilities originating from this time period are primarily biomedical ones. They may result from prematurity, injury, oxygen deprivation, or infections acquired during the trip through the birth canal.

Premature infants are babies who were born too soon. They are no more likely to have congenital disabilities than any other infant (Santrock & Yussen, 1989). They are at risk, however, because of their immaturity and lack of preparation to survive independently. Many premature infants require the use of oxygen and some suffer a form of blindness called "retinopathy of prematurity" caused by an excess of the very oxygen which preserved their lives (World Health Organization, 1992).

Oxygen deprivation may occur during a prolonged or difficult birth, and, because the brain suffers damage very quickly without a fresh and

adequate supply of oxygen, brain damage can result. The effects of this damage may include impairments in the areas of motor control, intelligence, and sensory processing. The severity of the impairment reflects the severity of the damage done to the baby's brain.

Several sexually transmitted diseases can be contracted by a baby during the trip through the vagina. These infections include syphilis, AIDS, gonorrhea and herpes. Gonorrhea only affects the eyes of the infant, but herpes can result in severe disabilities due to nervous system damage (Shurtleff & Shurtleff, 1981). AIDS can also infect a baby through breast feeding.

### Childhood Causes of Disability

Disabilities originating during childhood may be caused by biomedical and environmental factors.

#### Biomedical Factors

##### Injury as a cause of disability.

The types of injuries children are most likely to experience change with the age of the child.

Tiny babies are rather floppy and slippery, and they have a tendency to put things in their mouths. These characteristics place them at risk for two types of accidents. First, they can fall when they slip out of restraints intended to care for and protect them, such as people's hands, cribs, high chairs, and playpens (Saskatchewan Institute on Prevention of Handicaps,

1991). The resultant injuries can produce motor or intellectual impairments as well as temporary damage such as bruises and broken limbs. Second, they can choke on small objects such as tiny toys, or pieces of toys. This type of accident can result in suffocation, anoxia, and brain damage.

Curiosity, lack of experience, and improved mobility combine to increase the toddler's chance of injury. Toddlers often fall when trying to get something they want, or see something that interests them. They may be injured when they investigate tools, pots on the stove, or electrical outlets. Cleaning products seem to hold a fascination for toddlers; according to the Saskatchewan Institute on the Prevention of Handicaps, thousands of poisonings involving household chemicals and children under four years old are reported each year (1991). Many of these accidents result in disabilities.

Spinal cord and brain injuries are of special concern due to the serious consequences of damage to the central nervous system. Such injuries often occur as a result of inadequate protection when children are riding in motor vehicles, or as passengers on bicycles.

#### Childhood disease as a cause of disability.

Childhood diseases can retard a victim's future development. One of the most severe cases of disability I have seen was the result of meningitis suffered by the child in early infancy. This little one has sensory and motor limitations, and may have intellectual ones as well. It is impossible to assess the child's intelligence at present, because there is no appropriate method of evaluation for a youngster so severely handicapped.

Disabling conditions can sometimes result from common infectious diseases. Encephalitis, an inflammation of the brain which can cause mental retardation, is a possible complication of such childhood illnesses as

mumps, chicken pox, and measles. Measles sometimes cause visual impairment. Ear infections which often accompany children's colds, can result in conductive hearing loss. Because of the tragic results of possible complications, even mild childhood diseases should be carefully monitored.

### Environmental Causes of Disability During Childhood

Though many children are resilient enough to grow up normally in spite of socio-environmental conditions such as neglect, poverty, famine, and even war, some do not. For some children environmental deprivation has a debilitating effect on the development of abilities such as language use, adaptive behavior, and cognition. Deprivation can include poor nutrition, poor housing, lack of social interaction and limited opportunity for varied experiences. These conditions are frequently associated with poverty, but can occur in any environment. They may sometimes be a symptom of child neglect or abuse.

Poor nutrition and starvation have been proven to have an effect on many areas of development. According to Jeppeson (1988), "hunger produces nervousness, irritability and a decreased ability to learn" (page 5), thus it can have a negative effect on all aspects of a child's development. Negative effects increase with the degree of malnutrition. A severe vitamin A deficiency can cause blindness in children after they are weaned (World Health Organization, 1992). A protein-calorie deficit during the first six months of life affects mental development (Crump, 1984) and may damage the developing nervous system (Galler, 1984; Jeppeson, 1988). Malnourishment is also associated with an increased susceptibility to infections.

Poor housing can be associated with a variety of disabling conditions.

Chances of accidental injury increase when buildings are in poor condition. Cheap housing often consists of older buildings which may still have lead paint on walls and woodwork. Children often ingest this paint and get lead poisoning which affects the nervous system. Old buildings are often cold and drafty, and have substandard (or non-existent) plumbing and heating which increases the risk of disease and infection.

Limited social interaction and reduced opportunity for a variety of experiences are social-environmental factors which affect linguistic, emotional, and cognitive development. This type of environmental deprivation can occur in any home where language use is limited and life experiences lack variety.

Environmental deprivation can interfere with educational potential. Lack of exposure to reading and writing can adversely affect children's chances of academic success because this form of communication is unfamiliar. Reading and writing are less important when basic survival is in question; this can interfere with a child's motivation to learn academic skills.

Cultural differences can be risk factors for two reasons: discrimination and lack of understanding. Discrimination based on racial and cultural differences may affect a family economically and socially. Economic discrimination affects job opportunities, parental employment, and family income. It can result in hardship and poverty, which produce the risks described above. Social discrimination may add to the isolation of the family as a group and family members as individuals. Isolation can limit social interaction and experiences and have a harmful effect on the development of children in the culturally different family. Lack of understanding of cultural differences can result in a "mismatch" between what children experience at home and what is expected of them at school (Day,



1985/1990; Garcia & Malkin, 1993; Harry, Torguson, Katkavich, Guerrero, 1993; Lynch & Hanson, 1992). This mismatch can lead to inappropriate schooling, which may result in intellectual impairments and functional limitations.

Deprivation during the developmental period is a contributing cause for many disabilities. Malnutrition, and increased risk of injury and infection, contribute to the number and severity of existing impairments. Limited opportunities for social interaction, lack of richly varied experiences, and low exposure to all forms of language, increase the risk for impairment of intellectual and linguistic development. Schools which do not consider the cultural and linguistic differences of students can deprive children of an adequate education.

Environmental risk factors, whether they are economic, social, cultural, or physical, intensify the effects of biological impairments and increase the likelihood of disability. Since deprivation is often associated with poverty, low socio-economic status itself becomes a risk factor. This has a special significance for people who live in this province because Saskatchewan has the highest incidence of low income among children in the country (Cregheur & Devereaux, 1991).

### Causes of Disability in Adolescence and Early Adulthood

Teenagers and young adults are often involved in high-risk, physical activity. Because of this active life-style, injury is a common cause of disabilities which originate during this period of life. According to Pope and Tarlov (1991) the group "at highest risk for sustaining traumatic brain injuries are people between the ages of 15 and 24, especially males.... Older

adolescent males and young men are at greatest risk of spinal cord injury" (page 12). The causes of these injuries include falls, swimming accidents, motor vehicle accidents, and physical violence.

### Causes of Disability in Late Adulthood and Old Age

As people age, the prevalence of disabilities increases. Chronic health conditions appear which interfere with the individual's quality of life. Limitations of mobility and agility result from degenerative conditions such as rheumatism and arthritis. Strokes may cause brain damage which can affect language skills, mental ability, or physical activity. The prevalence of sensory impairment also increases with age.

The incidence of injury is high in elderly people (Campbell, 1989). Poor coordination may result in falls or other accidents. Increased frailty caused by such factors as brittle bones and thin-walled blood vessels increases the amount of damage done by accidents.

### Summary

There are many causes of disability, both biomedical and socio-environmental. Causal factors may operate independently, or combine to produce a disability. It is important to know the causes of a disability in order to prevent further occurrences. However, despite all that is known about the causes of various disabilities, there are many conditions for which no cause has been identified.

## The Effects of Being Disabled

For those of us who have not experienced severe disability, it is difficult to understand the effects that such conditions can have on one's life. It is often difficult to know what to do when we see someone with a disability. Will they be offended if I look at them? Can I ask what happened? Do they need help? Should I help? How?

To get a feeling for the attitudes expressed by individuals with disabilities, consider the following excerpts from the Government of Canada's publication, Surmounting Obstacles (Smith, 1983):

I find that people have some very funny myths about disabled people. For one thing, they think that we are fragile. I find just the opposite ...

Disabled people are constantly adjusting on a daily basis to difficulties that many people face only in a crisis. So who are the sheltered people in our society?

The strangest thing about disabled people is that we usually think, feel and react like 'normal' people, yet people expect us to react differently.

Joan Green

For a long time I was miserable about my condition, but now I'm getting used to it. I try my best to be happy all the time.

There are so many things I can't do because the money isn't there. I can't even afford a phone and I need one badly....

Before they design another (nursing home), they should talk to handicapped people about their needs. The bathrooms are all built for skinny guys, you can't even get in there with a wheelchair.

Julius Hager

There was a lot of blatant discrimination by the other kids, but I think that children are really innocent. They become programmed by their parent's attitudes. It's crucial that disabled children get into a normal school setting as early as possible so that they can get used to being with normal kids early in life. It's also crucial because then normal kids can get used to physical disabilities, and start educating their parents.

Canada is basically a materialistic society which is very hung up with money, and with visual beauty. Persons with a physical disability are automatically excluded from so-called "normal" activities simply because we are visibly different from other people. And because we are physically different, it is assumed that this fact changes us as human beings: For example, it is assumed that it changes our sex life, that we become asexual, that we become sick persons.

Len Seaby

In the next section of the paper, I will consider some of the points brought up by these people and others. Emotional adjustment, social issues, practical considerations, life-style choices, and the rights and requirements of those who are disabled will be included.

### Emotional Adjustment

Peoples' reactions to their disabilities vary with the individual, the severity of the handicap, and the time of life when the condition began. A person's emotional adjustment can be made more difficult by social discrimination and the limited concessions made by the community.

For those individuals who are born with an impairment, the emotional adjustment is on-going; it changes with the different phases of life. These people have never experienced what we consider a normal life, and the awareness that they are different may develop slowly as their social contacts increase. People with congenital handicaps may have more difficulty developing some skills. For example, developing "mainstream" language is harder for someone born deaf than it is for a person who becomes deaf after the age of three. People with congenital conditions must deal all their lives with the reality and permanence of their situations, but they do not experience the intense loss and adjustment difficulties of those who are suddenly disabled.

People who acquire an impairment through injury or sudden disease have a more dramatic and immediate adjustment to make. They must cope with their medical problems. They have to adjust to a new social situation and accept new attitudes and expectations from others. They may have to live with new limitations on their access to community facilities and services and suffer new limitations of opportunities. In addition, they may be coping with job loss, family crisis, and marital stress. Is it any wonder that their emotional turmoil often includes anger, guilt, grief, jealousy, resentment, helplessness, and frustration? Sudden disability is a terrible situation to cope with, but it is one that may happen to any of us at any time.

A slow degenerative condition puts somewhat different emotional stresses on affected individuals and those around them. The shock of adjustment is cushioned by time before impairment and functional limitation occur. The person may have time to put in place structural features required for continued mobility. Time may offer a chance for the person to get training to lessen the eventual effects of the condition, and thus avoid experiencing a disability which affects the quality of life. However, there is

still the emotional turmoil of anger, resentment, guilt, and jealousy to work through before attaining acceptance.

