

A Report to
The Honourable A. B. R. Lawrence, M.C., Q.C.
Minister of Health

on

Present Arrangements for the Care and Supervision of Mentally Retarded Persons in Ontario

by
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August 1971

ONTARIO DEPARTMENT OF HEALTH

August 15th, 1971.

The Honourable A. B. R. Lawrence, M.C., Q.C., Minister of Health for the Province of Ontario, Parliament Buildings, Queen's Park,
Toronto 5, Ontario.

Dear Sir,

I have the honour to submit my report on the present arrangements for the care and supervision of mentally retarded persons in Ontario.

Yours very truly,

Mark B. Williston

CONTENTS

PART I The Back	(gron	nd to the Inquiry	
		• • .	
IHE IEK	M2 O	F REFERENCE	3
STATEMI	ENT C	OF PRINCIPLES AND OBJECTIVES	4
TERMINO	DLOG	Υ	5
THE CAS	E OF	FREDERICK ELIJAH SANDERSON	8
THE CAS	E OF	JEAN MARIE MARTEL	13
FINDING TO THE S	S AND	D CONCLUSIONS IN RELATION ERSON AND MARTEL CASES	19
HISTORI	CAL I	BACKGROUND	21
			27
PART II			
		ities for the Care of	
		arded Persons	
INTROD	UCTIO	NC	35
THE DEP	ARTI	MENT OF HEALTH	35
۸.		NTAL HEALTH DIVISION	55
	1.	The Hospital Schools(Mental Retardation Services Branch)	35
		(a) Ontario Hospital School, Orillia	35
		(b) Rideau Regional Hospital School, Smiths Falls	37
		(c) Ontario Hospital School, Cedar Springs (d) Midwestern Regional Children's Centre Palmerston	37
	2	Committee of the control of the cont	38
	2.	Ontario Hospitals(Mental Retardation Services Branch)	39
		(a) Ontario Hospital, Aurora	39
		(b) Ontario Hospital Cohourg	20

• •		Adult Occupational Centres(Mental Retardation Services Branch)	40		(a (1	children's Boarding Homes	51
۲,		(a) Adult Occupational Centre, Edgar			3. D	ay Nurseries Branch	
		(b) Prince Edward Heights, Picton		В.		L DEVELOPMENT SERVICES DIVISION	55
	4.	Mental Retardation Units in Psychiatric Hospitals (Psychiatric Services Branch)	41			amily Benefits Branch	5.4
		(a) Kingston Psychiatric Hospital,				amily Services Branch	
		Mental Retardation Section	41			he Field Services Branch	
		(b) Lakehead Psychiatric Hospital,	43			ocational and Rehabilitation Services Branch	
		Mental Retardation Section				iomes for the Aged Branch	
	5.	Facilities Operated by Local Boards				Aunicipal Welfare Administration Branch	
		(a) Adult Homes				a) The Homemakers and Nurses Services	
		(b) Schedule II Facilities			(1	b) General Welfare Assistance	56
	6.	Diagnostic Centres	44	THE DEP	PARTMEN	NT OF EDUCATION	
		(a) Children's Psychiatric Research Institute, London			1. s	pecial Education Branch	57
		(b) Mental Retardation Centre, Toronto				he Youth and Recreation Branch	
	7.	Other Clinics which Assess the Mentally Retarded		THE PAR			
	,.	(a) Community Psychiatric Hospital, Windsor		THE DEP	PARTMEN	NT OF PUBLIC WORKS	58
		(b) Mental Retardation Clinic, Chedoke-McMaster	•	INTERES	STED CO	MMUNITY GROUPS	50
		Centre, Hamilton	. 47	A.	ONTA	RIO ASSOCIATION FOR THE	20
		(c) Whitby Psychiatric Hospital, Out-Patient Department	. 47		MENT	ALLY RETARDED	58
		(d) Sudbury-Algoma Sanatorium, Child Health		В.	THE C	ANADIAN ASSOCIATION FOR THE	
		Centre, Sudbury		0		ALLY RETARDED	
	8.	Approved Boarding Homes	. 48	C.		R ASSOCIATIONS FOR HANDICAPPED PERSONS	
	Ch:	(Mental Retardation Services Branch) Idren's Services Branch	. 48	D.	SERVI	CE CLUBS	62
n		BLIC HEALTH DIVISION	. 10				
В.		Special Health Services Branch	49	PART II	II		
	1.	Homes for Special Care		Suggestio	ions		
	2.	Local Health Services Branch		ТНЕ РИА	ASINC DO	WIN OF LADOR INCOME.	
		OR GOOVER AND DAMES OF ORDEROES	C 1	THE MEN	NTALLY	OWN OF LARGE INSTITUTIONS FOR RETARDED	65
THE DE		MENT OF SOCIAL AND FAMILY SERVICES	, , 51				
A		IILDREN'S SERVICES DIVISION	5 3			ENT OF THE INSTITUTION	
	1.	Child Welfare Branch		A.	KEEPI	NG THE CHILD IN HIS HOME	70
	2.	Children's and Youth Institutions Branch	31	•			



	ons for Abolition of the Means Test	
		1
he I	mplications of Social Care	
3.	RESIDENCES IN THE COMMUNITY 73	,
	(a) Specialized Foster Homes	_
	(b) Long-term residences for children	5
	(c) Temporary specialized boarding houses	_
	for children	
	(d) Residential treatment centres	5
	(e) Supervised long-term residential	15
	nouses for the addit	16
	(I) Apartments and co-operative nousing	76
	(g) Hall-way nouses	76
	(h) Unronic care facilities	
C.	ADVANTAGES OF SMALLER RESIDENTIAL FACILITIES .	76
D.	SUPPORTING SERVICES	77
	(a) Home visiting and counselling services	78
	(b) Direct financial assistance	78
	(c) Short-term crisis relief	78
	(d) Day nurseries	79
	(e) Day care centres	79
	(f) Special day care services	79
	(g) Day care centres for retarded adults	79 7 0
	(h) Specialized homemaker services	79
	(i) Qualified baby-sitters	80
	(j) Foster Grandparents	80 80
	(k) A neighbourhood social work team	80
	(1) Guardian services	82
	(m) Citizen advocacy	82
		83
		83
	1- 1	
E	A COMPREHENSIVE CENTRE FOR RESEARCH,	
	DIAGNOSIS, MEDICAL TREATMENT AND COUNSELLING	84
		84
	(a) Research	
	(b) Diagnosis and Assessment	
	(c) Family Counselling Services	
	(d) Hospital	
	F DATA COLLECTING BANK	. ಶ≀

UNIFIED CENTRAL PLANNING AND RESPONSIBILITY	90
REGIONAL SELF-SUFFICIENCY IN THE DELIVERY	
OF THE SERVICES	96
PART IV	
Method of Proceeding and Acknowledgements	101

PART I

The Background to the Inquiry

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The Background to the Inquiry

THE TERMS OF REFERENCE

On June 8th, 1971, you asked me to act on your behalf in undertaking an investigation into the present arrangements for the care and supervision of mentally retarded persons. You requested that I inquire into the adequacy of care and supervision of mentally retarded persons with particular reference to the question of governmental and public responsibility towards them when they were not under direct custodial care by the Government.

You asked me in particular to look into two specific cases. One involved the death of Frederick Elijah Sanderson, a mentally retarded person, who allegedly hanged himself on March 5th of this year while working out of the Rideau Regional Hospital at Smiths Falls, Ontario. The other case was that of Jean Marie Martel, who had been officially discharged from the same hospital on April 4th, 1968. On February 18th, 1971, he was found walking on the roadway, apparently intending to leave his foster home. His nose, ears, fingers and toes were said to be frostbitten. In giving these instructions, you stated:

While these two specific cases have pinpointed our concerns in this area, they do more than that. They indicate far more significant and very topical issues of a general nature relating to the whole area of treatment and care of the mentally retarded.

While I have asked Mr. Williston to look into both of these specific cases, I have emphasized to him that I want him to provide us with some clear direction as to both government and public responsibilities towards such persons.

Mr. Williston will be able to shed light on both the government's responsibility as well as those responsibilities which should be undertaken by the public at large.

I have chosen an experienced lawyer to undertake this study because he has both the training and experience to analyse the factual situation of these two specific cases. But more important, as we move into this whole area of human rights we immediately get involved in fundamental legal issues, particularly those concerning the civil rights of citizens, whether or not they are retarded.

I have asked Mr. Williston to report his findings and recommendations to me by August 15, at which time I will cause his report to be made public.

STATEMENT OF PRINCIPLES AND OBJECTIVES

- 1. The problems concerning mentally retarded persons cannot be viewed in isolation. Civilized society must provide every child with the opportunity of developing to his optimum potential. It has an obligation to all handicapped alike the crippled, the deaf, the blind; those who are mentally retarded or emotionally disturbed; those with cerebral palsy or perceptual handicaps to make certain that each is educated or trained so that he can reach his true potential. Thereafter, society must provide each with such assistance, protection, opportunity and shelter as will enable him to take his place as a contributing member of the community and ensure to him a decent standard of living so that he can walk through life with dignity.
- 2. The furnishing of the basic necessities and support to enable a person to function in society must be recognized as a basic human right to be provided for at public expense and not discharged as a matter of chance or charity. A handicapped person has special requirements which demand a totality of care that can never be fulfilled in a crisis-precipitated service system based on categories of need. A "means test," which further culls out and earmarks the handicapped, should never apply.
- 3. This is a moral and ethical responsibility on the part of the public and the government towards a mentally retarded person, particularly to those who are not subject to direct custodial care, which may seldom be necessary at all.
- 4. Mentally retarded persons should be helped as far as possible in the context of their families, the communities in which they live or to which they will return, and the schools they attend.
- 5. Society should thus do everything in its power to enable the mentally retarded to live with his own family during his formative years and thereafter be

kept within his own community. If this is not possible, he should not be put into an institution which isolates him from his community. He should be placed in surroundings and circumstances as close as possible to the way he would live in normal life, with the hope that he will be able, after training and education, to assume a productive position in his community. It is too much to expect that any person could spend years in a large institution and, after having been "discharged" into a strange community, be able to cope with the problems that will beset him in the outside world.

- 6. Many of the retarded living in the community will at times need special care and supervision. This is especially true of persons who have spent many years in a large isolated institution. Equally, their families or the persons on whose doorstep they have been placed, will not be able to handle the problems unless provided with special training, supervision and assistance. They need as much help as the retarded person.
- 7. If a mentally retarded child is to be provided with the assistance he needs to face the problems of adult life and is to be given the opportunity to develop to his ultimate potential, he must at all times be given the greatest possible degree of participation in life. Society must maintain for him the maximum degree of normalcy in all of his experiences to allow him a healthy and happy development as a total person.