Parents who discover that their baby is handicapped suffer tremendous emotional upheaval. It has been compared to the death of the imagined "ideal" child that every parent expects to have (Day, 1985). The grieving process is compounded by resentment that an imperfect substitute has been left in the place of the anticipated infant. The reactions of friends and family members can be devastating at this time (Featherstone, 1980). However, the emotional reactions of parents vary, and professionals must not assume that a specific pattern of reaction is inevitable. Cultural values have a large influence on the degree of trauma the parents experience (Hanson, 1992).

Though common emotional reactions can be identified among large numbers of people who must cope with disabilities, they cannot be assumed to exist in every person or every family. Interventions should be individualized to meet the needs, wants, and culture of the person and the family (Lynch, 1992).

### Social Issues

Disabilities have many effects on the social lives of those afflicted. These include the attitudes of others, the effect of personal appearance and behavior, leisure activities, and sexuality. The next section of this paper will consider these issues.

## Attitudes of Others

The attitudes of other people are the major problems faced by people who have disabilities (Saskatchewan Human Rights Commission, undated brochure). Even when non-disabled people have good intentions, there is often friction between them and the disabled people they meet. On the one hand, there is a lack of understanding on the part of the nondisabled and, on the other hand, there is limited patience on the part of the individuals with handicaps. Unhappy situations occur because the nondisabled people assume that the disabled individual needs help, and the natural scenario which would occur between equals is upset. People who are disabled may react with anger and frustration when they are patronized or when inappropriate assistance is forced upon them (Makas, 1988/1990).

Makas (1988) studied "positive attitudes" by comparing what disabled and nondisabled people meant by the term. Factor analysis identified two attitude clusters among the nondisabled which were rejected by those with disabilities. He described them as follows:

... the "Give the Disabled Person a Break" cluster and the "Disabled Saint" cluster. Items that comprise the Give the Disabled Person a Break cluster involve special concessions made for disabled individuals. Disabled respondents rejected this notion. They indicated that they neither want nor expect special treatment because of their disabilities.

Items in the Disabled Saint cluster represent positive characteristics frequently attributed to persons with disabilities. Disabled respondents ... rejected these attributes as defining persons with disabilities (page 29).

In Makas's study (1988), the attitudes that people with disabilities regarded as positive differed from those regarded as positive by the nondisabled respondents. The attitudes appreciated by those with disabilities either did away with the special category of "disability" altogether, or supported their civil and social rights.

People without disabilities thought that positive attitudes were those which were "nice" and "helpful". They did not realize that this sort of response actually placed the recipient in a needy position. When asked to respond in an especially positive manner, these behaviors, which the people with disabilities found offensive, increased. Consequently, the more positive the nondisabled people were trying to be, the more likely they were to offend.

The attitude conflict described above can be resolved by educating the nondisabled public. Relationships between people with disabilities and those without can be improved through open communication and personal interaction (Makas, 1988/1990). Another way to change public attitudes toward people with disabilities is through positive media presentation.

#### Media portrayal and public information.

Traditional images of people with handicaps include such figures as the Hunchback of Notre Dame; Mr. Hyde; Captain Hook; and Lenny from Steinbeck's Mice and Men. Dangerous people are often portrayed as "scarred, maimed, ugly, deformed, physically and mentally handicapped, monstrous." (Bogdan, Biklen, Shapiro, & Spelkoman, 1982/1990, p. 138). Children are exposed to negative images about people with disabilities from books, movies, plays, television, and comics. Such stereotypes influence the reactions of people toward individuals who are obviously different (Goffman,



1963). We can see these stereotypes at work when people react with hostility to the idea of a group home in their neighborhood (Hahn, 1981/1990).

Movies often show "people with disabilities in a negative and unrealistic way, preferring the sensational or pitiful to the everyday and human side of disability." (de Balcazar et al. 1988/1990, page 10). In spite of this, there have been many positive movie representations of disabled individuals. Examples include a 1930 film called City Lights, where Charlie Chaplin befriends a blind girl; the 1946 movie Best Years of Our Lives about a sailor who came back from the war after losing both arms; and Miracle Worker, the film about Helen Keller produced in 1962. Mask, Children of a Lesser God and My Left Foot are modern examples of movies which give fairly realistic views of people who are disabled (Michal-Smith, 1987; Nagler, 1990).

The Special Olympics creates an active and appealing image of people with disabilities. Public news reports of these events are carried by many forms of media: radio, newspaper, and television.

Television has presented some excellent depictions of people with handicaps; Fifth Estate did a sensitive presentation of a girl with Fetal Alcohol Syndrome, and Oprah Winfrey has respectfully interviewed individuals with conditions such as Pader-Willi Syndrome. Such portrayals help remove the stigma suffered by people with disabilities.

### Personal Appearance Related to Social Attitudes

Personal appearance can influence the way individuals are treated socially and affect their professional and economic opportunities. For example, consider the importance of a good first impression at a job

interview.

For people with physical disabilities personal appearance is a particularly sensitive issue. Physical differences may be seen as unattractive or even revolting (Hahn, 1988/1990). People's initial reactions tend to focus on an obvious disability rather than on the person. Kaiser, Freeman and Wingate (1985) questioned people with disabilities. Sixty percent of those questioned believed that other people noticed their disabilities first and their individual appearance second. Many of the respondents agreed that this trend reversed if they were attractively and fashionably dressed.

Individuals who have physical handicaps may find it difficult to get attractive clothing that is suitable, comfortable, and easy to put on. Clothes specifically designed for people with disabilities often look odd because of big zippers, or velcro closures in unusual places. Regular clothing is preferred because it reduces the wearer's visible difference and helps the person to fit in with the general population. Some individuals choose clothes which will conceal their disabilities. Others divert attention by the use of eye-catching clothing such as T-shirts with controversial slogans. A few people with physical disabilities enjoy the extra attention they get and dress flamboyantly to encourage it (Kaiser et al, 1985/1990). Clothes give people with disabilities the choice of normalizing their appearance or emphasizing their uniqueness, according to their mood of the moment.

Many people with physical disabilities manage their personal appearance in ways that reduce the stigma associated with their differences (Goffman, 1963). This increases their social acceptance by non-disabled people.

## Behavior and Social Acceptance

Enthusiastic and outgoing behavior can overcome the stigma of disability and increase a person's social acceptability (de Balcazar et al., 1988/1990; Goffman, 1963). Conversely, socially inappropriate behavior can cause people to ostracize anyone displaying it (Duchan, 1987; Knoblock, 1987). Such behavior as repetitive aimless motions, drooling, and messy eating habits stigmatize a person who exhibits them. According to Knoblock, "particular behaviors such as lack of eye contact or difficulty moving ... may make it difficult for some ... to attend to children or to sustain their own level of involvement" (page 247).

The education of individuals with impairments includes training to help them behave in ways which fit the general perception of normal. For example, individuals with visual impairments are taught to face someone who speaks to them. This approximation of the eye contact common in most conversations helps a sighted person to feel at ease in the situation.

People who are mentally retarded find the mastery of normal social behavior patterns difficult. They have trouble learning to interpret social interaction, and judge appropriate responses, because continual analysis of complex, constantly changing, situations is required.

Social behavior skills are the most involved and convoluted skills for anyone to master, yet they are needed in order for a person to experience social acceptance and participation in community life. For many people this participation includes church activities, parties and dances, involvement in sports, clubs, and organizations. These and other leisure activities are highly valued parts of a normal social life.

### Leisure activities

Because of their low rate of employment, people with handicaps tend to have more leisure time than the general population. According to a 1985 study by Day, disabled people usually choose leisure activities which are inexpensive, passive, or solitary. Watching television, reading, walking, relaxing, and listening to records were the five most common activities. A large number of the people queried said that they would rather travel, work, or socialize, but that they could not because of lack of money, motivation, or health (Day, 1985/1990).

People with disabilities have the same social needs as everyone else. These needs include friendship, love, and intimacy. Sex is both a social concern and a need, and this is the area of social life we shall consider next.

### Sexuality and Disability

The combination of sexuality and disability is an extremely upsetting one for many people. In the next section we discuss several aspects of this combination. Specifically, we will consider sexual identity, sexual abuse, sex education, marriage and parenting.

#### Sexual identity of people with disabilities.

During the thirteenth century, the public was fascinated with physical differences. This allowed many people with disabilities to support themselves through jobs such as court jester, entertainer, or good luck charm (Hahn, 1988/1990). Flagrant sexual exploitation of the people in these roles led to condemnation from the church and a decrease in such

employment opportunities. Consequently, many people with disabilities were forced to beg to survive. Because disabled people were more successful than other mendicants, healthy people disfigured themselves and their children, so they could share in the relative prosperity. The combined repression of sex and the increased perception of people with disabilities as needy, produced a common stereotype which "portrayed disabled women and men as the aesthetically neutered objects of benevolence and assistance." (Hahn, 1988/1990, page 314).

One of the major goals of normalization must be the acceptance of people with disabilities as neither sexual objects nor asexual beings, but as people with the same needs and desires that others experience.

#### Sexual abuse of disabled people.

Individuals with disabilities face the very real possibility of sexual abuse or exploitation. It has been estimated that as many as 68% of girls and 30% of boys with mental retardation will be sexually abused before the age of 18 (The Roeher Institute, 1988).

Factors that increase disabled individuals' vulnerability to abuse are: "being viewed as powerless by abusers, being taught to be passive, isolation within families or institutions, lack of disabled adult role models, and lack of personal privacy" (Corbett, Klien & Bregante, 1987). Lack of information about abuse and sexual matters is an additional risk factor. A disabled person may be more vulnerable to sexual exploitation because lack of affection or social interaction causes a great need for attention, and any kind of attention may be better than none (Krents, Schulman, & Brenner, 1987). Many disabled people require physical touching during care. This increases their vulnerability because they are encouraged to tolerate intimate handling

even by unfamiliar caregivers. Most people with disabilities who are abused suffer at the hands of people with whom they are acquainted (McPherson, 1990). In addition, reports of abuse are more likely to be discounted when the victim is disabled (Sobsey & Varnhagen, 1988).

People with disabilities need programs on the prevention of abuse to "inform them of their right to trust their feelings, to say 'no', to tell someone, to live in a safe environment, to not permit any touch or behavior which frightens, confuses or hurts them." (Cole, 1986/1990, p. 371). Ensuring that people with disabilities receive comprehensive sex education is a strong deterrent to sexual abuse (Corbett et al. 1987; Krents et al. 1987).

#### Sex education for people with disabilities.

Sex education for people with handicaps should include programs for children with disabilities and programs for adults who have become disabled. The two groups of people have very different informational needs.

Young people with disabilities not only need the same information as their peers, but also require knowledge about possible effects of their own particular conditions. Each disabled individual needs precise information about his or her physical condition and its effects on sexual ability, response, and reproductive potential. This is especially true if there are genital abnormalities, paralysis, or tactile differences.

Sex education for young people with mental retardation is a special challenge. Individualized instruction may be needed to teach girls to cope with such self-care issues as menstrual needs and birth control. Social skills training is essential to help both sexes deal with appropriate sexual behavior in various contexts.

Mature people who become disabled also need sex education. These adults need information about the effects their condition will have on their sex lives. The rehabilitation process should include information about changes in sex drive, orgasmic responsiveness, and possible adaptations of sexual behavior (Corbett et al. 1987). See Appendix A for educational and informational resources.

### Love, marriage, and children.

The task of finding another person with whom to establish a long-term, intimate relationship is more difficult for people with disabilities than it is for those without (Corbett et al. 1987; Nagler, 1990). Couples where each person is disabled find that they are "often not taken seriously by nondisabled people. They are frequently told that they 'look cute together'. Their relationship is presumed to be nonsexual." (Corbett et al. 1987, p. 204). Love relationships between disabled and nondisabled people have problems such as physical dependency, the opposition of family and friends, and social stigma.