These objectives, in my submission, can best be accomplished by:

- (a) having one Department of Government responsible for the overall planning, programming, budgeting, financing and co-ordination of the services for all handicapped persons;
- (b) having regional self-sufficiency in the delivery of those services to the communities.

In this way it will be possible to plan a framework for a continuum of province-wide services extended to all handicapped children and not merely to those in institutions operated by the state.

TERMINOLOGY

The term mentally retarded (or mentally deficient or defective) is applied to persons who are seriously lacking in intelligence and who, because of their subnormal functioning, require special training, education and social services. Mental retardation usually originates during the development period and is associated with impairment in maturation and learning.

For the purposes of planning services for retarded persons, it is usual to classify them in terms of the gravity or severity of the mental handicap as measured by intelligence tests and abnormality in social behaviour. Until a very few years ago, retarded persons were generally graded under the labels of "Idiot," "Moron," "Imbecile." The terms in common usage today are somewhat less harsh, but they still involve assessment by gradation which is not very precise. An intelligence quotient test is subject to considerable variation and error and can change quite substantially during life. It is by no means infallible if used as a method of predicting academic or vocational potential. Motivation, personality and emotional stability are important contributing factors which must also be taken into account. In this report, I must use the nomenclature of the day.

Based on an estimate that about 3% of the population is mentally retarded (Intelligence Quotient 70 or less), there are approximately 210,000 mentally retarded persons in Ontario. The mentally retarded are generally divided into four groups:

- (1) Mildly retarded, or educable,
- (2) Moderately retarded, or trainable,
- (3) Severely retarded,
- (4) Profoundly handicapped.

Mildly or educable retarded persons account for about 75%. In terms of intelligence, they fit into an Intelligence Quotient range of between 50 to 70. They are educationally subnormal. Their ultimate understanding would ordinarily reach that of a normal child of 8 - 12 years of age. They can master academic work of Grade 2 to Grade 6 in special classes in the regular school system. They are capable of simple work training but require a measure of supervision especially in vocational and job placement. About 90% of the mildly retarded can learn to take their place as ordinary citizens doing ordinary jobs and so become integrated into society.

The dividing line between those who can acquire the rudiments of reading, writing and arithmetic, and those who cannot, is generally considered to be an Intelligence Quotient of about 50. There are a few children, however, with an Intelligence Quotient as low as 40 who learn to read and write and often persons with Intelligence Quotients as high as 60 do not learn to read, write or do the simplest arithmetic.

Moderately (or trainable) retarded persons have an Intelligence Quotient ranging from 32 - 50. Their mental age at adulthood is from 4 - 8 years of age. They are capable of mastering only the rudiments of grade school if specially

taught. Instruction is by constant repetition, sensory activity and social training. They have difficulty in thinking anticipatorily. They are short on judgment and the ability to make important decisions. A number of them, with a great deal of perseverance and time, can be trained to read to about a Grade 2 level. Almost all of the moderately retarded will require care and support throughout the entire duration of their lives. Downe's Syndrome children (Mongols) usually fall into this classification.

The severely retarded have an Intelligence Quotient ranging between 18 and 32. They have a mental level between 2 and 4 years. They can usually be toilet trained and taught to dress themselves and make their own beds. They need programs geared to personal mangement, hygiene and social training. They can participate in industrial therapy and can do simple assembly and packaging work and have a meaningful occupation on a limited scale.

The profoundly retarded have an Intelligence Quotient under 17 and a mental age of under 2 years. Since they do not learn to guard themselves against common dangers they will almost always be entirely dependent upon others for protection and care. They can be trained to do only the very simplest things. Some of them cannot be toilet trained or learn to dress themselves. Training may be particularly difficult if they have associated physical disabilities. All that can be done for them is to provide care, shelter and activity. However, it has been effectively demonstrated that, with special teachers, therapists and trained volunteers, even the most profoundly handicapped child can profit from a structured program.

The mentally retarded may also suffer from associated physical afflictions and abnormalities. This is especially the case with severely or profoundly retarded. A large number of the moderately retarded lack co-ordination, many have minor brain dysfunction. While some retarded persons are physically very attractive, others have the stigmata of retardation. Some are prone to emotional and psychiatric problems; they can develop frustrations and loneliness. Often they are teased and misunderstood and have been outrightly ill-treated. While they often find it difficult to communicate, they generally are affectionate and responsive to kindness and attention. The number of mentally retarded who have violent or dangerous propensities is exceedingly small.

Mental retardation can seldom be "cured" in the same manner as a disease. However, the development of mentally retarded persons can almost always be improved by education, training and special care. His condition may be alleviated by treatment of physical and emotional disabilities associated with the mental handicap.

The mentally retarded in Ontario are presently located, in approximate terms, as follows:

A. In Institutions

B.

mum	Facilities for the profoundly and severely		
	mentally retarded and physically handi-		
	capped young children	650	
	Homes for Special Care		
	- severely retarded	1,300	
	Children's Boarding Homes	150	
	Community Residences	200	
	Mental Retardation Branch Institutions	6,500	
	Ontario Hospitals (Psychiatric Hospitals)	2,500	11,300
Reta	rded in Workshops and Schools		
	Nursery schools	1,500	
***	Special Schools - Trainable	5,000	
	- Educable	45,000	
		•	

C. Retarded in the Community

Adult Workshops

There are no statistics available as to the number of mildly retarded who are working and have been integrated into the community and of the number of moderately retarded who are being kept at home. Based on the estimate that 3% of the population falls below the level of 70 IQ, there would be

145,100

53,600

2,100

210,000

THE CASE OF FREDERICK ELIJAH SANDERSON

On March 5th, 1971, the Nepean Police Department was called to the farm of Justin Dervin, located on County Road No. 10 not far from Richmond, in the Regional District of Ottawa-Carleton. The police discovered the body of Sanderson hanging from a length of baling twine in the barn. At the time of his death, Sanderson was a ward of the Kapuskasing Children's Aid Society, and a resident of the Rideau Regional Hospital School. As a result of the death, an inquest was conducted by Dr. Roger Hughes on April 28th and May 3rd in Ottawa.

Frederick Elijah Sanderson was a Cree Indian born on the 11th day of April, 1952, at Smokey Line, Ontario. At the time of his death he was considered to be mild to moderately retarded, having a mental age of approximately 10 years. The Hospital School records show that Sanderson's mother entered into a common-law union with a Moses Sanderson about the year 1940. Sanderson's father died in 1955 and his mother in 1956. Sanderson was placed in the home of friends who attempted to care for him; however, at the age of 4 he was taken into the care of the Children's Aid Society. During the Children's Aid Society's wardship, Sanderson was in thirteen foster homes, many of them being for a very short duration. Sanderson commenced school in 1959 at the age of 7 years. Having repeated Grade 1 three times, he was admitted to the Ontario Hospital School, Smiths Falls, on September 10th, 1962.

An assessment at that time showed no physical abnormalities. It indicated that he was capable of communicating by way of a number of well-constructed and relevant long sentences. Apart from a minor problem in articulation, he had no difficulty in communicating. He was able to do simple arithmetic. He got along with other boys on the ward. He had some concept of right and wrong which he translated appropriately.

The Hospital School records indicate that he was functioning at the "low moron level" of intelligence and that cultural deprivation was the cause of Sanderson's condition. The assessment was: mental retardation associated with diseases and conditions due to unknown prenatal influence, cerebral defect, congenital mental retardation.

The Hospital School records indicate that a Stanford-Binet test in North Bay on August 13th, 1959, showed an Intelligence Quotient of 69. Testing at the Hospital School on November 22nd, 1962, on the basis of the Wechsler Intelligence Scale for Children, showed a verbal Intelligence Quotient of 58, a performance Intelligence Quotient of 60 and a full-scale Intelligence Quotient of 55. Hospital School records state that Sanderson was admitted to the Hospital School so that he could benefit from the academic and occupational training programs offered.

The Hospital School clinical records of Sanderson from 1963 through 1968 are cryptic and uninformative. The annual progress notes run from three to thirteen lines. No objective conclusion could be drawn from a review of the records as to the progress of Sanderson during this period. The records indicate, however, that in 1968 Sanderson was functioning at the Grade 2 level.

In December of 1968 certain discussions were held at the Hospital School to explore the possibility of placing Sanderson back within the community. As a

result, Sanderson's brother was asked to accept him. In March of 1969, the brother and his wife attended at the Hospital School together with the social worker from the Kapuskasing Children's Aid Society. The brother was interviewed at that time and was told that Sanderson tended to be easily led and would need constant supervision. In the week of April 8th, 1969, Sanderson was placed with his brother in Kapuskasing. Sanderson was returned to the Hospital School at the end of June, 1969; the reason given was that there was some marital disagreement.

On July 14th, 1969, Sanderson went on a leave of absence to Mr. Justin Dervin, R.R. 2, Richmond. Shortly before Sanderson's placement, Mr. Dervin called the Hospital School, spoke to the rehabilitation officer and asked if there was a boy available to help him on the farm. Dervin on two previous occasions had obtained residents from the Hospital School. He was told that there would be a resident available shortly. An arrangement was made that Sanderson would be given \$5.00 a week spending money by Mr. Dervin and that an additional sum of \$20.00 a month would be sent to the Hospital School by Dervin to the credit of Sanderson's account. If Dervin incurred any clothing expenses he would subtract them from the \$20.00. Dervin was also to provide room and board for Sanderson. There is no other record that Dervin had any discussions with anyone from the Hospital School with respect to Sanderson, prior to his being placed on the farm.

A social worker took Sanderson to the farm. The previous two residents from the Hospital School had lived upstairs. The social worker assumed that Sanderson would be treated the same way. But circumstances had changed and Sanderson was relegated to sleeping in a room in the basement. In other respects he was treated as a member of the family. He ate at the same table and watched television with them.

Sanderson was generally called at approximately 5:30 to 6:00 a.m. to go to the barn and help with the chores. He would work for an hour or so, have breakfast and then finish between 9:00 and 9:30 a.m. He would return to work at approximately 3:30 to 4:00 p.m. and would finish at about 6:00 and have his dinner.

When a social worker from the Hospital School visited the Dervin farm, he formed the view that Sanderson was able to express himself, able to converse and able to convey his feelings. The social worker did not visit Sanderson's room, nor was he shown around any part of the house except for the kitchen. He was never told that Sanderson was sleeping in the basement.

The Hospital School records show that Sanderson was visited on the Dervin farm on July 30th, 1969, August 7th, 1969, and August 12th, 1969. On

August 12th, 1969, Sanderson stated that he wanted to go back to the Hospital School; the worker felt that he was "homesick." He also stated that he never really wanted to do farm work. On August 20th, 1969, Sanderson was taken from the Dervin farm and returned to the Hospital School. On September 5th, 1969, Sanderson was returned to the farm. Subsequent visits to the Dervin farm revealed that Sanderson had a tendency to become homesick and was subject to a few periods of depression. Mrs. Dervin stated that Sanderson was a good worker and was the best of any of the lads that they had had from the Hospital School. On December 3rd, 1969, Sanderson spent the night at the Hospital School. He also went back to the Hospital School for a visit between February 18th and 21st, 1970. Mrs. Dervin asserted that Sanderson's trips back to the Hospital School hurt him more than they helped. She stated that for about a week after a trip to the Hospital School he did very poorly on the job and that he once complained to her that he did not see why he had to work while all his friends were sitting back at the ward of the Hospital School doing nothing.

On April 3rd, 1970, while Sanderson was at the Hospital School for a dental appointment, he stated that he did not want to go back to the Dervin farm as he did not like it there, and refused to return. On April 6th, 1970, while still at the Hospital School, Sanderson is reported to have said that he really liked the Dervins but wanted to stay at school to learn how to read and write. Sanderson remained at the Hospital School until June 3, 1970, at which time he was returned to the Dervin farm to replace a resident who had taken Sanderson's place but was unable to do the heavier work. Sanderson is said to have been happy about the placement. On September 3rd, 1970, Sanderson went to the Hospital School for his three month medical review. The records of the Hospital School indicate that the Dervins were pleased with his work and his only problem was his "sweet tooth" and his blatant tendency to tell lies.

On the next day, Sanderson refused to return to the Dervin farm. On September 9th, 1970, he apparently indicated a readiness to go back and consequently was returned to the farm. Sanderson visited the Hospital School from December 8th to December 9th, 1970. There is no record to indicate that he was having any problem. The last visit to Sanderson by the social worker was on December 22nd, 1970, when Christmas presents were delivered to him. The next scheduled visit by a member of the Hospital School staff was to have been made on March 10th, 1971.

On March 5th, the morning of his death, Sanderson was awakened at approximately 5:30 a.m. He then went to the barn and up into the hayloft and threw down feed for fifty cows. At approximately 8:00 a.m. Sanderson came into the house for breakfast. He appeared to behave normally. Although he mentioned the impending visit from the social worker, he showed no

apprehension and looked forward to it. After breakfast at about 9:10 a.m. Sanderson returned to the barn to finish his chores. At approximately 9:50 a.m. the Dervin boy was sent to the barn to assist Sanderson and at that time found him hanging from a rafter. He called his father who notified the police. Neither appeared to think of cutting Sanderson down as he was believed to be dead.

The Nepean Police arrived at the Dervin farm at 11:01 a.m. on March 5th, 1971. At this time they were taken to the hayloft where they observed Sanderson still hanging. The Coroner, Dr. Roger Hughes, was called and the deceased was pronounced dead. He was hanging from a double length of bale twine, 3'10" in length, which was secured at one end to an angled upper brace beam support on the east side of the barn. There was a slip-knot in the other end of the bale twine which was around the deceased's neck.

Sanderson was wearing a blue denim jacket and pants, leather work gloves and rubber boots, Footmarks were observed on the top of the lower horizontal brace beside the vertical support beam indicating the method used to obtain the necessary height required to put the noose around his neck. The feet were dangling approximately 1'4" below the lower horizontal brace and 2'9" above the hay level. The deceased's cap was found 4' north of the vertical beam. A search of the body, the surrounding area, as well as the dwelling, was made for a suicide note. None was found. There was no evidence of foul play.

The bale twine from which Sanderson was found hanging was placed in the barn sometime prior to the death. The twine had been used to get up on different levels of bales and workers would support themselves by placing one hand inside the loop. Sanderson, prior to his death, had spent many hours in the hayloft playing.

Sanderson's basement living quarters consisted of a room approximately 12'10" in length, 9'4" in width and 6' in depth. The room had a wooden floor covered by linoleum; the masonite walls were unpainted; a blanket substituted for a door. There was an 18 by 36 inch window on the south side of the room. The furnishings consisted of a double bed, spring and mattress, two bed sheets and a pillow case, two tattered worn blankets, an old quilt, an electric space heater, a small white dresser, chair, and a TV stand which served as a night table for a lamp. The room was dirty and untidy; some dirty clothes were scattered about. The area surrounding the bedroom was filthy and the basement floor was damp due to water seepage. The room where Sanderson lived, however, was dry.

I must come to the conclusion that, on the standards set by our society, the quarters provided for Sanderson to sleep in were not fit for human habitation.

The Coroner's Jury found that Frederick Elijah Sanderson died by his own hand by strangulation on the 5th day of March, 1971. The jury stated:

Frederick Elijah Sanderson

The jury deplores the lack of professional supervision afforded the deceased in this case from the time of his first placement until the time of his death.

We strongly recommend that future placements include the following:

- 1. An initial recorded interview with the prospective employer defining the working conditions and hours of work.
- 2. A thorough investigation of the living conditions and accommodation to ensure that they meet a reasonable and just standard.
- 3. A professional assessment of the motivation of the prospective employer should be made.
- 4. A thorough assessment of the home environment should be made to ensure that a true benefit would accrue to the patient and that rehabilitation could be expected.
- 5. The person assigned to make the assessments recommended above should be a graduate social worker.
- 6. Regular visits to the place of employment should result in a written report outlining the degree of compliance with the above. In addition, the visiting official should assess the physical and emotional well-being of the patient as a result of private discussion with the patient.
- 7. Visit reports should be read and discussed with the visiting official's supervisor and other disciplines as appropriate. Each report should be signed by the supervisor after this discussion.
- Because of the serious nature of the employer's agreement, it should be recommended for approval by the social worker making the initial visit and authorized by a senior hospital authority.

THE CASE OF JEAN MARIE MARTEL

During the inquest into the death of Frederick Elijah Sanderson, the Coroner received information which indicated to him that there had been cruelty to another retarded person, Jean Marie Martel. He went to the Ontario Provincial Police Detachment at Bell's Corners and requested that an investigation be conducted. Thereafter several newspaper articles followed, in the Ottawa Journal on May 22nd, and 25th, the Ottawa Citizen on May 26th, and Le Droit on May 26th, in which (in summary) it was alleged:

- a retarded farm worker was forced to work 12 to 15 hours a day on a diet of macaroni and ketchup, supplemented by such nutrients as calf starter and ensilage;
- he had to wash outside in an unheated garage;
- he was locked in his room when allowed into the farm house at night:
- he was forced to shovel a driveway at 2:00 a.m. in the dead of winter, dressed only in light clothing, resulting in gangrenous frozen fingers, crippling his hands for future farm work;
- when found, he was also suffering from malnutrition and diarrhoea and gave off a tremendous body odour, requiring his hospitalization for treatment of all these conditions; and finally,
- that this man was under supervision of the Rideau Regional Hospital School social workers, although not technically their patient, and that this was one of similar situations in existence in that area.

These charges were based to a considerable extent on statements taken by the police from people who met and cared for Jean Martel after he had run away from his foster home. These persons in turn were repeating what Martel is alleged to have told them.

My investigation of the facts reveals the following:

Jean Marie Martel was born of French parentage on January 21st, 1947, at Iroquois Falls, Ontario. He commenced school at age 7 and at 14 was making slow progress. His early years were spent with the grandparents and after their deaths in or about 1961 he lived with his mother at Wawa, Ontario. In appearance, Martel was dull and pathetic looking, awkward and ungainly.

In December, 1962, Martel was admitted to the Smiths Falls Hospital School as a resident. Early in 1963, a Stanford-Binet test in French established his basic mental age as 6, his Intelligence Quotient as 44, and qualified him in the high imbecile range of intelligence (now classified as trainable and moderately retarded). The diagnosis of his condition was "mental retardation

associated with disease and condition due to unknown prenatal influence. Cerebral defect congenital." He was otherwise physically sound. Over the next six years at the Rideau Regional Hospital School, Martel learned to speak English reasonably well. He received no academic schooling but was placed in a utility group where he had a good record of co-operation and behaviour.

In September, 1967, Martel was placed on the farm of Hillis Thompson of Richmond, Ontario, as a farm helper, initially on a three week trial basis. He began work at \$40.00 a month together with room and board with the arrangement that he could leave at any time — it was to be his decision alone. The rehabilitation officer provided Martel with the telephone number of the Hospital School and also his personal residence in case of difficulty. The report on this new home indicated that the standards were not high but that Martel appeared to be happy and contented. No detailed investigation was made of the Thompson family but the rehabilitation officer came to the conclusion that the Thompsons were warm and friendly. He thought Hillis Thompson was a nice man against whom there were no bad reports.

After the first three months, Martel was brought to the Hospital School for a twenty-four hour overnight stay at which time he was interviewed and had a complete medical and dental checkup. All was in order and he was returned to the Thompson farm. Another three month period of probation followed during which he is alleged to have corresponded with his mother and was occasionally visited by the rehabilitation officer. On April 4th, 1968, Martel was officially discharged from Rideau Regional Hospital School after a final medical checkover and interview which cleared him of having any problems. A letter was written to his mother informing her of her son's severance from the care of the institution. The rehabilitation officer took the position that upon discharge there was no legal obligation on the part of the Hospital School to maintain the role of an overseer but, as a moral obligation, the Hospital School did extend assistance when called upon to do so. This would consist mainly of finding another home or another place of employment.

During 1968, conditions between the Thompsons and Martel began to deteriorate. In December, Hillis Thompson became ill and went to the hospital. According to Mrs. Thompson, Martel hit a cow in a fit of temper and ran away. Another farmer in the area, Walter Foster, found Martel and took charge of him. Martel was scared and refused to return to the Thompson farm. Since he had been officially discharged from the Hospital School, it was believed that he could not be returned. His mother was reluctant to have him back. The rehabilitation officer knew that another farmer, Andrew Paauw, was on their list as wanting a farm helper. Accordingly, on December 31st, 1968, he was taken to the Paauw farm.