Public attitudes which oppose the idea of disabled people as sexual beings, intensify when the question of their having children arises. There is concern about the ability of a person who is disabled to bear children or to parent a child adequately, and doubt about the ability of disabled parents to have a normal child.

The eugenics movement, a widespread belief in the need to prevent the spread of defective genes by preventing people with disabilities from having children, resulted in extreme methods of birth control. For example, disabled men and women who lived in institutions were strictly segregated. Sterilization without the consent of the individual was a common practice

until the 1960s (Taylor & Searl, 1987). The debate concerning sterilization still goes on in the case of severely disabled people (Ferguson & Ferguson, 1992; Fredericks, 1992; Halle, 1992).

The stereotype that equates disability with helplessness encourages other people to try to control the lives of those who are disabled. This social factor limits the options available to handicapped individuals and reduces their quality of life. The quality of life for people with disabilities is also limited by practical considerations. These factors are examined next.

### Practical Considerations

As evidenced by the personal remarks quoted earlier, people with disabilities have the same concerns that plague everyone else in our society: finances, social acceptance, and finding a washroom in a time of need. Handicapped people, however, have personal and practical problems specific to their particular requirements and limitations. De Balcazar, Bradford and Fawcett (1988) studied the major concerns of disabled people in 10 states. Their most common concerns fit into the following categories:

- 1) affordability and availability of assistive devices.
- 2) employment and financial concerns.
- 3) accessibility problems.

The next section of the paper will examine these concerns.

### Assistive Devices

Saskatchewan offers its residents with disabilities a wide range of benefits at no personal charge. These services include "mobility aids,



respiratory equipment, and environmental aids such as wheelchairs, commodes, walkers, and other self-help devices which assist in daily living in the home" (Saskatchewan Health, 1981). People who are paralyzed due to certain diseases or injury may be eligible for medical supplies, medication, and assistive devices through the Paraplegia Program.

Despite government programs, some people in Saskatchewan still have problems obtaining the assistive devices they need. Equipment is available in major centres, and rural residents may find it difficult to go there to get the devices they need. Long waiting periods sometimes occur before equipment is available. I know of one woman who waited over a year for a bath chair she needed to help her care for her granddaughter.

Some assistive devices, such as glasses, must be paid for by the individual. According to Statistics Canada (1990), many people need equipment that they do not have. Over 48,000 Canadians with hearing impairments need, but do not have, hearing aids. Over 25,000 people lack the vision aids they need. Over half of these people do not have the required sensory aids because they could not afford them (Statistics Canada, 1990).

The affordability of essentials is an issue for many people with disabilities because, as a group, their incomes are lower than average.

### Employment and Finances

The annual incomes of people with disabilities are lower than those for the general population (Statistics Canada, 1990).

Table 2.4

## Income for People in Saskatchewan

Total Annual Income	Percentage of Population	
	(disabled)	(nondisabled)
less than \$4,999	37%	22%
\$5,000 to \$9,999	19%	14%
\$10,000 to \$14,999	13%	16%
\$15,000 to \$19,999	9%	10%
\$20,000 to \$24,999	7%	9%
\$25,000 to \$29,999	5%	7%
\$30,000 and over	9%	22%
median income	5000-9999	10000-15000

The discrepancy in income described in table 2.4 is related to the high unemployment rate among people with disabilities. In 1986, only a little over 40% of the disabled population aged 15 to 64 was employed (Statistics Canada, 1990). At the same time the employment rate for the nondisabled population was 70%. Jobs held by people with disabilities tend to fall into the unskilled and semi-skilled categories rather than the managerial or professional categories (Nessner, 1990).

According to the 1988 study done by de Balcazar, Bradford and Fawcett, people with disabilities are concerned about the following aspects of their employment situation:

1. lack of reasonable accommodations in the workplace,
2. work disincentives within the social welfare system,
3. lack of job-seeking skills and lack of information about job training and job search assistance,
4. job discrimination and lack of equality of opportunity.
5. limited job opportunities.

The federal government Employment Equity Program, which includes people with disabilities, attempts to address some of these problems. The purpose of the program is to

eliminate practices that result in employment barriers for the four groups (women, aboriginal people, visible minorities and people with disabilities), and to ensure that those groups achieve a degree of employment proportionate to their representation in the work force as defined by qualification, eligibility, and geography" (Moreau, 1991, page 26).

Another factor that limits job opportunities for many people with disabilities is their level of education.

### Education

Educational requirements for jobs are often a barrier to people with disabilities because they tend to have less formal education than their peers. Statistics Canada (1990) gives two main reasons for this discrepancy: that disabilities caused interruptions in people's education, and the need to attend special classes or special schools. Some people are so severely disabled that they cannot go to school. In 1986, for example, there were over 100 Saskatchewan children aged 5 to 15 who had never attended school (Statistics Canada, 1990).

In 1986, only 5% of the population with disabilities had achieved a university degree, compared to 11% of the general population. Conversely, 29% of those with disabilities had grade nine or less, compared to 11% of the general population (Nessner, 1990). Since the best paying jobs generally require high levels of education, this places many disabled people

at a disadvantage.

### Medical Costs and Concerns

Canadians have a good Medicare system which eases the financial drain associated with a disability. There are, however, health-related costs which are not paid for by public funds. These include the cost of some drugs, costs of dietary supplements, and costs associated with travel to service facilities.

Prompt access to services is a problem for some people in Saskatchewan. Since the 1993 restructuring of our health care system, many people with chronic health impairments worry about delays getting medical help, and feel extremely vulnerable.

The availability of specialized services within the province is a concern and can be an extra expense. For example, until recently a child who required open heart surgery had to go to Edmonton for the operation. For those who want a second opinion on a diagnosis, it is often necessary to go out-of-province at their expense.

### Problems Associated with Accessibility

I recall a publicity cartoon which showed a car parked in a space clearly marked for the disabled. The approximate message of the caption was "Don't let this be the only time you put yourself in our place!" Unfortunately, many drivers do not heed such signs. One of the annoyances mentioned by disabled people is that police do not often ticket offenders and that the courts do not enforce these parking laws (de Balcazar et al. 1988/1990).

Our town is an example of how accessibility limitations can increase the effect of a disability. A member of our family suffered a stroke which left him with a mobility impairment that necessitates the use of wheelchair. He got around quite well with his wife's help until winter came. Snow and ice conditions severely limit the number of places they can visit; the existing wheelchair ramps are often dangerously icy, and snowbanks make it difficult to push the wheelchair from the car to the cleared sidewalk. These problems of accessibility make his handicap much worse in winter and severely curtails the couple's social life.

Disabled people's problems do not end when they finally reach a building. Exterior doors may be difficult to open. Doors and hallways may not be wide enough for a wheelchair or walker to be maneuvered easily. Washrooms can also pose many problems for someone who is in a wheelchair: they may be too small; they may not have grab-bars; and sink, towel dispensers, and mirrors may be inconveniently placed. All of these factors make people's lives more difficult and limit the number of places they can go.

Housing options for people with handicaps are also limited due to lack of accessibility. With proper adaptations for daily living, many people with disabilities can live independently. Unfortunately, many either cannot find, or cannot afford, such housing.

Accessibility is a major issue for people with disabilities. It limits the places they can go, what they can do, the stores they can shop in, the jobs they can hold, and the places they can live. Lack of access makes a joke of the entire concept of equality. Access, or lack of it, determines whether a functional limitation becomes a disability.

## Rights of the Disabled

Canada was the first country in the world to guarantee equality for the disabled in its constitution. Canada also belongs to the United Nations whose charter states that "Everyone has the right to life, liberty and security of person" (Baker, 1990).

### The Right to Equality

Despite constitutional protection, discrimination and lack of accessibility create a situation where people with disabilities must struggle for equality. Discrimination shows itself in many areas of life (Bayles, 1985). House owners may consider disabled individuals to be a rental risk (Dean, 1987/1990). Residents may not want group homes in their community (Bogdan et al. 1982/1990). Employers may not wish to hire people with obvious physical differences (Hahn, 1981/1990).

Equality of opportunity requires appropriate education, and the provision of necessary public services (Day, 1985). Equality of opportunity also requires that housing, transportation, employment sites, and community buildings be accessible despite the extra costs of adaptation. These costs can be high. For example the Toronto Transit Commission invested "over 20 million dollars in an effort to make Toronto's subway system accessible to the mobile-impaired" (Nagler, 1990, page 464). Only with such provisions can people with disabilities contribute fully to our society, yet persuading officials to part with the necessary funds is a major struggle, especially in tough financial times.

## The Right to Life

There are three aspects to the concept that everyone has the right to life. The first is the question of abortion, the second involves the decision to use drastic medical intervention to sustain life, and the third is the provision of minimal financial aid to preserve life.

### Abortion.

The abortion debate has a special poignancy when the possibility of a handicapped infant is involved. New technology allows the in utero diagnosis of many genetic and chromosomal abnormalities. Parents who have these procedures done in the early stages of pregnancy can then decide whether or not to abort an affected fetus (Cole, 1987).

Some people feel so strongly that they have the right to make this choice that physicians in the United States have been successfully sued for "negligent genetic counseling that resulted in 'wrongful birth' of an affected child" (Pueschel, 1991). According to Pueschel (1991), people who believe that abortions are necessary in such cases, give the following reasons:

- a) It benefits the individual woman and her family.
- b) It also benefits society because such procedures have a eugenic effect in eliminating defective genes from the gene pool.
- c) It reduces the financial burden to society.
- d) It is preventive medicine.
- e) It increases the quality of life for the family.
- f) The fetus has a right to be born healthy. (page 186)

Arguments against abortion as a method of preventing disability are based on the sanctity of human life, and on the fact that many people with congenital handicaps live happy and productive lives. Many parents of children who are handicapped stress the benefits that they have received from parenting a "special" child (Featherstone, 1980; Peuschel, 1991).

At the present time, therapeutic abortions are legal in Canada, so parents must make the decision. Professionals have an obligation to ensure that parents receive factual information, clear explanations of various options, and sensitive counseling. Whenever possible, it is beneficial for the prospective parents to have the chance to talk to parents who have a child with the diagnosed disability (Pueschel, 1991).

#### Life-support.

The second aspect of the right-to-life debate is the question of whether or not to use drastic medical interventions to sustain life. Parents of disabled children sometimes refuse life-saving medical procedures, because they feel that their children would be better off dead. When such refusals have been legally challenged, the courts' decisions have been based on quality of life criteria, rather than on the guarantee of an individual's right to life (Baker, 1990).

#### Financial support.

The third aspect of the right-to-life concept in Canada is the existence of a subsistence level of welfare for those who cannot support themselves. The amounts provided barely cover the cost of minimal housing and diet, but they do sustain life (Baker, 1990).



## The Right to Die

The opposite side of the right-to-life debate is the right to die. Recent court cases have considered the right of a seriously ill or disabled person to die by doctor-assisted suicide. So far, this has not been endorsed by the legal system, though the law has allowed deliberate death by withholding of services or by starvation. For example, Elizabeth Bouvia, a severely handicapped young woman in California, was allowed to starve herself to death (Fine & Asch, 1988/1990). Court decisions in cases of this sort, as in those which involve the use of life saving medical procedures, have been based on a judgment concerning the person's quality of life.

Any struggle for individual rights can be strengthened if group action can be taken.