This farm is located on Lot 7, Concession 8, Marlborough Township in the Regional Municipality of Ottawa-Carleton. The property is at the very end of the township road and consists of a two-storey frame farmhouse to which is attached an unheated garage. A short distance away, across the yard, is a larger combination of a calf shed and heated garage or workshop in which a truck and large implements are stored. There is also a barn and other smaller buildings for chickens and feed. The stock of cattle is limited.

On his visits to the Paauws, the rehabilitation officer was impressed. The house was spotlessly clean and the farm was equal to most of the farms in the area. Martel was provided with a well-furnished, clean bedroom of his own in the house. Paauw was a hard working and a hard driving man. Martel was paid \$5.00 a week in wages. In addition, he received \$105.00 a month as a Disabled Persons Allowance from the Department of Social and Family Services. The cheque was made to Mrs. Paauw. She bought his clothing and says she gave him \$20.00 a week as spending money.

During the first three months the relationship between the Paauws and Martel was good. Martel apparently behaved well and there were not too many problems. During the winter of 1969 Martel had minor frostbite to his fingers and had to be taken to Richmond for medical treatment. Thereafter, the relationship between the Paauws and Martel rapidly deteriorated. Martel began to develop some obnoxious personal habits. Although the Paauws obtained medical assistance, he became morose and shiftless and started wandering away from the property. Things came to a head when Martel exposed himself to some little girls. To use Paauw's own words, "I kicked him in the arse, what would you do?"

From then on Paauw lost all patience with the retarded youth and had no time for him. The Paauws began objecting to the fact that Martel was eating too much and doing so little. They said he had to be watched continually and could not be counted on to complete any small chore he had been given. He was a voracious eater. He shared the common table but would eat at any other time he could obtain food. Mrs. Paauw felt that she had to constantly watch the refrigerator. For this reason Martel was locked out of the house when, occasionally, the Paauws left the farm. The Paauws' dissatisfaction with Martel's conduct was brought to the attention of the rehabilitation officer in the summer of 1970; however, nothing was done.

In the summer of 1970, Martel injured his hand in a truck door. The occurrence was reported to the Hospital School. As a result of the injury one-third of the distal part of the tip of the finger was lost together with part of the fingernail. Martel was medically treated for this injury. Later in the summer

of 1970, Martel's mother and foster father visited the Paauw farm for a period of two days. Martel's mother confirms that on this visit the tip of the finger was missing and that Martel appeared to suffer no disability. Martel's mother, on her visit to the Paauw farm, observed no evidence of any mistreatment by the Paauws toward her son.

In the fail of 1970, Martel began soiling his trousers. For this reason, Mrs. Paauw would not let him into the house until he cleaned himself. To do this, she would provide him with a bucket of warm water. He usually washed in the unheated garage attached to the house.

Martel froze his fingers on February 4th, 1971. He wandered off to the village on a bitterly cold day. He was found by the Paauws in Richmond without mitts. Later, Mrs. Paauw noticed him biting the black skin off his fingertips. She began a treatment of salt water baths and bandages, but Martel refused to keep on the bandages.

On February 11th, 1971, Martel again wandered from the farm and showed up at the Todd farm nearby. He was returned. On February 18th, Andrew Paauw had a business transaction to attend to in town and, since his wife was in the hospital, he locked Martel out of the house and left him with some small chores. On his return, Martel was missing. At 11:00 a.m. Martel was seen on foot and picked up two miles from the Paauws' farm by Walter Foster who, coincidentally, had found him "making off" from the Thompson farm two years earlier. Martel was still in farm clothes; the odour was overpowering. His nose, ears and fingertips were frostbitten. Foster took him to the farm of Raymond Disselberger nearby and left him there.

Mrs. Disselberger called the married daughter of the Paauws and she in turn advised the Smiths Falls Hospital of Martel's whereabouts as he had voiced his determination never to return to his foster home. The rehabilitation officer later called on the Disselbergers and asked them to keep Martel overnight which they agreed to do. Martel was made to bathe and was given clean clothes. While waiting for the rehabilitation officer to arrive, the Disselbergers were visited by another neighbour who took pity on Martel and, when the rehabilitation officer arrived, offered to care for the lad until another place could be found. When the rehabilitation officer went to the Paauws' farm he had no difficulty in obtaining clean and adequate garments.

Martel was taken to Kemptville District Hospital that night at 9:00 p.m. where the following diagnosis was made: "gangrene secondary to frostbite to tips of all digits of right hand and index, middle and ring finger of left hand, with wet gangrene of the tips of the middle fingers bilaterally." The attending

physician considered this condition to be "domiciliary" and one which could quite easily be treated under direction at home but, because Martel now had no settled connection with such a source, he was obliged to admit him at the hospital. His hospital file and charts over the period when Martel was a patient from February 19th to March 15th, 1971, indicated that he was not suffering from either diarrhoea or malnutrition. His stay was uneventful and the nurses described him as of low mentality, age level 6-9 years, but an eager helper with a good appetite. He smoked a pipe fairly regularly and had no apparent bad habits.

Martel is now living with his mother and her husband in Michipicoten Harbour. He appears to be happy. His mother has no complaints as to his conduct and is prepared to keep him so long as he continues to receive his Disabled Persons Allowance. Martel is not now suffering from any disability as a result of the frostbite or gangrene.

Following the newspaper publicity, the Crown Attorney for the Regional Municipality of Ottawa-Carleton requested the Ontario Provincial Police to enter into an inquiry into the allegations of cruelty to Martel by his employer, Andrew Paauw. They were instructed to look into the various aspects of the case, especially in relation to possible dereliction of trust on the part of the Rideau Regional Hospital School, and the rehabilitation officer in particular; and into the allegations that Mr. Paauw had ill-treated Martel and had thereby contravened that section of the Criminal Code dealing with the duty of persons to provide the necessities of life to a person under his charge, if that person, by reason of insanity or other cause, is unable to withdraw himself from that charge, or to provide himself with the necessities of life; also to look deeper into the background of the conditions and principals involved in the Sanderson matter, in co-operation with the Nepean Township officers who conducted that investigation, if it were shown that there existed a relationship between the two cases. An investigation was made by an inspector of the Criminal Investigation Branch, who reported as follows:

I am convinced that a charge against Mr. Andy Paauw would not succeed as there are no grounds to support it. Early in this investigation, I became assured that following upon their letter to Mrs. Cecile Lambert in Michipicoten Harbour, Wawa, Ontario, in which they advise her of her son's discharge on April 4, 1968, that the Rideau Regional Hospital School was no longer legally burdened with Jean Martel's future, and could not be held criminally responsible for whatever restrictions were placed on them for aftercare.

FINDINGS AND CONCLUSIONS IN RELATION TO THE SANDERSON AND MARTEL CASES

I have outlined the facts in both cases in some detail. The recitation of them almost dictates the conclusion.

There was in the Sanderson case fault on the part of the rehabilitation officer and the social worker assigned to the case. The inspections were too casual; the records were incomplete and unconvincing, although Sanderson was visited on quite a number of occasions. The general conditions in the house were marginal. Sanderson's sleeping quarters in the basement were deplorable. No adequate inspection was made. I do not think, however, that this negligence was a major contributing cause of Sanderson's death. While Sanderson had expressed dissatisfaction with working on the farm, there was nothing in his history to indicate to anybody that he had suicidal tendencies. This was a case of a young man who hungered for attention and human support which had been completely turned off. There is no evidence on which a firm conclusion can be substantiated but, in my opinion, it was a case where, in an attempt at reconciliation or attracting attention, a young man made a gesture which backfired. No social worker, however experienced, could have predicted this event, although, if adequate inspection had been made, the accident would not have happened - he would have been immediately removed.

In the Martel case, the house was spotless and the lad was, in my opinion, physically well looked after and I find little substance in the charges that he was not properly fed or clothed. But in this case there was such a complete breakdown of the social relationship between Martel and the Paauws that tragedy became inevitable unless somebody stepped in. There was nobody to do anything about it. He had nobody to complain to. While the rehabilitation officer had given him two telephone numbers which he could use in case of need, I am quite convinced that Martel did not have the ability to dial the number without assistance. He could not read, write, do arithmetic or handle money. Martel had been "discharged" from the Hospital School in April of 1968. Technically and legally, he was not the responsibility of the Hospital School or of any social worker or rehabilitation officer connected therewith, and no person or organization in the community other than the Paauws had assumed any duties towards him. In the Martel case, the social worker did not have anything to do with the placement in the Paauw household. Martel left his placement and went there himself. Anything the social worker did was done gratuitously. I attach very little, if any, blame to him.

In both the Sanderson case and the Martel case, there was a strong responsibility on those who took in the retarded person which, in my opinion,

was not discharged. I doubt very much, however, that in either case a criminal proceeding would be successful.

The basic fault lies in a system under which such accidents have occurred in the past. Tragedy will strike again in the future unless drastic but basic changes are made.

The Mental Health Act provides:

- 20. (1) The officer-in-charge may, upon the advice of the attending physician, place a patient on leave of absence from the psychiatric facility for a designated period of not more than three months, if the intention is that the patient shall return thereto.
- (2) Leave of absence may be permitted upon such terms and conditions as the officer-in-charge may prescribe.
- 26. (1) A patient shall be discharged from a psychiatric facility when he is no longer in need of the observation, care and treatment provided therein.
- (2) Subsection 1 does not authorize the discharge into the community of a patient who is subject to detention otherwise than under this Act.

Section 1(k) provides:

'psychiatric facility' means a facility for the observation, care and treatment of persons suffering from mental disorder, and designated as such by the regulations;

These sections have been interpreted to mean that a resident in an Ontario Hospital School must be discharged after he has been on leave of absence from the Hospital School for the designated period or an extension thereof. I must not be taken as agreeing with this interpretation. In my opinion, it does not matter how long or how often a patient is placed on leave of absence, he should not be discharged until a person in authority in the Hospital School is prepared to make the decision that the patient is no longer in need of the observation, care and treatment provided therein.

This interpretation of the legislation is not realistic when applied to a mentally retarded person. A retarded person should seldom be "discharged" unless an agency or some person in the community, apart from his employer, is willing to take the responsibility for his care and supervision. There are many instances of mentally retarded persons who could and should be discharged from the Hospital School except for the fact that no agency in his community is willing or able to take the responsibility for him.

The catchment admission area for Rideau Regional Hospital School is 176,600 square miles. It includes the Counties of Nipissing, Sudbury, Algoma, Cochrane, Timiskaming, Manitoulin, Haliburton, Peterborough, Northumberland, Hastings, Lennox and Addington, Renfrew, Frontenac, Lanark, Leeds, Grenville, Dundas, Stormont, Glengarry, Russell, Carleton, Victoria, Durham and Prince Edward. Therein are such places as Sudbury, Sault Ste. Marie, Moosonee, Picton, Cornwall, Wawa and Ottawa.