## The Disabled as a Minority Group

People with disabilities are considered to have many of the same problems as other minority groups. Meyerson (1988) states that discrimination of the disabled is partially based on the belief that they are biologically inadequate or inferior. He points out that other groups such as women, blacks, and certain ethnic groups were also believed to be inferior. Standardized test results were used as evidence to support this belief, but further study showed that the disparity in test scores resulted from cultural bias and socio-economic factors (Sattler, 1992). We are beginning to regard disability as a condition affected by similar circumstances. Lack of opportunity, and lack of public willingness to make provisions to allow impaired persons to participate in the social, educational, and economic life

of the community are both a cause of disability, and the result of discrimination.

If Canadians with disabilities are viewed as a minority group, their 3.3 millions are second only to the over 6 million French-speaking people in our country (Filion & Mavrillac, 1986). The problem with viewing disabled people as a minority group arises from their lack of a group identity. There is no common history to unite people with disabilities. With the exception of the hearing impaired, they have no common language or culture. No sense of community develops among people with disabilities since most of them are surrounded by non-disabled family and friends. This lack of a sense of community may be changing as organizations such as People First gather members and advocate for equality and respect.

In spite of the progress made in recent years, disabilities have negative effects on the emotional, social, and practical aspects of people's lives. It is possible to reduce these effects through the provision of support services.

### Service Requirements

The quality of life for people with disabilities depends on the availability of services. These services can include residential, custodial, therapeutic, medical, vocational, educational and developmental provisions. Not all people with disabilities require the same services, or the same intensity of services. For example, two people may require custodial care, but one may need diapering, while the other does not. Service needs vary with the severity of the disability.

In this section I will first consider the services needed for disabled children and their families, then the services required by disabled adults, and finally, I will discuss the cost of these services.

### Services Needed by Disabled Children and their Families.

Families with disabled children become involved with a wide variety of services in order to meet their child's needs. These needs change as the child grows. For example, the services needed to maximize an infant's development are quite different from the services required by an adolescent who will soon need a job and an independent living arrangement.

Needs associated with a child's health may include services such as specialized medical procedures, assistive devices, personal care, and drug therapy. Assessment and programming services such as physiotherapy or occupational therapy may also be needed. Provisions may have to be made for health-related services in the school when the child becomes a student.

Educational and developmental needs also change as the child matures. Infants and toddlers can receive developmental services from the Early Childhood Intervention Programs (ECIPs) in the province. Schools must provide individualized education programs for all students with special needs. Schools may provide communication services such as speech therapy, sign language, and Braille instruction; teach mobility instruction and personal orientation; and develop plans to address the student's academic, social, and functional skills. As the student reaches high school age, vocational training and independent living skills may take precedence over academic studies and the adolescent could spend a large portion of the day in the community rather than in the school.

The daily care of a child who is severely handicapped can be a taxing

job. For example, a child who may have a seizure at any time of the day or night requires constant monitoring, and a child whose behavior is self-injurious requires 24 hour a day protection. Services are available to help a family cope with this task. Saskatchewan Social Services provides respite care, to give families a temporary break from this burden. There is also a temporary custody alternative available through which parents can place their child in a special foster home for a limited period of time. These services can be immensely important to allow a family to recuperate from the constant strain of caring for a family member with a disability.

All of the services described above are provided by government either through social services, public health, Medicare, or the education system. The drain on the public purse is immense, but money and effort put into the developing child may reduce later requirements and costs.

#### Services Needed by Adults Who are Disabled.

Since the limitations of adults with disabilities vary greatly, their service needs vary as well.

Special communication services are required by people with many sorts of impairments. For the hearing impaired, hearing aids are available. Closed-caption television is a valuable service for them. Special telephone services for the hearing impaired include amplifying units, adjustable bells, and telewriters. Motion impaired people may be loaned automatic dialers and hands-free phones. Artificial larynx or voice amplification units are available for the speech impaired. Enlarged dials or push button phones help the visually impaired. Emergency call buttons are available to enable a person to get assistance in the event of a fall or injury.

Some adults with disabilities need support to live outside their nuclear

families. An individual may require the high level of care provided by an institution or the less intense care provided by supported living programs. Home care programs provide help with activities such as cleaning and shopping to help people live independently.

Job support services are available for those with disabilities. Vocational programs for competitive employment include apprentice-type situations and job coaches. Non-competitive employment is also available in sheltered workshops or activity centers. The ultimate goal of job support services is to enable a person to hold independently a position in competitive employment.

Saskatchewan offers people with disabilities a wide variety of medical, educational, residential, and vocational services. Unfortunately, these services are not equally available to all who need them.

### Availability of Services

Availability of services in Saskatchewan is affected by lack of funds, and the need to serve a small population distributed over a large area.

Services for the disabled are concentrated in larger centres in Saskatchewan, and may not be available in the North or in rural areas. It is logical that highly specialized medical services are concentrated in the major centres of Saskatoon and Regina because of the relatively low demand. Less esoteric services such as speech and language services, physiotherapy, occupational therapy, and psychological assessments should be widely available in smaller centres. This is not always the case. Shortages of such services impose an extra burden for families who must travel long distances. Some people may simply not be able to take advantage of these services.

Early Childhood Intervention Programs (ECIPs) cover most of the

province, including the areas of La Ronge and Ile a' la Crosse. The interventionists visit each family's home regularly, so there are no travel costs for the family, and the programs are accessible to everyone. Unfortunately, because of limited funds, the ECIPs can only serve a limited number of cases at a time, and there may be a long waiting period for their services.

Group homes and supported living programs are scarce in rural Saskatchewan. Even in the cities there are long waiting periods before residential spaces become available.

Services which fill the needs of people with disabilities are extremely important to their quality of life. Saskatchewan's yearly investment of millions of dollars in support services reflects the government's awareness of their vital importance.

### Cost of Services

#### Medical services.

Most medical services are paid for by government funds, and Saskatchewan residents often are not aware of these costs. In the United States, these expenses are more obvious. According to Birenbaum and Cohen (1993), the cost of medical care for a youngster with severe disabilities is almost 10 times as much as that spent on a nondisabled child. In Canadian funds, this amounts to approximately \$4700 per year in extra medical cost. Birenbaum and Cohen's estimate did not include the costs of therapy, visual or dental care, drugs, special clothing, dietary supplements, aids and equipment, personal care services, or costs of assessment at a facility such as the Kinsmen Children's Centre. These additional costs are

substantial and, in Saskatchewan, most of this expense is paid out of public funds.

Residential services.

For individuals in residential care the annual costs vary with the type of service provided as shown in table 2.5.

Table 2.5

Annual Costs for Residential Services

Type of Residence	Cost (in Canadian funds)		
	Saskatchewan	Nebraska	Michigan
Group Homes	\$20,884	\$14,631-\$37,242	\$33,252-\$66,505
Family Care Homes		\$5,320-\$26,602	\$13,301-\$33,252
Apartment Living (minimal supervision)	\$5,015	\$9,310-\$15,961	
Supported Living (independent residence)	\$3,085		

(Adapted from information provided by: Ashbaugh & Nerney, 1990; Canadian Imperial Bank of Commerce, January 20, 1994; Saskatchewan Social Services, 1993.)

Saskatchewan Social Services spent a total of \$9,526,700 on residential services during the 1991-1992 fiscal year.

Vocational services.

Schalock and Keith (1986) list the 1983-1984 costs per person for vocational training and placement alternatives in Nebraska as follows:

Work activity or sheltered workshop	\$12,000-\$15,000
Semi-competitive employment	\$12,000-\$19,500
Competitive employment	\$9,500-\$11,000

(taken from table 5, page 32).

Saskatchewan provides the following variety of vocational services. The costs per person during 1991-1992 were:

Activity Centres	\$4,271
Sheltered Workshops	\$2,829
Long-term employment programs (semi-competitive employment)	\$6,477

(Social Services, 1992).

The figures given above do not include any savings there may have been in terms of Social Assistance payments, nor do they include any estimate of job satisfaction. Again, when compared to the American figures, Saskatchewan's expenses are not high, yet the total drain on the public coffers for these programs amounts to \$7,540,900 per year.

Though it is difficult to get itemized costs for medical services, educational programs, residential services and vocational assistance, one general tendency is apparent: "high-need clients cost more to serve than either moderate- or low-need clients" (Schalock & Keith, 1986, page 31). Consideration of the cost of services for any individual who is disabled can only be done accurately on a case-by-case basis because each person's needs



are unique. However, to give an idea of the life-time cost for people with one type of affliction, Dr. Brian Habbick stated that it would require an estimated \$1,000,000 to provide the special services needed by one child who has Fetal Alcohol Syndrome (F.A.S. Symposium, Saskatoon, SK. October 14, 1993).

### Conclusion

In summary, disabilities interfere with quality of life of in a multitude of ways. Daily living skills pose severe difficulties. Leisure activities and community participation are limited. Educational achievement may be restricted. Employment is more difficult to find than it is for nondisabled people. Social stereotypes and discrimination affect every aspect of life.

Efforts to lessen the effects of disabilities and to reduce the number of people affected are essential. Prevention programs not only reduce the tremendous human cost of handicaps but also decrease the enormous financial burden imposed by the service requirements of people with disabilities. Money devoted to preventive efforts is a good investment in both the ethical and the practical sense.

The next section of this paper will consider the current efforts being made to prevent the occurrence of disabilities and to reduce the effects of those conditions already existent.

## Section 3

### PREVENTION OF DISABILITIES

Prevention of disabilities has two major benefits - one humanitarian, the other financial. Pope and Tarlov (1991) state that prevention "will not only significantly improve the quality of life for millions of Americans but also could save billions of dollars in costs resulting from dependence, lost productivity, and medical care" (page 1).

This section defines prevention, discusses prevention rates, describes current prevention efforts, examines the cost-effectiveness of preventive efforts, and outlines the "Prevention of Disabilities" program.

#### **Defining the Prevention of Disabilities**

Prevention means "to keep from occurring" (The Concise Oxford Dictionary). Prevention of disability is two-fold. It first attempts to eliminate the causes of disabilities and secondly attempts to reduce the severity of those already in existence.

#### Primary, Secondary and Tertiary Prevention

There are three types of prevention: primary, secondary, and tertiary. Preventive efforts can involve medical, educational, or social strategies, or any combination of these. For example, a program intended to reduce the

risk of disabilities for the infants of pregnant teenagers who smoke, drink, or use drugs might combine medical treatment, health education, peer counselling, and group pressure to achieve its goal.

### Primary Prevention

Primary prevention reduces the incidence of disabilities by preventing risk factors which cause impairment. If primary prevention efforts succeed, they completely eliminate any possibility that disability will occur. Primary prevention is aimed at the general population rather than at an identified "high risk" group.

### Secondary Prevention

Secondary prevention targets an existing risk factor and removes or reduces it. When secondary prevention is successful, the disability will not occur. However, since the risk factor did exist and some damage may have been done before secondary prevention began, the impairment may be reduced rather than prevented. Efforts in the category of secondary prevention are aimed at an identified group of people who either show symptoms of a disabling condition or are considered to be "high risk" for the development of such a condition.

### Tertiary Prevention

Tertiary prevention is implemented when a pathological condition exists. It "promotes adjustment to irremediable conditions and minimizes further complications or loss of function" (Scott & Carran, 1987, page 801).

When tertiary prevention is successful progression along the continuum from pathology to disability is slowed, halted, or even reversed. Tertiary prevention is focused on a limited population who have a specific condition.

### Examples of the Levels of Prevention and Their Interaction

An example of all three types of prevention can be found in efforts to reduce the incidence of Alcohol Related Birth Defects (ARBD) and Fetal Alcohol Syndrome (FAS).

Programs that discourage people from drinking are examples of primary prevention. If a woman never drinks alcohol, her child has absolutely no risk of FAS.

Secondary prevention encourages pregnant women who have been drinking, to quit. In these cases the risk factor, alcohol consumption during pregnancy, exists. The less alcohol an expectant mother drinks, the less risk there is that her child will have FAS. Secondary prevention reduces the possibility of ARBD, but cannot entirely eliminate it.

If a child is born with ARBD or FAS, an example of tertiary prevention occurs when programs are put in place to help minimize the effects of the impairment. These programs include medical procedures, social supports, and educational efforts.

Strategies for prevention are often effective at more than one level. For example, consider the case where parents of a linguistically deprived child are trained in language development skills. The techniques they learn will likely be applied to all the subsequent children in the family. In this way, what was secondary prevention addressing the risk of the first child, becomes a primary prevention effort for children born to those parents at a later date.

Despite the interplay of the different levels of disability prevention, it is convenient for discussion purposes to use the categories of primary, secondary and tertiary prevention.

### Prevention Rates

Theoretically-possible rates for the prevention of disabilities, and realistic rates are very different things. Prevention possibilities and limitations will be considered below.

#### Theoretically Possible Prevention Rates

If we define disability as the interaction of a person's "physical or mental limitations with social and environmental factors" (Pope & Tarlov, 1991, p. 1), then most disabilities are preventable. In the specific area of mental retardation, Drash (1992) points out that 80 to 85% of all cases could theoretically be prevented. This is an idealistic goal since improved social attitudes, better community accessibility, environmental clean-up, and the elimination of poverty would all be required for its attainment.

The goal of total prevention of disabilities raises a major ethical question: to what extremes are we, as a society, willing to go to prevent handicaps? Enforced sterilization for anyone believed to carry defective genes might prevent some disabilities, but would it be ethically acceptable? Prenatal diagnosis of some conditions such as Down Syndrome is now possible. Should this evaluation be mandatory and abortions performed whenever an affected fetus is found? Some people seriously advocate these approaches to prevention (Pueschel, 1991).

Disabilities caused by injury are also, theoretically, completely preventable. The reality is that some accidents will happen, no matter how careful, or well-informed, the population. Accident related injuries are a major area for preventive efforts. If the injury rate here is similar to that in the U.S., 5 million Canadians would be injured each year; of these, about 130,000 would have head injuries and 7000 would suffer "moderate to severe traumatic brain injury" (Pope & Tarlov, 1991, page 12).

Many developmental disabilities are totally preventable. All those which are associated with pollutants can be prevented through environmental clean-up. Developmental delay due to deprivation would not occur in a society that provided a nurturing environment for all its children.

#### Limitations of Prevention Effectiveness

Total prevention of disability will never be attained for three reasons: lack of knowledge, lack of individual effort, and lack of social commitment.

##### Lack of knowledge.

Though there are many areas where disabilities are preventable, it must be pointed out that there are many conditions for which there is no currently known method of prevention. For example, the precise causes of many congenital intellectual impairments are unknown, so these disabilities cannot be prevented (Drash, 1992). Similarly, there is no effective preventive measure for many of the degenerative conditions associated with aging.

Some methods of biomedical prevention are not within the province of the medical profession because they are an individual responsibility. Lack of

public knowledge limits prevention; one must know preventive strategies and life-styles in order to practice them.

Lack of individual effort.

Lack of effort in the prevention of disability is evident on the individual level. The benefits of a healthy life style, and the health problems which result from smoking, drugs, and alcohol use, are well known. In spite of this, 28% of young people between the ages of 12 and 18 smoke daily, and 17.5% of them, almost 20,000 Saskatchewan young people, drink on a weekly basis (Advisory Committee on Alcohol, Drugs and Youth, 1986). This lack of individual effort to maintain health and thus prevent disability is all too prevalent.

Lack of individual effort in the area of accident prevention is obvious as well. Saskatchewan law makes the use of seatbelts mandatory in order to protect citizens from injuries and impairments, yet police must stage campaigns to enforce this legislation. There are provincial regulations governing the type, positioning, and use of children's car seats, but I still occasionally see people driving with a child standing up beside them on the front seat. This should classify as child abuse!

Education and legislation can only do so much in the way of prevention. Individual life-style choices and preventive efforts are also required to ensure the reduction in the incidence of disabilities.

Lack of commitment on the part of society.

Lack of commitment to prevent disabilities is evidenced in society's willingness to put other concerns, especially economic ones, first.

Our society knows that alcohol abuse is harmful, but efforts to prevent it are inconsistent and contradicted by media advertising which associates alcohol consumption with success and popularity. The government shows its lack of commitment to disability prevention by its operation of liquor stores and its reliance on "sin taxes" levied on tobacco and alcohol as a source of income.

The disabling effects of hunger, disease, and deprivation are drawn to our attention during newscasts about places such as Somalia and Bosnia. The public seems unaware that many low-income families in Canada today face deprivation in housing, nutrition, and other necessities for optimal child development. Society's attempts to eliminate, or even to reduce, poverty have been unsuccessful. There are effective methods for counteracting some of the results of deprivation, but efforts in this direction are hampered by lack of public funds committed to the purpose.

### **Current Prevention Efforts**

This section of the paper first describes current prevention strategies, then discusses the cost-effectiveness of prevention programs.

### **Primary Prevention Efforts**

There is a close relationship between the causes of disabilities and disability prevention. Because of this, the classifications of biomedical and socio-environmental are as appropriate for the discussion of prevention efforts as they were for examining the causes of disability.



## Primary Prevention of Biomedical Causes of Disability

Biomedical prevention efforts include services such as prepregnancy planning, prenatal and obstetrical care, and immunization.

### Prepregnancy planning.

Ideally, all babies are planned for and wanted by both parents; prepregnancy planning helps people achieve this goal.

People have many reasons for not wanting to have children at a particular time in their lives; impermanent relationships, educational or professional priorities, financial problems, or age and health concerns are only a few of the possibilities. Part of prepregnancy planning is to postpone pregnancy until both partners feel that they are ready to be parents. This requires the use of some form of birth control.

Once a couple decides to have a baby, they can increase their chances of having a healthy, normal child. Prepregnancy planning gives the parents-to-be time to establish good nutritional and exercise habits and to "kick" bad habits such as smoking or alcohol abuse. They should see a doctor at least three months before conception. At that time the doctor checks for medical conditions such as the: health problems in the mother, e.g., thyroid disease or diabetes; infections such as venereal disease; RH factor incompatibility; and the mother's immunization for rubella (Fotheringham et al., 1983). All of these preconception efforts are primary prevention intended to reduce as much as possible the chances of having a child with an impairment.

### Prenatal care.

Prenatal care helps insure that both mother and baby are as healthy as possible, and that any problems are addressed immediately. Prenatal clinics provide a combination of primary and secondary prevention. They not only try to prevent conditions that might put a fetus at risk, but also strive to reverse, reduce, or minimize risks that already exist.

Saskatchewan has an extensive prenatal care program which reaches the majority of expectant mothers. In the cities, care is readily available. In rural areas, public health nurses provide services to residents by making regular visits to small centres where they hold clinics for those living in the immediate neighborhood.

### Obstetrical and postnatal care.

Obstetricians attempt to ensure that all births are safe and that the infants are healthy. Most births in Saskatchewan occur in a hospital setting because rapid access to special medical staff, procedures, and equipment may be vital if an emergency arises.

Medical procedures at the time of birth can prevent disabilities. Visual impairment is prevented by the use of medication to protect the eyes of the neonate from infections which may be picked up on the way through the birth canal (World Health Organization, 1992). Careful monitoring of newborn babies and rapid treatment of anoxia can prevent mental disabilities.

After a baby is born, the public health nurses visit mother and child at home as soon as possible to give support and help. Later, at the Baby Clinics, nurses monitor babies' growth and screen them for sensory, physical, or

developmental problems. Immunizations are started at the age of two months.

### Immunization.

Immunizations have reduced or eliminated many causes of disability. Two good examples are rubella (German measles) and polio myelitis. In the past, rubella epidemics occurred every three to ten years, leaving a legacy of babies with impairments such as blindness, hearing impairment, and mental retardation (Fotheringham et al. 1983). Polio devastated the province in the 1950s leaving many people with physical impairments. The occurrence of such epidemics has been drastically reduced because Saskatchewan's immunization program reaches almost all of the population.

### Primary Prevention in the Environment

The goal of primary prevention in the environment is to remove those causes of disability that reside in the social, cultural, and physical aspects of our lives. These risks include injuries associated with our daily activities, life-style and behavior patterns such as alcohol and drug abuse, lack of parenting skills, and the many characteristics of poverty which place people at risk. All of these socio-cultural/environmental areas should be addressed through primary prevention methods such as education, social and economic programs, and legislation.

### Educational efforts at primary prevention.

The realization of risk, and the resultant change of behavior, often comes from education. Educational efforts include school courses, safety programs, media presentations, publicity campaigns, health education, accident prevention, and parenting and life skills courses.

Education of the youth of our province is primarily the concern of the school system. Schools promote healthy life styles through programs about health, safety, sex education, and the dangers of drug and alcohol abuse. Home economics and life skills courses provide information to improve an individual's life style. These are valuable and integrate many concepts which help to prevent disability, but there is no specific emphasis on the prevention of disability, and Saskatchewan has no school program which focuses on this goal.

Informational programs which help prevent disability concern many groups in Saskatchewan. Not only are there associations like the Saskatchewan Alcohol and Drug Abuse Commission (SADAC) and the Canadian National Institute for the Blind (CNIB) which are concerned with particular issues, but we also have a unique organization concerned with all aspects of the prevention of disability: the Saskatchewan Institute on Prevention of Handicaps.

The Institute's mandate is "to promote province-wide awareness of preventive measures to reduce the incidence of handicapping conditions in children" (1993). The Institute provides information through the production and distribution of pamphlets and brochures, newsletters and magazine articles, public service announcements, and videos. They also lend videos and teaching materials. In 1992-1993, more than 43,000 items were requested from the Institute from places as far away as British Columbia and

Newfoundland, the Yukon and the United States (Saskatchewan Institute on Prevention of Handicaps, 1993).

Personnel from the Institute are involved in many active teaching programs. They coordinate the Nobody's Perfect parent education program, and "deliver health promotion and health education programs throughout the province" (Saskatchewan Institute on Prevention of Handicaps, 1993, p.10). In 1992-1993, these programs included five sessions with the women at the Pine Grove Correctional Centre and 66 other talks and workshops. When invited, the Institute's instructors will go into the schools to make presentations on the prevention of disabilities.

Other educational efforts can help prevent developmental disability associated with poverty. Examples of programs which help people break the cycle of poverty are those which build positive self-concepts, discourage teen pregnancies, encourage young people to stay in school, offer job training and experience, or give life-skills training.

From the above description, it is obvious that education is a powerful tool for primary prevention of disabilities.

#### Social and economic programs to prevent disability.

Low socioeconomic status is a powerful risk factor for the development of intellectual impairment (Kopp & Kaler, 1989; Ramey, 1992) and other types of disability. Because of this, many social and economic programs to prevent disability are aimed at reducing the prevalence of poverty. Programs such as social assistance, income subsidies, and unemployment insurance are intended to alleviate poverty. Job retraining programs and employment equity increase an individual's opportunity to earn a steady income.

Other programs try to alleviate the risks associated with poverty. These include programs to provide food for those who cannot afford nourishing meals. Food banks and community kitchens are examples, but efforts such as cooperative kitchens have been tried in some communities. Some schools provide lunch programs or other forms of nutritional supplements as well. In some communities there are life skills courses which teach people to budget, shop efficiently, and cook healthy meals so they get the most nutritional value from each dollar spent.