The Department of Health basically employs social workers who are attached to the staff of a hospital or a hospital school. On the staff of the Rideau Regional Hospital School there are some ten social workers, only three of whom are fully qualified. It is significant to note that the Hospital School social staff dealing directly with Sanderson were not academically trained professional social workers.

The mentality of persons who are being, or who should be discharged from the hospital school, is such that many of them cannot be expected to satisfactorily exist outside of an institution, unless given care, supervision and protection. There is no possible way whereby the staff of the hospital school could even begin to cope with the problem of the residents who are or should be returned to their community. Yet at the present time there is, with few exceptions, no social worker, no person or organization in any of the local communities who is legally charged with this responsibility.

Who should have this responsibility? The answer seems obvious — the community to which the retarded person belongs or to which he has been returned. But that community can only fulfill such obligation if it is given planning, direction and financial assistance by the Provincial Government.

HISTORICAL BACKGROUND

The present puzzling and anachronistic methods employed in dealing with the problems of mental retardation can only be understood by first looking at the circumstances and ideologies which give rise to them. Governmental systems can only be comprehended in terms of their developmental history. It would, therefore, be useful if I gave a brief historical background of the care and treatment of the mentally retarded.

The history of attitudes and practices toward the mentally retarded in Ontario is similar to and closely aligned with trends throughout the rest of North America and Europe. In the early days, attitudes of hopelessness, revulsion, ignorance and fear led to gross neglect, inactivity and inhumanity toward the

mentally retarded. They were left unprotected and allowed to roam the countryside or were restrained at home or confined to jails.

In France early in the 19th Century, the first scientific attempt was made by a physician, J. M. G. Itard, to educate a mentally retarded child known as "the wild boy of Aveyron" who, when captured, walked on all fours, drank while lying on the ground, could not talk or understand what was said. He viciously attacked any person who came too close. Itard attempted by quiet education to lead him to a normal existence.

The experiment by Itard led to further work by E. O. Seguin, who entered upon a career of the systematic education of mentally retarded persons. In 1846, he published "The Moral Treatment, Hygiene and Education of Idiots and Other Backward Children," which was an immediate popular success. In 1848, Seguin emigrated to the U.S.A. where he established the first school for the mentally retarded and acted as a consultant to those interested in establishing residential facilities for mentally retarded children. He became an evangelist in the cause.

In or about 1840, a Swiss physician, J. J. Guggenbuhl, came to the conclusion that cretins could be cured. Having observed that cretinism was abundant in the valleys but did not occur at higher elevations, he established a hospital at Abendberg, more than 4,000 feet above sea level. He prescribed a variety of medications, special diets, exercise and massages. He publicly claimed great success.

Around the middle of the 19th Century, after years of mistreatment and neglect, a wave of optimism developed based on the belief that mentally retarded persons could be cured. Early pioneers in the field thought that most retarded persons could be educated to such a degree as to enable all of them to function independently in society. The building of early institutions was accompanied by hope and euphoria. A number were to be congregated in small, community, family-type residences so that expert and intensive attention could be concentrated on them. The residence was regarded as a temporary boarding school where the child could develop the normal skills and then return to his environment.

It soon became evident, however, that the experiment was not living up to expectations. Many of the students could not be returned to society even after they had received all the instruction which the school could offer. The best that happened was that a number were taken back home where they became comparatively harmless members of society. Sometimes, after the death of their relatives, they drifted into pauperism and petty crime. It was finally learned that many of the mentally retarded would need life-long care and supervision.

Disillusionment set in when this early concept, so fine in its ideology, appeared to have failed. Eventually more and more people recognized that retarded children were not being cured by the prescribed methods. Itard had not achieved his goal. The "wild boy" had been taught to walk, comprehend the meaning of many words and to prefer civilization to the isolated existence of the outside world; but still he exhibited many anti-social characteristics. Itard, having failed to accomplish his high objective in its entirety, believed that he had failed and gave up the experiment. Guggenbuhl was completely discredited in an official investigation by the Swiss Government which found that the patients, contrary to Guggenbuhl's description, were not all cretins and that not a single cretin had been cured. He was shown to have smuggled in normal children whom he later presented as products of his system. Even the living conditions in the institution were found to be deplorable.

Soon after 1870, thinking changed and policies were reversed. Developmental attitudes degenerated into philanthropic ones. The retarded person was regarded as an innocent victim of fate or parental sin and it was thought that instead of schooling he should be given care and protection. It was said that the retarded person must be protected from society. The retarded person was moved out of society to provide him with protection from persecution and ridicule. The idea developed that it would be advantageous to congregate large numbers together. Thus, institutions changed from small intimate houses to facilities for thousands of residents. Increasing emphasis was placed on making the retarded person work. Beginning about 1880, farm colonies came into vogue. It was almost universally accepted that mentally retarded persons could best be cared for in isolated, bucolic surroundings. The belief became prevalent that with enough land, an institution could become self-supporting. This reasoning was stimulated by the fact that land in a rural area was cheap and such placing of institutions created employment opportunity in underdeveloped areas. This concept of institutionalizing a retarded person for his care and protection inevitably caused three harmful trends in the development of institutions: (1) isolation, (2) enlargement, and (3) economization.

The concept of treating the retarded person as an object of pity and charity did not last long. It was soon succeeded by one emphasizing the menacing nature of deviancy. With the segregation of mentally retarded persons behind walls, well away from the community, the scourge notion grew, i.e., that mentally retarded persons would soon overpopulate the land. It was repeatedly stated that the great majority of the feeble-minded came from family stock that transmitted feeble-mindedness from generation to generation. Some even contended that feeble-mindedness was an important factor as a cause of juvenile delinquency, adult crime, sexual immorality, prostitution, the spread of venereal disease, illegitimacy, vagrancy, and almost every other form of social evil or

disease. It was widely believed that every intellectually impaired person was likely a delinquent and that most criminal offenders had an intellectual impairment.

Institutions were then regarded as colonies where undesirables could be separated from the rest of society. Inexpensive segregation was seen as the only feasible method of combatting the social menace. To accomplish this, it was thought necessary to strip the mentally retarded person of all amenities and comforts. The "deviants" were segregated from the opposite sex, asexualized and dehumanized. They were supported in inhumanely run, regimented institutions. So keen were the officials that there be no possibility of sex or propagation by these deviants that upon death men and women were sometimes buried in separate burial grounds.

The mildly retarded and the profoundly retarded; the bedridden and the physically able; the young and the old; the rebellious and the docile, were housed together in huge dormitories. There were large wards where the physically handicapped were confined to bed, provided with minimal care, and given little in the way of stimulation.

The enlarged institutions became plagued by the triple problem — overcrowding, understaffing and underfinancing. Maintenance of the buildings was poor and the staff overworked, undertrained and underpaid. Personnel became increasingly difficult to recruit. No effort was made to relocate the inmates into the community. They received little training or education. Parents and friends were not encouraged to visit the children. Those capable of being absorbed into society constituted a major labour force for the institution and were too valuable to be released.

Having developed large rural institutions in outlying communities, the country then entered World War I. A surge of interest was revived in America in the 1920's among professional persons, which was generated by people returning from overseas. A small group of doctors specializing in mental retardation came to Canada from France. The Great Depression, with its tragic influence, set in before significant advances could be made. The Depression was followed by World War II. Wars and the Depression stifled progress in the development of social services other than those considered essential to the survival of the country.

In the field of mental retardation, a renaissance occurred two decades ago starting a new era in the patterns of care. The baseline was public interest, public concern and public endeavour. This was part of an overall movement, reacting from the horrors of war, which created new interests in civil rights, definition of

students' rights, medicare and legal aid. This concern for humanity eventually seeped down to the mentally retarded. Many people had become repulsed at what they were slowly learning about back rooms of the large institutions. People throughout the world began to react.

The universal declaration of human rights, adopted by the United Nations, proclaimed that all of the human family, without distinction of any kind, had equal and inalienable rights of human dignity and freedom. The declaration of the rights of the child, also adopted by the United Nations, proclaimed the rights of the physically, mentally or socially handicapped child to special treatment, education and care as required by his particular condition.

Parents of retarded children began complaining, criticizing and badgering for legislative action. In order to keep their children out of institutions and aid them in returning to society, parents of retarded children banded together to promote understanding and foster community services. New patterns of care started to emerge with the establishment of small regional facilities. In 1954, the World Health Organization proclaimed:

Every child has the right to expect the greatest possible protection against the occurrence of preventable physical or mental handicap before, during and after birth.

Every child also has the right to develop his potential to the maximum. This implies that all children, irrespective of whether or not they suffer from mental or physical handicap, should have every access to the best medical diagnosis and treatment, allied therapeutic services, nursing and social services, education, vocational preparation and employment. They should be able to satisfy fully the needs of their own personalities and become, as far as possible, independent and useful members of the community.

In 1961, President John F. Kennedy appointed a panel of professionals to make a comprehensive study of mental retardation in the U.S.A. A program for national action to combat mental retardation was submitted to the President by his panel the next year. In 1965, Senator Robert Kennedy visited several State institutions for the mentally retarded. His reaction, widely published in the various news media, shocked and infuriated millions of Americans. In 1967, Blatt and Kaplan published a book, "Christmas in Purgatory," which illustrated, by photographs surreptitiously taken, the deplorable style of the residential facilities in the mental institutions they visited. In 1967, the President's Committee on Mental Retardation took stock of the national effort being made to combat mental retardation and in its report emphasized the poor status of

residential care, which was described as a disgrace to the Nation. By slow degrees, the scandalous living conditions in the large institutions were improved. The staff members became actively interested in better programs.

In Europe even more progress was made. Scandinavian countries, in particular, began to develop a broad network of human welfare services whereby the mentally retarded could be maintained in the community. They proved that to administer to their needs it was not necessary that the mentally retarded be separated, segregated and removed from society. The concept which became known as "normalization" emerged as one of the most important contributions to the care and treatment of mentally retarded persons, As expressed by N. E. Bank-Middelsen of Denmark, this principle is given in the formula, "to let the mentally retarded obtain an existence as close to the normal as possible." Bengt Nirje of Sweden wrote, "the normalization principle means making available to the mentally retarded, patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society." This principle gained almost universal acceptance throughout Europe and America.