Good day care and preschool programs prevent developmental delay by providing children with a nurturing environment, a wide assortment of learning opportunities, and rich linguistic experiences. Such programs have proved to be very effective in the prevention of mild mental retardation among children of low socioeconomic status (Bryant & Ramey, 1985; High/Scope Educational Research Foundation; Ramey & Gowen, 1984; Ramey, 1992).

Efforts at cross-cultural awareness encourage the respect, acceptance, and understanding of linguistic and cultural diversity. This reduces discrimination and the social isolation of people whose culture differs from that of the majority. Increased awareness on the part of professionals, especially concerning the effects of culture on child care and social interaction helps ensure that education, social, and medical services are appropriate and acceptable to the family (Garcia & Malkin, 1993; Harry et al, 1993; Lynch, 1992).

#### Primary prevention in the physical environment.

Prevention of disability caused by aspects of the physical environment include national strategies regarding pollution reduction, provincial

incentives for housing development and repair, and local improvements such as the provision of bicycle paths.

Many primary prevention efforts in the environment are associated with safety. Initiatives to improve streets and roads or improve traffic control systems are primary prevention because they reduce the possibility of injury. Community projects which provide safe playing areas, bicycle paths well away from vehicle traffic, and pedestrian over- or under-passes are primary prevention efforts. The removal of snow from sidewalks and the use of salt on icy spots are examples of individual homeowners' efforts at the prevention of injury.

The reduction of pollutants in the environment is primary prevention because such substances can cause disabilities. For example, at Grassy Narrows, Ontario, in the late 1970s, industrial pollution resulted in the risk of mercury poisoning, which causes neurological damage, for anyone eating fish taken from the English River system. We have environmental protection agencies that are supposed to prevent this sort of pollution, but there is reason to be less than optimistic about the effectiveness of such efforts in the face of corporate profits.

#### Legislation as prevention.

We have many laws intended to protect us from injury, pollution, violence, and disease. However, more needs to be done.

In 1983, the Special Committee on the Disabled and the Handicapped recommended the development of a national policy on the prevention of disabilities. The policy was to include four points:

- \* Reduction of the incidence of birth-related disability through promotion of high standards of prenatal, perinatal, and post-natal care.

- \* Reduction of the incidence of, or, where possible, the eradication of communicable diseases.
- \* Promotion of safe and healthy work environments.
- \* Promotion of lifestyles that enhance physical and mental well being with particular emphasis on stress management, on the effects of drinking, on safe driving, and on the safety aspects of sport and recreational activities.

(page 126)

Ten years later, these goals are still appropriate. Though government offices dedicated to occupational health and safety, workplace health and safety, and environmental health and safety exist, biomedical conditions are still a common cause of disability.

### Secondary Prevention

Unlike primary prevention, which is provided to the general population, secondary prevention is aimed at particular groups of people who have "the highest likelihood of experiencing the target outcome (a high-risk group)" (Pianta, 1990, p. 307). These individuals have an increased vulnerability to certain biomedical or socio-cultural/environmental causes of impairment.

#### Secondary Prevention Aimed at Biomedical Risks.

When a biomedical risk exists, efforts made to prevent or minimize the effect of that risk are classified as secondary prevention. Two examples



of secondary prevention explored below address genetically based disabilities and teenage pregnancy.

### Genetic counselling.

Genetic counselling can prevent some of the genetically based birth defects that affect one in every 10 Canadians (Saskatchewan Institute on Prevention of Handicaps, 1986). People who should consider genetic counselling include: those who are concerned that they might have, or "carry", an inherited disorder; couples who have a child with a disability that may have been inherited; women who have had two or more miscarriages; and people who are concerned that their jobs or life-styles may pose a risk to pregnancy (Ince, 1987).

Some inheritable genetic conditions can be identified through medical procedures such as blood analysis. Some "high risk" groups have been subjected to mass screening to try to reduce the incidence of genetic conditions common within those segments of the population (Bennett, 1981).

"Pedigree analysis" is a form of genetic counselling which is done if there is a known abnormality in the family of either potential parent. This procedure takes the family histories, or pedigrees, of both partners, and analyzes them using the patterns of inheritance to determine the risk of this particular couple having a child with an inherited birth defect (Abroms, 1981).

Genetic services in Saskatchewan are available, at no cost, from the Department of Medical Genetics, University Hospital, Saskatoon (Saskatchewan Institute on Prevention of Handicaps, 1986).

Prenatal examinations check for another genetic cause of impairment, Rh blood factor incompatibility. If an RH negative mother is carrying a baby with the RH positive blood factor, her body may produce antibodies which can destroy the blood cells of the fetus and cause disability or death. Treatment of the mother with anti-immune globulin prevents the formation of these antibodies (Fotheringham et al, 1983).

#### Adolescent pregnancy.

Pregnant teenagers, especially very young ones, are another identified "at risk" group. In Saskatchewan over 1,600 teenage girls had babies in 1992 (Prince Albert Daily Herald, September 21, 1993). Concern about teen pregnancy is increasing as there is some indication that the pregnancy rate among very young girls is rising (Leishman, 1980; Levy et al. 1992).

Babies born to extremely young mothers are more at risk than those of older mothers. These infants are more likely to be small, premature, or have neurological abnormalities; more of them die (Fotheringham et al, 1983; Levy et al, 1992; McDonough, 1985). These children are more at risk than those of older women due to socioeconomic causes as well as biomedical ones. Young mothers who do not give their babies up for adoption are more likely to end up raising their children in poverty due to lack of education and limited employment opportunities. They are also more likely to experience social isolation and repeat pregnancy (McDonough, 1985).

According to McDonough (1985) prevention programs for pregnant adolescents should have the following goals:

1. Minimizing the obstetrical complications for the pregnant adolescent and the neonatal complications for the infant.

2. Fostering positive attitudes, parenting skills, and parent-child interactions.
3. Reducing the social isolation of the young mother and her infant.
4. Eliminating repeat out-of-wedlock pregnancies.

(page 69).

Saskatchewan Public Health has free, accessible support programs available for these young women. The Pregnant Adolescent Support Program (PASP) was designed to reduce the risks of teen pregnancy. Scott (1992) found that the young women who took part in PASP considered it a valuable program and that they had made positive changes in their life-styles during pregnancy. For example, they reduced their smoking and drinking and improved their nutrition level.

In spite of the availability of free prenatal care, some women do not get medical consultation until late in pregnancy, and others only at the time of birth. These mothers-to-be are often young, poor, or members of minority groups (Fotheringham et al. 1983). Efforts are being made to contact these women and offer them prenatal care, counselling and support. The Prince Albert Public Health Region, for example, puts a great amount of effort into helping these women. Nurses contact them in malls, schools, community centres, and in other areas where they "hang out" in order to give them medical advice.

### Secondary Prevention of Disabilities in the Social Environment

A great deal of the secondary prevention effort is in the area of social environment. These efforts can be effective in preventing impairments at any stage of life, from the prenatal period to old age.

Educational efforts are varied and address many age groups. Parenting classes to help new parents develop parenting skills are an effective method of prevention (Morgan, Nu'man-Sheppard & Allin, 1990). Provision of rich experiences and nurturing environments for preschool children from poor environments is secondary prevention of disabilities. Programs which prevent school dropout and offer counselling to students are secondary prevention efforts (Pianta, 1990).

The government, through Social Services, provides secondary prevention in several ways. It reduces the risk of disability caused by infections, poor housing, and inadequate diet by providing funds to cover basic needs for those in financial straits. They provide counselling and educational programs to help parents, families, and individuals cope with their problems.

Social prevention efforts include child protection to reduce the injury and neglect of children. These efforts may include the removal of youngsters from dangerous or negligent homes and placing them in foster care.

Secondary prevention of those disabilities which are acquired during adulthood includes personal and community efforts. A man who knows he is at risk for heart disease is practicing secondary prevention when he watches his diet, exercises daily, and goes for check-ups on a regular basis. When a community starts a local campaign to increase the use of seatbelts, reduce drunk driving, or prevent abuse within families, it is practicing secondary prevention against a targeted risk.

## Tertiary Prevention

Tertiary prevention includes all efforts designed to lessen the effects of an existing disability and improve a person's quality of life. This type of prevention is the most narrowly focused because the individual is actually affected. It may include medical intervention, social skills training, educational programming, or physical adaptations of the environment.

### Tertiary Prevention: Biomedical.

Tertiary prevention in the medical field relies heavily on the early detection of conditions which may affect a child's development. Once these conditions have been identified, they are treated by surgical, chemical, or dietary means.

Biomedical procedures classified as tertiary preventions can be extremely effective. Examples are phenylketonuria (PKU) and hypothyroidism. Both of these conditions can be diagnosed at birth, and both are highly treatable. PKU, an enzyme defect which can result in severe mental retardation, is treated by placing the child on a special diet. This diet completely prevents the disability (Coleman & Olson, 1987). The effects of hypothyroidism are prevented by giving the child thyroid hormone therapy (Fotheringham et al., 1983).

Public health nurses offer parents advice on child care, screen infants for sensory or developmental problems, and make referrals to specialists at the parents' request. These specialists may include the following: pediatricians for medical, physical and growth concerns; Early Childhood Psychologists for developmental assessment; Speech and Language Pathologists for concerns with the development of language; and Early

Childhood Intervention Programs (ECIP) for developmental delay, concerns about parenting skills, or parental support. All of these services are available without direct cost to the consumer.

For people with physical or sensory impairments, adaptive appliances are available through Saskatchewan Health.

### Social Services and Tertiary Prevention

Community Living Division of Saskatchewan Social Services provides services such as counselling, residential and vocational programs, referrals, child protection, and respite care.

### Tertiary Prevention in Education

Tertiary prevention in the education field has two goals: first, to teach a person to cope with a disability; and second, to help the person achieve the highest possible level of education, in spite of a disability.

Parents are a child's first teachers, but many need help with their children early in life. Some support programs available are specific to the disability, such as the Canadian National Institute for the Blind, and HOPE for Autism. General support services are provided by Saskatchewan's Early Childhood Intervention Programs (ECIPs).

The ECIP programs provide both secondary and tertiary preventions. Their success has been documented by Dr. Bloom (1991) of the University of Saskatchewan's Department for the Education of Exceptional Children.

ECIP services are available to children and families in all parts of the province, including the remote northern areas. Referrals of babies and young children who are developmentally delayed, or at risk for delay, are

accepted from parents, medical personnel, or Social Services. Once a child is accepted onto a program, an Interventionist visits the home and works in cooperation with the family to maximize the child's development. ECIP provides such services as assessment, program development, instruction, and parent support.

In the schools, tertiary prevention is begun as soon as possible after a problem has been identified. Severe disabilities are identified early in a child's life, and appropriate programming can be started as soon as the child enters school. Saskatchewan schools may accept children with severe disabilities in an early entrance program, even when they are as young as three years of age. Thus, provision is made for developmental skills instruction for the child, and for easy transition into the regular school system.

For those with mild physical, sensory, or mental impairments, diagnosis may not be made until well after the child enters school. Screening for visual and auditory acuity should be done on a regular basis to identify children with slight impairments. These conditions should then be remedied and their existence taken into account in the classroom situation. Teacher awareness of student difficulties can be improved by training the instructor to pinpoint specific types of weaknesses and decide whether or not a referral is needed.