On October 24th, 1968, the International League of Societies for the Mentally Handicapped expressed their opinion as to the rights of the mentally retarded as follows:

Article I.

26

The mentally retarded person has the same basic rights as other citizens of the same country and same age.

Article II.

The mentally retarded person has a right to proper medical care and physical restoration and to such education, training, habilitation and guidance as will enable him to develop his ability and potential to the fullest possible extent, no matter how severe his degree of disability. No mentally handicapped person should be deprived of such services by reason of the costs involved.

Article III.

The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to productive work or to other meaningful occupation.

Article IV.

The mentally retarded person has a right to live with his own family or with fosterparents; to participate in all aspects of community life, and to be provided with appropriate leisure time activities. If care in an institution becomes necessary it should be in surroundings and under circumstances as close to normal living as possible.

Article V.

The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interest. No person rendering direct services to the mentally retarded should also serve as his guardian.

Article VI.

The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If accused, he has a right to a fair trial with full recognition being given to his degree of responsibility.

Article VII.

Some mentally retarded persons may be unable, due to the severity of their handicap, to exercise for themselves all their rights in a meaningful way. For others, modification of some or all of these rights is appropriate. The procedure used for modification or denial of rights must contain proper legal safeguards against every form of abuse, must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic reviews and to the right of appeal to higher authorities.

Above all'— the mentally retarded person has the right to respect.

The exciting thing today is that the people appear to be ready to experiment with different patterns of services shaped to the emerging social order so that after a century of entrenchment, changes can be made which can effectively correct the errors of the past.

Ontario

The first asylum in Ontario was opened in January, 1841, at the Old York Jail in Toronto in which there was no specific provision for retarded persons. This building was soon found to be inadequate and the old unoccupied east wing of the Parliament Buildings was requisitioned. It was abandoned in 1850 when the "Provincial Lunatic Asylum" was opened at 999 Queen Street. In 1859, the Government modified a hotel in Orillia and used it as a branch of the Toronto Asylum. It was called a "Convalescent Lunatic Asylum." In a few years the building, which had become dilapidated, was closed down and the patients were transferred to London where in 1873 an "Idiot Branch" asylum was opened to accommodate twenty-eight patients.

Demands for facilities soon increased and in 1876 the Orillia Institution, having been reconditioned, was re-opened as Canada's first hospital training school for "feeble-minded" children. It was identified by a sign as "Hospital for Idiots and Imbeciles." The first residents were thirty-five retarded persons transferred from the London Asylum and nine from the jails. In 1885, due to the overcrowded conditions, new premises were purchased one mile from town on the shore of Lake Simcoe for the site of the new hospital school. The new institution comprised a main building and two three-storey cottages. The purchase of adjacent lands in 1911 provided for a farm and increased the area to four hundred and fifty-six acres. Additional buildings were erected in 1915 providing accommodation for one thousand, two hundred residents. In the same year, a school facility in Cobourg was turned into an Ontario Hospital for delinquent retarded girls, and in 1950 a hospital was taken over at Aurora to provide an annex for the most difficult and unwanted men. In 1951, a huge hospital school was opened at Smiths Falls but the overcrowding was still desperate.

In June of 1961, a new \$12,000,000 complex was opened at Cedar Springs. It was built on the plans of the Smiths Falls Hospital and originally it was to have matched the latter's bed capacity, but public interest and protest persuaded the Government to build it at only half its intended size.

The historical growth of demand and facilities was paralleled by the personalities who marked developments in the field. Dr. Alexander H. Beaton, who became recognized as one of the leading authorities on mental retardation in North America, was Medical Superintendent at Orillia from 1867 until he retired in 1916. He began a long career by campaigning for better accommodation and for a training school which was opened in 1888. The school then flourished until 1896 when political attacks based on the high cost and the futility of education for idiots resulted in the gradual reduction of the teaching staff from eight to two. The school was closed in 1902, re-opened in 1904, closed in 1907, and began again in 1908.

With the appointment of Dr. Helen MacMurchy in 1906 as Provincial Inspector of the Care and Control of Feeble-Minded Persons, a radically different approach to the problem was introduced. She believed that the mentally deficient group was most dangerous to society, and conducted a vigorous campaign to warn the government and the public of the dangers of feeble-mindedness, in her annual official reports, public speeches and newspaper articles. Dr. MacMurchy distrusted the growing professional confidence in

intelligence quotient tests. She believed that medical and physical examinations were the only complete diagnostic procedures.

To add to this hazard for the mentally retarded, after Dr. Beaton's retirement in 1916, Mr. J. B. Downey was appointed Superintendent at Orillia. Downey's purpose was to reduce the cost of running the institutions rather than to improve the services. He put residents to work on a farm he developed on institution land, and he had the asylum maintenance staff teach manual work for the purpose of reducing institutional costs.

In 1927, the Premier of Ontario sent to England to secure Dr. B. T. McGhie as successor for Downey. Dr. McGhie's first step was to establish a liaison between the faculties of medicine and psychology of the University of Toronto and he engaged three psychologists to re-organize the training at Orillia. Again the hospital school at Orillia achieved high status.

The Depression and the Second World War created new problems for the institution. Shortages of staff and money, coupled with an expanding operation, led to a rapid growth and this added problems of overcrowding. The services and programs of the early years disappeared and Orillia became a typical large institution — overcrowded, isolated, undermaintained, and lacking in leadership. The number of residents doubled.

Developments that have taken place in programs of care for the mentally retarded in Ontario must be seen against the background of large, overcrowded institutions like the Hospital School at Orillia, which in 1960 had a population of two thousand, eight hundred, and that at Smiths Falls, two thousand, six hundred. In 1960, the hospital school was truly a "closed" institution and no parent was allowed beyond the front hall.

The attitude of staff from central office right through to ward staff was, "We can take care of the retarded better than their families — that's why they were sent to us... families should release their children to us and not interfere with our management." This is not to suggest undue harshness on the part of staff, as there were many fine people who related very well to their charges, and many of the residents were allowed some of the freedoms and privileges that today's residents enjoy. The availability of funds was always a problem and concern for costs was reflected in the fact that there were few, if any, toys in the wards, and the patients' clothing tended to have a very institutional appearance. In addition, the buildings were very old and almost entirely wooden floored. These floors, though polished and clean on the surface, had large cracks that absorbed the excrement and dirt of the ages and exuded a strong, unpleasant but familiar odour.

One of the main features to strike a visitor was the uniform of the staff. Male attendants were dressed in military-type uniforms of gray with a black stripe down the trouser leg; ward aides had a gray (latterly blue) uniform, very washed out in colour; nurses were attired in white and physicians wore laboratory coats continually, while keys dangled from every waist,

Overcrowding was most apparent in wards where profoundly and seriously retarded adults, naked or near naked, sat rocking, or aimlessly walking or crawling, often dirty. There was little attempt at programming their activities. Conditions such as these prevailed in Orillia and Smiths Falls until the new systems were introduced beginning in 1964, and until three years ago at Aurora. Patients were organized into work gangs to perform many of the routine tasks necessary to the operation.

A most demoralizing fact of life was that admissions at all institutions were invariably arranged through Members of the Legislature. The function of the central office was to handle political demands for admission and to tell, rather than ask, the superintendent what persons would be admitted, and when. To complete the picture, admission procedures were rather heartless, with no opportunity for pre-admission visits, and an almost knife-like separation at the moment of admission; any communication with the family came only from the individual initiative and dedication of a member of the staff.

The real turning point in the development of services for the retarded in Ontario was the Federal-Provincial Conference on Mental Retardation held in October, 1964. Dr. M. B. Dymond, then Minister of Health for Ontario, was appointed Co-Ordinating Minister for Mental Retardation for the purposes of the Conference. He established the first inter-departmental committee on services to the mentally retarded. This committee included representatives from Government departments such as Welfare, Education, Corrections and Health, as well as representatives from the Ontario Association for the Mentally Retarded.

As a result of the Conference, a planning document known as the "Blueprint" was prepared and was presented to the Legislature by Dr. Dymond on June 7th, 1965. The development of services for the retarded since that time has been along the lines suggested in the Blueprint. This Blueprint was substantially implemented months ahead of schedule.

During 1965, the Department of Education accepted responsibility for the school program within the facilities for the retarded.

The Mental Retardation Services Branch was established in April 1966, and given responsibility for all facilities engaged in caring for the mentally retarded.

Two other recommendations contained in the Blueprint which were implemented at this time were the establishment of the unit system and the development of a staff training program. The unit system represented a breaking away from the hospital model towards an emphasis on training programs designed for groups of persons with similar capabilities. A multi-professional committee was appointed to design an organization pattern for the implementation of this new concept.

Since implementation required new kinds of staff, a second committee was given the task of developing a staff training program aimed at meeting the needs of the mentally retarded within the framework of the unit system.

To assist in the task of training or retraining more than two thousand staff, a Co-Ordinator of Staff Development was appointed. A cardex system, designed to encourage individual programming, is now being adopted throughout the facilities for the retarded. Along with a total revision of curricula and an extension of the internal staff training program, there has been an increasing involvement of community colleges in training staff suitable for mental retardation facilities.

There has also been a change of emphasis from institutional to community care, which involves moving residents out of facilities whenever possible. Meanwhile, acceptance of the American Association on Mental Deficiency standards for space and staffing has provided the Mental Retardation Services Branch with guidelines to more humane residential programming.

The Branch has also been acting as program consultant to psychiatric hospitals at Kingston, Thunder Bay and Woodstock, all of which have sufficient numbers of mentally retarded patients to warrant the establishment of mental retardation units. These units have internal organization similar to that of other mental retardation facilities.

Nursing care for the mentally retarded, traditionally a responsibility of hospital schools, has been largely transferred to infant nursing homes (Schedule II) and homes for special care. These programs are designed to allow the profoundly and severely retarded to receive nursing care while remaining close to their families. The Homes for Special Care program also provides home-like residential placements for persons leaving institutions but remaining in need of sheltered accommodation.

This process of providing care for the mentally retarded outside the institution was further advanced by the passage in 1966 of *The Homes for Retarded Persons Act* and *The Vocational Rehabilitation Act*, both administered by the Department of Social and Family Services.

The Homes for Retarded Persons Act provides financial assistance for community residences to accommodate mildly retarded persons capable of functioning in the community with a moderate amount of supervision, while The Vocational Rehabilitation Act allows further development of sheltered workshops and other training programs that provide an incentive for mentally retarded persons to remain in the community, living either at home or in a community residence.

The problem of politically dictated admissions has been overcome by the introduction of a priority rating scale which measures a person's need for institutional placement. The success of this program is the result of close co-operation with public health nurses across the province who have accepted the responsibility for applying the priority rating scale to all persons awaiting admission to mental retardation facilities. This has generally resulted in admissions being granted on the basis of need rather than political pressure.

The development of out-patient services has been a priority of the Branch since its inception. There are now eleven clinics which provide diagnosis and counselling for retarded children and adults. In addition to providing assessment for institutional services, these clinics are becoming vital units in the discharge planning network.

PART II

Present Facilities for the Care of Mentally Retarded Persons

PART II

Present Facilities for the Care of Mentally Retarded Persons

INTRODUCTION

Any consideration of present facilities for the care of the mentally retarded must inevitably deal with their deficiencies. I make it clear that I have no criticisms whatever of the staff of your Department. In the last section I have emphasized that progress has been made in the last ten years of which the people of the Province can be justly proud. Nor am I implying any criticism on the part of those persons who are working for and with the mentally retarded. On the contrary, I have nothing but the highest praise for them; personnel in overcrowded and understaffed wards have worked competently and sometimes ingeniously to give devoted and humane service to alleviate the hardships of this segment of humanity.

I have been asked, as I understand it, to look beyond the immediate signs of distress among the mentally retarded and to examine the underlying problems. I cannot do so unless I bring into sharp focus what I find wrong with the present system. On the other hand, I believe that no person has the right to criticize unless he is prepared to present a viable alternative.

THE DEPARTMENT OF HEALTH

A. MENTAL HEALTH DIVISION

1. The Hospital Schools
(Mental Retardation Services Branch)

(a) Ontario Hospital School, Orillia

The Ontario Hospital School in Orillia is now the regional hospital school for the Central Ontario planning area. Its catchment admission area covers the Counties of Halton, Peel, York, Ontario, Simcoe, Muskoka and Parry Sound. It provides a residential program of hospital care, activity and educational

programs and adult training to the mildly, moderately, severely and profoundly retarded of all ages. There are on staff, nurses, occupational therapists, paediatricians, physiotherapists, psychiatrists, psychologists, public health nurses, social workers and residential counsellors.

In or about 1963, in order to relieve the overcrowding, the hospital school took over the Sanatorium located at Gravenhurst. It is administered from Orillia and referred to as "the Muskoka Unit." Its residents are almost all female. It cares for infants, adolescents, adults and geriatrics. The unit has about three hundred and sixty profoundly, severely, moderately and mildly retarded women and girls.

Ontario Hospital School, Orillia, provides an out-patient and community consultation service which provides a travelling clinical team to Simcoe, Muskoka, Parry Sound and the northern part of Ontario Counties, and to Sault Ste. Marie, Kirkland Lake and Timmins. The unit has on occasion gone to other places, for example, Kapuskasing, Moosonee and Chapleau. The clinics are held regularly in the local health units and scheduled by the Public Health personnel.

This hospital school is located on six hundred beautiful acres. Most of the buildings, however, are old and antiquated. Two in particular constitute a very serious fire hazard. There should he an immediate investigation by a fire marshall. There is serious overcrowding. For any particular group, residential, recreational activity and educational facilities are located in the same complex of buildings. There is a very serious shortage of professional staff.

During April of 1971, the daily average resident population was one thousand, eight hundred and fifty-seven. The ward staff, or those dealing directly with the residents, was six hundred and fifty-three persons. The minimum required under the standards set by the American Association for Mental Deficiency is nine hundred and ten. There is thus a deficiency in staff of two hundred and fifty-seven, or an understaffing of twenty-eight per cent of the minimum requirements.

During April of 1971, the daily average resident population in the Muskoka Unit was three hundred and fifty-eight. The ward staff, or those dealing directly with the residents, was one hundred and thirty-eight persons. The minimum required under the standards set by the American Association for Mental Deficiency is one hundred and ninety-six. There is thus a deficiency in staff of fifty-eight, or an understaffing of twenty-nine per cent of the minimum requirements.

(b) Rideau Regional Hospital School, Smiths Falls

This hospital school, comprising about one thousand acres along the Rideau River, was opened in February, 1951. Everything except for one small residence is encompassed in one huge building, covering four acres. The connecting corridors go for miles.

The catchment admission area for this hospital school includes the Counties of Nipissing, Sudbury, Algoma, Cochrane, Timiskaming, Manitoulin, Haliburton, Peterborough, Northumberland, Hastings, Lennox and Addington, Renfrew, Frontenac, Lanark, Leeds, Grenville, Dundas, Stormont, Glengarry, Russell, Carleton, Victoria, Durham and Prince Edward in the southeastern and northeastern planning areas. It provides residential programs for nursing care, activity and educational programs and adult training to mentally retarded persons of all ages and all degrees of mental retardation and physically handicapped conditions.

The only advantage this hospital school has over Orillia is that it is newer, easier to keep clean and less of a fire hazard.

During April of 1971, the daily average resident population was two thousand and seventy. The ward staff, or those dealing directly with the residents, was seven hundred and eighty-two persons. The minimum required under the standards set by the American Association for Mental Deficiency is one thousand and fifty-five. There is thus a deficiency in staff of two hundred and seventy-three, or an understaffing of twenty-five per cent of the minimum requirements.

(c) Ontario Hospital School, Cedar Springs

Cedar Springs was opened in June, 1961. It was to be the size and an exact replica of Smiths Falls. But public protest persuaded the Government to build only half of the project. The finished structure lacks a gymnasium, an auditorium, a chapel and a swimming pool. It does not have a physiotherapist, an occupational therapist or a speech therapist. It is located eighteen miles from Chatham on three hundred and sixty acres stretching to Lake Erie. But a one hundred foot drop from bank to water makes it impossible for the residents to use the beach.

The catchment admission area for this hospital school includes the Counties of Essex, Lambton, Kent, Elgin, Middlesex, Oxford, Perth, Huron, Bruce, Grey, Dufferin, Wellington, Waterloo, Brant, Norfolk, Wentworth, Haldimand, Lincoln and Welland, in the southwestern planning area. It provides accommodation for one thousand mentally retarded persons with all degrees of retardation and physical handicaps. For programming purposes, there are four

38

units — Hospital, Progressive Activity (for the more severely retarded ambulatory resident), Education (for children attending the academic school) and Adult Rehabilitation and Training. It has an out-patient service for the assessment of retarded persons and counselling for families living in Kent County.

There is great difficulty in procuring professional staff and visits from the parents are exceedingly difficult because of the isolated location. Blenheim and Chatham are the nearest places.

During April of 1971, the daily average resident population was nine hundred and thirty-seven. The ward staff, or those dealing directly with the residents, was three hundred and fifty-four persons. The minimum required under the standards set by the American Association for Mental Deficiency is four hundred and sixty-nine. There is thus a deficiency in staff of one hundred and fifteen, or an understaffing of twenty-four per cent of the minimum requirements.

(d) Midwestern Regional Children's Centre, Palmerston

Strictly speaking, this is not a hospital school as it does not have a hospital; it contains a few hospital beds.

This is a new residential facility opened in 1965 in the southwestern planning area with accommodation for children over six years of age. The location is not ideal. The philosophy which considered that children should be housed in one large building was outmoded before it was constructed. It provides activity and educational programs for its residents with a limited out-patient service for families in its immediate vicinity. It has a school operated by the Department of Education.

While this is supposed to be a children's centre, there are now thirty adults who were admitted when they were under sixteen years of age but could not be placed elsewhere. There are essentially no programs for these adults.

Again, there is difficulty in recruiting professional staff; for example, there is one social worker. There is an attempt to relate to the University of Waterloo and the University of Guelph.

During April of 1971, there was a daily average resident population of two hundred and sixteen. The ward staff of one hundred and five meets the standards set by the American Association for Mental Deficiency.

2. Ontario Hospitals

(Mental Retardation Services Branch)

(a) Ontario Hospital, Aurora

This facility presently provides accommodation for men over the age of sixteen years. The greater number of residents are the more seriously retarded, limited in potential, and under long-term care. All residents are ambulatory. Resident referrals may come from any part of Ontario.

The hospital building was constructed in 1915 and was originally used as a school for boys. The facility was taken over by the Department of Health in 1950 to ease overcrowding at Orillia and the pressure of the waiting list. Over the past several years, redecorating and minor modifications have been carried out. Nevertheless, the facility is obsolete.

The residents are housed in "cottage units." These "cottage units" are in fact all under the same roof and consist of parts of the upper floors of the hospital building. The residents sleep virtually elbow to elbow.

The present programs at the facility emphasize the development of self-care and living skills. There is a recreation program in effect providing such activities as swimming or excursions and social activities.

During April of 1971, the daily average resident population was one hundred and ninety. The ward staff, or those dealing directly with the residents, was fifty-eight persons. The minimum required under the standards set by the American Association for Mental Deficiency is ninety-eight. There is thus a deficiency in staff of forty, or an understaffing of forty per cent of the minimum requirements.

(b) Ontario Hospital, Cobourg

This facility, in the southeastern planning area, provides training and rehabilitation programs for mildly to moderately retarded women over the age of sixteen years. Many of the women have social problems and some have severe behavioural problems. There are, in addition, several non-ambulatory geriatric patients.

There are some sixty to seventy residents who, in addition to being retarded, are suffering from some form of psychoses. At times, they become disruptive to the programs. Efforts are presently under way to transfer those residents with a primary diagnosis of psychoses to other facilities.

The main hospital building was constructed before 1900 as a school. In 1915, the facility was turned into a hospital and at that time a temporary annex

Department of Health

was erected. The facility became a mental hospital in 1920. To date, the temporary annex is used for residential living accommodations. The buildings, particularly the annex, are obsolete and a fire hazard. The toilet facilities are appalling.

The training programs emphasize the domestic arts. Occupational functions include community training and employment. There is, however, no regular school program presently in effect, even though there are approximately eighty residents who might benefit therefrom.

During April of 1971, the daily average resident population was two hundred and eighty-one. The ward staff, or those dealing directly with the residents, was one hundred and eleven persons. The minimum required under the standards set by the American Association for Mental Deficiency is one hundred and twenty-three. There is thus a deficiency in staff of twelve, or an understaffing of nine per cent of the minimum requirement.