Saskatchewan schools provide placement for children who have different types and levels of disability. Variations may include the following:

1. regular classroom placement,
2. regular classroom placement with some form of support or adaptation,
3. regular classroom placement combined with segregated placement,
4. placement in a classroom which is almost totally segregated,
5. placement in a special school for the severely or multiply handicapped.

The current movement is toward inclusion of children with special needs in regular classrooms so the number of segregated classrooms and special schools is declining.

Educational programming provisions may vary from simple to complex, as follows:

1. Assignments may be provided which contain a selection of activities from which students can choose. The variety should be such that each student has the possibility of achieving success.
2. Special assignments may be provided for students whose capabilities are significantly different from those of the rest of the class.
3. Special materials may be used which allow partial participation in the class. Examples of this sort of adaptation are the provision of taped readings of a text for a student who is visually impaired, or the provision of prepared notes for someone with a motor problem.
4. Special programming provides an appropriate course of study for the individual student.
5. Special services may be provided by Speech and Language Pathologists and Educational Psychologists.
6. Varying degrees of individual attention and supervision may be provided.

Educational transition programs have been developed to help people with disabilities move from the school environment to a work situation. These programs consist of a combination of academics, skills instruction, social interaction training, and practical work experience within the community. Transition programs show promise for remedying the negative economic situation experienced by many disabled people.



## Social and Community Efforts at Tertiary Prevention

Efforts to increase the accessibility of services in a community can be classified as tertiary prevention. As businesses and organizations provide better access, people with physical impairments are able to carry on their lives more normally. This reduces the effect of their limitations on their quality of life.

Social limitations caused by discrimination decrease as people become more accustomed to seeing and interacting with people with disabilities. Movies and television programs which emphasize the similarities between disabled and non-disabled individuals help encourage a positive attitude. School inclusion exposes students to individual differences and encourages social interaction between all types of people. Hopefully, the next generation of adults will accept people with disabilities as "just people" and grant them the equality they now lack.

### **The Cost of Prevention**

Expenditures to prevent disabilities are essential, but how much money should we actually invest in such efforts? Is prevention worth the cost? I believe it is, but I found it surprisingly difficult to prove this contention. In order to discover if prevention is cost effective, it is necessary to discover the cost of prevention.

## Difficulties in Identifying the Cost of Prevention

Isolating the costs of disability prevention is difficult because these costs are included in the cost of many general services, even though the prevention of disabilities is not the primary focus of effort. How much of the cost of these programs should be attributed to the prevention of disabilities?

The same strategies that reduce the risk of disabilities are part of good educational practice. Regular child protection programs reduce the risk of disability due to injury or deprivation. Health care costs are especially hard to sort out. For example, the prevention and treatment of sexually transmitted diseases helps prevent disabilities that might have occurred in the babies of infected mothers, but the disease must be treated whenever it occurs, not just in pregnant women. Again, how can we account for the cost of prevention versus the cost of routine care?

Many tertiary prevention programs could be classified as either prevention or as services. For example the provision of a Braille instructor for a blind student was an educational service. This assistance enabled the person to complete his education, get a job, and become self-supporting. Thus, the service performed a preventive role. The amount spent cannot be divided into service costs and prevention costs.

In view of the difficulties outlined above it was not possible to arrive at an accurate cost for the prevention of disabilities. Therefore, I looked for other means of establishing cost effectiveness.

## Cost Effectiveness

The cost-effectiveness of programs for the prevention of disabilities is judged by evaluating "the total benefits of some program against the total

costs of that program (or some comparison program) so that decision makers can allocate limited resources to the net benefit of society" (Bloom, 1986, page 28.). Studies reviewed by M. Bloom (1986), which use meta-analysis techniques developed to produce standardized results, show that primary prevention has been effective in certain medical, educational, and social programs. It is extremely difficult to do such analyses because monetary and non-monetary comparisons and predicted alternative outcomes are used. The most acceptable solution for any cost comparison at present is to carefully state the criteria used and rules applied for the inclusion and exclusion of data so that readers understand them, and then go ahead (Bloom, 1986).

The High/Scope Program at Ypsilanti, Michigan, recently completed a longitudinal study which shows that their program is cost effective. They compared their program and nonprogram groups about twenty years after the intervention was complete. Comparisons were done on such factors as number of arrests, monthly earnings, home ownership, education, and use of social assistance. They arrived at a saving of \$7.16 for each dollar which was spent (High/Scope Educational Research Foundation, undated). To date this is a saving of four and a half million dollars. The individuals in question are now 27 years old, so these benefits could well continue to accrue for the next 50 years.

A study by McCaughrin, Ellis, Rusch, & Heal (1993) proved that supported employment, which is a form of tertiary prevention, was more cost-effective than sheltered employment, which is an ongoing service. The study compared two groups in programs that had been running for five years; the savings per client, per year, ranged from \$1,132 to \$5,003.

Unless careful studies are done using control groups and experimental groups, the amount of money saved through the prevention of disabilities

can only be an "educated guess". The effectiveness of prevention programs may be judged by estimating the reduction of incidence, but cause/effect relationships are extremely difficult to prove. The question of cost effectiveness of programs for the prevention of disability is an area where more studies need to be done.

The closest I could come to a cost-effectiveness estimate is a rough comparison of government money spent on services for people with disabilities and the amount spent on prevention in Saskatchewan.

After going through various government documents, I was able to identify over \$100,000,000 spent in one year on services for people with disabilities (See Appendix B). The only government funds that I could find which were dedicated to prevention were those allotted to the Saskatchewan Institute for the Prevention of Handicaps. The Institute operates on a budget of less than \$250,000 per year (Saskatchewan Institute on Prevention of Handicaps, 1993), and slightly less than half of this is funded by the government. The figures I found would be far below the actual amount spent, but it is interesting that for every dollar the Saskatchewan government designates for the Institute, it spends over \$800 on services.

It is estimated that a child born with FAS would require about \$1,000,000 in special services throughout his/her life (Dr. B. Habbick, Fetal Alcohol Syndrome Symposium, Oct.14, 1993). The money saved by preventing one child from being affected would cover the Institute's entire budget for four years! Quite a dramatic comparison, but it is impossible to prove that any particular case of FAS has been prevented.

The cost-effectiveness of prevention of disabilities would increase exponentially if a monetary value could be placed on the cost of the frustration, pain, and guilt experienced by those who must deal with the problems posed by a disability.

In terms of efficiency, primary prevention gives the best return on investment because no further expenses are incurred. However, the number of non-existent disabilities cannot be measured in order to prove the efficacy of a new preventive program. An estimate can be obtained if a program is maintained for several years, and the new incidence rates compared to those compiled prior to the start of the program. This requires long-range commitment of funds and personnel which, given the present financial situation in Saskatchewan, is unlikely.

### **Summary of the Prevention of Disabilities**

Some disabilities can be prevented, others cannot. By the application of known techniques, a large number of disabilities can be prevented, or their severity reduced. Primary prevention is extremely effective because it targets the whole population, and, if it is successful, the disability addressed never occurs. Secondary and tertiary prevention efforts are also extremely valuable as they focus on specific groups with definite needs, and deal with their immediate situations. Some methods of disability prevention are controversial, but others involve the development of good health habits, good parenting skills, and adequate social supports.

Education about methods to reduce the risk of disability is a major part of primary prevention, but there is no curriculum in Saskatchewan schools which emphasizes the prevention of disabilities. The next section outlines a program designed to bring the issue of disabilities and disability prevention to the attention of students in grades seven, eight, and nine.

## The "Prevention of Disabilities" Program

People in Saskatchewan still develop disabilities that could have been prevented. It is estimated that 100 babies born in Saskatchewan this year will be diagnosed with Fetal Alcohol Syndrome (Saskatchewan Institute for the Prevention of Handicaps, 1993), and FAS is completely preventable! Almost 10% of births in Saskatchewan are babies born to teenaged mothers (Saskatchewan Health, 1992), whose infants are considered to be "at risk". In 1988, Saskatchewan had about 2500 children, four years old or younger, who had disabilities (Statistics Canada, 1990). Perhaps as many as 2000 of these cases could have been prevented (Drash, 1992).

From these statistics dealing with young children, it seems obvious that prevention techniques are either not known or not consistently applied in Saskatchewan. This province needs to emphasize the education of young people concerning the prevention of disabilities.

The following section deals with the rationale of the proposed "Prevention of Disabilities" program, and gives a brief description of the curriculum.

### Rationale

#### Why do we need a program about the prevention of disabilities?

In ancient times, babies born with birth defects were left on hillsides to die. In Biblical times, adults who were "blemished" were not allowed to participate in the religious life of their people (Leviticus 21:17-23). In modern times, the lot of people with disabilities is much improved in

comparison. However, they still suffer discrimination and hardship despite the millions of dollars spent every year to improve their lives. For both humanitarian and financial reasons, disabilities should be prevented whenever ethically possible.

A program about the prevention of disabilities is needed because preventable disabilities are still occurring. Either information about the prevention of disabilities has not reached people, or else it has not influenced their behavior.

#### Why choose grade seven, eight, and nine students for this program?

There are several reasons why these students are the best target group for instruction about the prevention of disabilities.

Students in grades seven to nine are between 12 and 16 years old, and must attend school under Saskatchewan law. Though it is not uncommon for students to "drop out" before finishing grade 12, most of them are still in school until 16. By targeting students in grades 7 - 9, we have a "captive audience". It is especially important to reach students who might "drop out" because this may be their only exposure to this information.

The second reason for choosing these students is that they are given many new responsibilities during this period. Twelve year olds are eligible to do babysitting, so child care and safety are important. Sixteen year olds have driver's licences, so it is appropriate to stress the use of seatbelts, car seats, and the dangers of impaired driving.

The third reason is that the people in the twelve to sixteen age group have common characteristics that make it an important time to emphasize positive life-style choices. At this age, the peer group is very important and social inclusion is a major concern. This tendency makes the early teen

years a good time to discuss the social issues of disability, and to encourage acceptance and the inclusion of people with disabilities. People in their early and mid teens experiment with many facets of life, and make decisions that can affect their whole lives, and the lives of others. Saskatchewan Alcohol and Drug Abuse Commission estimates that, by grade nine, three quarters of all the students have at least tried alcohol, and about a quarter of them have used Cannabis (1986). Some people in this age group become sexually active, so information on family planning, preparation for conception, and prenatal care is important. Many teenagers are involved in active physical activity and the importance of protection against injury should be emphasized. All of these tendencies are fairly common among people of this age group, therefore, information on the prevention aspects of their behavior choices is extremely important.

The fourth reason for aiming the Prevention of Disabilities Program at this age group is that it complements the Family Life Curriculum used in these grades. The Prevention of Disabilities Program can be used as a separate teaching module, or as resource material to expand the Family Life Curriculum.



## Description of the Program

The Prevention of Disabilities Program has three sections. The first one contains background information for teachers which outlines the causes, effects, and prevention of disabilities. The second part consists of a teaching module for each grade, with unit outlines and lesson plans. The third section lists possible resources: brochures, books, videotapes, and some organizations that might provide guest speakers.

Throughout the program, two basic concepts are advanced:

1. Some people in our society have problems that require the use of special services, but otherwise these people are just like every one else, with the same needs, wants, hopes and dreams.
2. Disabilities can often be prevented or made less devastating to those who are afflicted.
  - a) Whenever possible, disabilities should be prevented or their severity reduced.
  - b) Everyone can help prevent disabilities.

## Organization of the Teaching Modules

Each grade level module contains three units. The first one contains general information about disabilities; the second fosters positive attitudes towards people with disabilities; and the third emphasizes a specific aspect of the prevention of disabilities. The unit topics are outlined in Table 3.1.

Table 3.1

GRADE

UNIT TOPICS

General Information	Community Connections	Prevention of Disability
<p><b>Grade 7</b></p> <p>Definitions and prevalence statistics</p> <p>The effects of disabilities on the lives of people involved.</p> <p>Disabilities affect many people, and anyone may become disabled.</p>	<p>Everyone has limitations to what they can do, so we should be understanding of the limitations of others.</p> <p>Stimulations of sensory, physical, and intellectual impairments.</p> <p>How to help someone with a disability without giving offence.</p>	<p>Disabilities can be caused by injury.</p> <p>Personal safety: protective equipment for sports and work; use of seatbelts.</p> <p>Safety of others: protecting children when babysitting; helping elderly people.</p>
<p><b>Grade 8</b></p> <p>Constitutional and environmental causes of disability.</p> <p>Some disabilities are preventable, some are not.</p> <p>Services for people with disabilities.</p>	<p>Disabilities limit a person's options in life.</p> <p>Community factors which alleviate, or intensify disabilities.</p> <p>Personal involvement with people who have disabilities.</p>	<p>Child development milestones.</p> <p>Identification of disabilities.</p> <p>The importance of good child-rearing practices, especially social interaction and exposure to all forms of language.</p>
<p><b>Grade 9</b></p> <p>Preventable and non-preventable disabilities.</p> <p>Congenital disabilities can be prevented before and during pregnancy.</p> <p>Prenatal development, and the possible causes of disability during that time.</p> <p>The effects of alcohol during pregnancy.</p>	<p>How to increase community inclusion of people with disabilities.</p> <p>Personal involvement and advocacy.</p>	<p>Prevention of disabilities can start before conception.</p> <p>Many disabilities can be prevented during pregnancy.</p> <p>Optional: controversial topics to be discussed after approval by local authorities:                      birth control/family planning                      abortion as prevention                      sterilization</p>

## The Prevention of Disabilities Program and the Family Life Curriculum

The material covered by the Prevention of Disabilities Program fits well with the Family Life Curriculum for grades seven, eight, and nine. There are common concerns about the use of drugs, tobacco, and alcohol, the spread of sexually transmitted diseases, and teen pregnancy. The Family Life Curriculum promotes positive life style choices and responsible behavior, so does the Prevention of Disabilities Program. However, the Program gives reasons for making positive choices which concentrate on disability prevention. The Family Life Curriculum includes a lot of opportunities to consider personal attitudes, and social interactions within the family and the community. This coincides well with the Prevention of Disabilities Program's emphasis on social inclusion for people with disabilities.

### Summary of the Prevention of Disabilities Program

The Prevention of Disabilities Program has been developed in the hope that it will reach the largest possible number of teenagers. By ensuring that these people are informed about prevention methods, we can reduce the incidence of disability in both this generation and the next.

The Program has been designed to be taught as an independent course for grade seven, eight, and nine, but it can also be incorporated into the Family Life Curriculum which is already in use for those grades. Each grade's teaching module contains a unit of general information about disabilities, a unit to encourage positive attitudes toward people with disabilities, and a unit about methods for preventing disabilities. There is an extensive list of resources included.

## CONCLUSION

Disabilities affect every aspect of life for people who are afflicted. Their life style choices can often be curtailed and their quality of life reduced. Disabilities can, and should, be prevented because of the human suffering they cause, and the financial burden they impose.

Education about prevention methods is an excellent way to reduce the incidence of disability. Educating the young people of today can safeguard both this generation and their children, doubling the effectiveness of the effort expended. People from twelve to sixteen years of age are an extremely important target group for this educational incentive. The Prevention of Disabilities Program is designed to perform this function. It is my hope that teachers will find it useful and that this work will result in a reduced incidence of disability in our province.

## FURTHER READING

For those who are interested in reading more about disabilities and their effect on individual's lives, the following books are recommended:

Nagler, M. (Ed.). (1990). Perspectives in Disability. Palo Alto, CA: Health Markets Research.

This edited volume contains a wealth of material drawn from journal sources. The articles chosen cover a wide variety of topics in the field of disabilities. It is an excellent resource and a convenient way to obtain an overview of the field without doing extensive individual research.

Featherstone, H. (1980). A Difference in the Family: Life with a Disabled Child. New York: Basic Books.

This is a touching autobiography which explores the effects that having a child with a disability can have on family life and interactions.

Detailed information about prevention of disabilities can be found in the following books:

Abroms, K.I. & Bennett, J.W. (Eds.). (1981). Genetics and Exceptional Children. San Francisco: Jossey-Bass Inc.

Fotheringham, J. B., Hambley, W. D., Haddad-Curran, H. W. (1983) Prevention of Intellectual Handicaps. Toronto, On: The Martin Group.

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## APPENDIX A

### **Sex Information and Specific Disabilities**

Information for either the young people or the adults can be requested from the Sex Information and Education Council of Canada, (SIECCAN) 416-466-5304 (Barrett, 1984/1990; Keller & Buchanan, 1984/1990).

### **Information Programs for Special Education**

Information kits on emotional, social, and sexual behavior can be purchased from

James Stanfield Publishing Company, Inc.

Drawer 14,

P.O. Box 41058

Santa Barbara, CA, 93140

Phone: 1-800-421-6534 (U.S. & Canada)

Fax: 805-897-1187

The following social/sexual training kits can be rented for a small fee from the Saskatchewan Association for Community Living, John Dolan Library. More information can be obtained from:

Margie Inglehart,

3031 Louise Street,

Saskatoon, Saskatchewan

S7J 3L1

Phone: (306) 955-3344

Fax: 373-3070

Kempton, W. Life Horizons

Life Horizons I focuses on the physiological and emotional aspects of being male and female. It contains 5 slide presentations covering the following topics: parts of the body; sexual life cycle; human reproduction; birth control or regulation of fertility; sexually transmitted diseases and AIDS.

Life Horizons II deals with the moral, social, and legal aspects of sexuality. Slide presentations include building self esteem; moral, legal, and social aspects of sexual behavior; dating skills and learning to love; marriage and other adult lifestyles; parenting; and preventing or coping with sexual abuse.

Sexuality Education for Persons with Severe Developmental Disabilities provides supplemental materials for Life Horizons. Topics include parts of the body, appropriate sexual behavior, menstruation, and medical examinations.

LifeFacts I and II

LifeFacts I is a program on sexuality which teaches the biological facts, sexual behavior, sexual health, and relationships. There are two sets of teaching pictures, one explicit and one non-explicit to allow the instructor to determine what is appropriate for student needs and community attitudes.

LifeFacts II teaches self-protection skills. It addresses concerns such as the recognition of sexual abuse, self-protection strategies, and reporting and coping with sexual abuse.

## Tips

This program is for use with mildly retarded students age 10 to adult. Videos are available which teach skills in getting along with others, getting to know others, having friends, enjoying free time, living in the community, and being on the job.

## Circles

Circles I deals with intimacy and relationships. It teaches social distance and relationship building in a very graphic way.

Circles II is intended to help students avoid exploitation. They learn to recognize and react to sexual exploitation, and protect themselves.

Circles III is entitled "Safer Ways", and provides instruction on communicable diseases and casual contact, and sexually transmitted diseases, AIDS and intimate contact.

Victorian Health Foundation, Australia. Janet's Got Her Period.

This instructional kit includes a video demonstrating menstrual self-care, a storybook with colour photographs, a resource book for parents or professionals, and charts. It has a detailed task analysis of menstrual care.

## Coping with Anger: Module 2

This is a "BeCool" module to teach students the reasons that people become angry, how to distinguish fair and unfair anger, and when someone's anger is becoming dangerous. They learn "cool" approaches to cope with anger.

## Coping with Criticism: Module 3

This "BeCool" module helps students learn to cope with criticism and avoid its adverse effects. It defines criticism, explains why people criticize, and helps students distinguish valid from invalid criticism.



## APPENDIX B

The cost for services to people with disabilities in Saskatchewan were arrived at as outlined below.

### Medical Costs

Birenbaum and Cohen (1993), gave the average annual medical costs for 308 autistic individuals and 326 people with severe or profound mental retardation:

American average:	\$414/year
autistic child:	\$1000/year
autistic young adult:	\$1700/year
person with severe mental retardation:	\$4000/year

Therefore, the average medical costs are:

$$((1350 \times 308) + (4000 \times 326)) / 634 = \$2712.618/\text{year}$$

Canadian equivalents at an exchange rate of 1.3301

(CIBC, Jan. 20, 1994) are:

$$(2712.618 \times 1.3301) = \$3608.053/\text{year}$$

$$(414 \times 1.3301) = \$550.66/\text{year}$$

The extra cost of medical services due to disability is:

$$(3608.053 - 550.66) = \$3057.39/\text{year}$$

There are 23,820 people in Saskatchewan with severe disabilities (Statistics Canada, 1990). Using the figures extrapolated above we arrive at the following figures:

The total cost for the province is:

$$(23,820 \times 3057.39) = \$72,827,082/\text{year}$$

This figure cannot be considered as accurate because these individuals are of all ages, and medical needs change at different times of life. Also, this figure does not take into account fees for psychological assessments, therapy, and assistive devices that are paid for through public funds. In addition, it does not consider the costs of extra medical care for those who have mild to moderate disabilities. Because of this, I think it is fair to say that this is a minimum figure which can only be used to give an idea of the magnitude of expense incurred because of disabilities.

### **Social Services Community Living Division**

The Community Living Division of Social Services is "responsible for providing and facilitating community-based services and support to assist people with mental or physical disabilities to live and work as independently as possible within their own communities" (Saskatchewan Social Services, 1992, page 34). The Community Living Division provides residential, vocational, advocacy, and developmental services. Their budget for 1991-1992 was \$20,105,700.

This amount does not include the extra financial support required by many people with disabilities who are unable to find permanent employment income which will provide for their needs. The percentage of unemployed

During the 1991-1992 school year, Saskatchewan Education served 2,359 designated disabled students and provided vocational rehabilitation for 1,052 people.

K-12 special needs programs cost about \$45,000,000/year (Larry Carlson, personal communication, Feb.2, 1994).

The figures above are incomplete. They give a minimum figure for the cost of services provided by the Saskatchewan government for people with disabilities. However, the total below gives an idea of the magnitude of the amount spent yearly.

Health	\$72,827,082/year
Social Services	\$20,105,700/year
Education	\$48,600,000/year
-----	
Total	\$141,532,782/year

is higher for people with disabilities than for the nondisabled, so the percentage of individuals within that population who require financial support is also greater than average (Statistics Canada, 1990).

### Education

The major thrust of special education in Saskatchewan is toward mainstreaming, but special programming, support, and services are provided for students with physical, sensory, and intellectual impairments. Two programs are provided by the provincial government to pay for these services: Designated Disabled Pupil Funding, and Special Needs Program Funding (Saskatchewan Education, 1992). There is also a program for the Vocational Rehabilitation of Disabled Persons (VRDP) which is partially funded by Saskatchewan Education. Saskatchewan Education's Annual Report 1991-1992 lists the following support services:

- regional coordinators of special education,
- the SEINeS Network (Special Education Information Network for Saskatchewan) which provides electronic mail, teacher inservice, interactive classroom activities, bulletin board and technical aids "Swap Shop",
- the ACCESS (Assistance, Collaboration, Consultation, Evaluation, and Support Services in special education) Centre which offers consultative services and inservice training for teachers,
- the Saskatoon-based Psych-Educational Assessment Clinic
- services for students with hearing impairments
- the Advisory Committee on Deaf Education
- services to students with visual impairments