3. Adult Occupational Centres (Mental Retardation Services Branch)

(a) Adult Occupational Centre, Edgar

Edgar was established in 1966 by taking over the facilities of a radar station. It is a co-educational, residential, community preparation facility for young adults and older adolescents who are mildly intellectually handicapped and whose major needs are socialization, experience and counselling and training in appropriate behaviour in self-care, in work, and in constructive use of leisure hours. The goal is to return to the community as many trainees as possible as self-maintaining, contributing citizens and, for those who require a more sheltered living and work situation, a useful, satisfying and productive life at the Centre or in other available community programs.

Most of the trainees live in individual housing units which accommodate four or five trainees and are furnished as closely as possible to any normal home in the community. There are two basic programs, one to prepare the trainee to return to the community by providing the requisite training and counselling, and the other is for those who require a greater degree of sheltered living and sheltered work and for whom resources in the community are not yet available.

Recreational facilities provide the trainees with such activities as swimming, basketball, volleyball, badminton, floor and ice hockey, baseball, billiards, exercise and weight-training equipment, bowling, archery, broomball, track and field, miniature golf, ping pong, darts, football, soccer, gymnastics, and wrestling. Within the recreation department there is a large selection of clubs

(twenty-two in all) ranging from photography to art, woodworking and stamp collecting. As well as the clubs, there are other social functions such as dancing, bingos, movies, variety shows, concerts, camping, boating, fishing and community excursions.

This was undoubtedly a very fine concept. It has only one major defect. Edgar is too far from a population centre and the residents thus, while being trained for return to a community, can have no practical experience. Edgar accepts referrals from all over Ontario, thus making rehabilitation difficult for persons who are returning to their communities. Many of the residents come from Metropolitan Toronto and it is difficult to establish them in the City by finding accommodation, employment and providing supervision.

During April of 1971, the daily average resident population was two hundred and fifty. The ward staff of eighty-one meets the standards set by the American Association for Mental Deficiency.

(b) Prince Edward Heights, Picton

This facility, in the Lake Ontario planning area, will eventually accommodate approximately six hundred persons whose homes are in the Counties of Prince Edward, Lennox and Addington, Hastings, Northumberland, Peterborough, Hahburton, Victoria and Durham. The Picton complex includes ninety private homes and former Army barracks, set in fifty acres of quiet streets and fields.

The centre is operated in two sections. There is a Village Unit for the mildly retarded, which offers the residents the opportunity to live in ordinary houses with four or five persons in each. The homes in this unit are furnished in colonial style and have televisions, electrical appliances, including automatic dishwashers, clothes washers and dryers. A school, church and recreation facilities are in the process of development.

Former Army barracks will be known as the "Craig Unit." It will accommodate some one hundred and sixty more seriously retarded males and females. Most of the residents of this facility will be transferred from the Rideau Regional Hospital School, Smiths Falls, over a three year period. To date, there have been sixty transfers.

4. Mental Retardation Units in Psychiatric Hospitals (Psychiatric Services Branch)

(a) Kingston Psychiatric Hospital, Mental Retardation Section

This unit, in the southeastern planning area, accommodates one hundred and forty retarded adults. It provides diagnostic and consultative services to

other units in the hospital and treatment for disturbed and mentally ill adult retarded. Activity, educational and rehabilitation programs are arranged for adolescents and adults, sixteen years of age and upwards. Residents may have any degree of retardation but must be ambulatory. The unit is now combined with the mental retardation out-patient clinic. A travelling clinical team provides diagnostic, counselling and consultative services for the Counties of Haliburton, Hastings, Lennox and Addington, Frontenac, Lanark, Leeds, Renfrew, Peterborough, Northumberland, Prince Edward and Grenville.

(b) Lakehead Psychiatric Hospital, Mental Retardation Section

This section, in the northwestern planning area, is comprised of a children's unit and an adult unit. The children's unit has a bed capacity of one hundred and forty which accommodates children between the ages of six and eighteen who are ambulatory, educable and trainable. In conjunction with the ward program is an extensive education and training program sponsored by the Department of Education. The adult unit has a bed capacity of one hundred and sixty with the primary purpose of offering rehabilitation services which include adult education classes. The centre is supposed to provide diagnostic and counselling services for Thunder Bay, Kenora, Rainy River and Patricia Portion. Because of distances, there are no real services given to Rainy River or the northern part of Kenora. Local paediatricians staff the mentally retarded clinic but the staff of social workers and psychologists is entirely inadequate.

(c) Oxford Mental Health Centre, Woodstock

The mental retardation unit of this facility accommodates three hundred and seventeen adult ambulatory retarded residents. The nucleus of the residents, in addition to being retarded, are epileptics. The residents are originally brought to the centre from all parts of Ontario. The bulk of the residents range in age from forty-five to fifty-five. This centre does assessments for residents of Oxford County. Admissions to the centre from other Counties are arranged by the Children's Psychiatric Research Institute, London.

Approximately one-half of the residents of the facility are provided with activity and individual behavioural modification programs. The other fifty per cent of the residents are in training and rehabilitation programs. These residents participate in a sheltered workshop program and a work program within the facility. There is a recreational program in effect providing activities such as camping, excursions and social activities. There is presently under way a program for the selection of approved homes and the placement of residents in such homes.

The buildings are situated in pleasant park-like surroundings. The wards do not appear to be overcrowded. However, it may be noted that some of the ward

staff continue to wear "prison guard" type uniforms. There is a program under way at present to remodel, modernize and humanize the present facilities.

Facilities Operated by Local Boards

(a) Adult Homes

At the present time, there is only one such facility for adults operated by a local board. This is the Bethesda Home for Mentally Ill, Vineland, which is operated by a Mennonite community. It has seventy-six beds for mentally retarded persons, thirty beds for emotionally disturbed and four beds for emergencies.

(b) Schedule II Facilities

Schedule II units provide residential nursing care for young, profoundly retarded, multiply handicapped children. There are seven facilities which accommodate six hundred and forty-five children:

Facility	Location	Population
The Brant Sanatorium	Brantford	91
The Dr. Rygiel's Home for Children	Hamilton	100
Ongwanada Sanatorium	Kingston	100
Ontario Homes for Mentally Retarded Infants, Inc.	Plainfield	73
Fort William Sanatorium	Thunder Bay	108
The Sunbeam Home	Waterloo	123
The Christopher Robin Home	Ajax	50
	Total	645

These facilities, provided for under *The Mental Health Act*, 1967, Schedule II, are operated by local boards and financed by the Department of Health, Mental Health Division. The Mental Retardation Services Branch is responsible for overall supervision of the program.

The financing is on an annual budgeting basis, with Ontario Hospital Services Commission acting as fiscal agent. Any unusual changes in program or increased budgeting requirements are referred to the Director of the Mental Retardation Services Branch for his advice and consultation. Ontario Hospital Services Commission also provides nursing inspection and reports are forwarded to the Mental Retardation Services Branch. Admissions are arranged through Mental Retardation Assessment Clinics which provide the diagnostic and assessment service, family counselling and administer the waiting list for admission.

The Schedule II program was initiated before the Mental Retardation Services Branch was established and the Mental Health Division was in its present

form. At that time, the only out-patient clinic was at the Children's Psychiatric Research Institute, London. Contact with families indicated a real need for residential care for very young profoundly retarded children who did not require the total hospital school program. Tuberculosis sanatoriums which were strategically located and oriented to nursing programs were moving into new areas; three of these facilities agreed to establish children's units. Two other facilities at Waterloo and Plainfield, which were privately operated, came under Schedule II legislation and later the Hamilton and Ajax homes were established.

For the past two years, the Mental Retardation Services Branch has held regular semi-annual meetings of representatives of the board and administration of Schedule II facilities, the Chairman of the Residential Care Committee and staff members of Ontario Association for the Mentally Retarded, and administrators and clinical directors of the Children's Psychiatric Research Institute, London, and Mental Retardation Centre, Toronto, for the purpose of program planning and policy. Two units have affiliated parents' associations which are represented on their board, and the Branch and Ontario Association for the Mentally Retarded are encouraging further parent group involvement.

The facilities are designed for children and, consequently, mentally retarded persons must be moved out when they become too large for the cribs. Under existing regulations, they cannot be moved into approved homes or homes for special care or nursing homes unless they are first admitted to an Ontario Hospital or Ontario Hospital School. There is a real need for Schedule II facilities in northeastern Ontario and Metropolitan Toronto as there is no facility in the former and the latter is served by houses in Ajax and Plainfield, both a considerable distance from Toronto.

Diagnostic Centres

(a) Children's Psychiatric Research Institute, London

This institute was established under the aegis of the Mental Health Branch of the Ontario Department of Health by the conversion of a sanatorium in 1960 to service the needs in southwestern Ontario. It was the first community-centred psychiatric hospital in Ontario especially designed for the treatment of mental retardation in children. It was placed near the University of Western Ontario which was particularly interested in research into mental deficiency. The institute originally began as an out-patient clinic but has expanded to include day care and in-patient services as well.

This institute has since its inception played a leadership role in the services for the mentally retarded in this Province. It has enjoyed international acclaim, having on two occasions received awards of the American Psychiatric Association, the latest being their "Gold Achievement Award" in 1970, in recognition

of the institute's efforts in developing a comprehensive regional centre for mentally handicapped children (including emotional disturbance and learning disabilities).

Over the last ten years, the institute has expanded its role from an out-patient service to the mentally retarded to now encompass the emotionally disturbed child and adolescent with provision of in-patient services for both groups of young persons. It has developed an impressive research program both independent of and in association with the University of Western Ontario — Faculties of Medicine, Psychology, Biochemistry, Sociology, Nursing — to mention only the most prominent.

The operational data for 1970 was as follows:

(a) (b) (c) (d) (e) (f) (g)	Total new out-patients Total out-patient interviews Total day care sessions Total in-patient admissions Total in-patient discharges Total in-patient days Daily average population (1970)	740 21,200 10,063 h 474 470 35,992 101.1	patients (rated beds were 100
(h) (i)	Average length of stay, based on discharges (1970) Laboratory — in addition to biochemical tests, urinalysis, haematological tests, the laboratory contributed to the materialization of data implicit in research projects conducted at Institute for a total of 108,080 Laboratory Units (D.B.S. Units)	71.1	until October, then increased to 136) days
(j) (k)	Electroencephalograph examinations Total meals served	895 174,462	
(1)	Meals on wheels supplied to older people in the community (This program is self supporting)	2,201	

The centre has acquired a highly skilled research staff. The cytogenetic department has been very active in performing cytogenetic cultures at the Institute and the Ontario Hospital School in Cedar Springs. Eight hundred and eighty-one cultures were obtained and many chromosome abnormalities were

discovered. A technique was developed for diagnosing the presence or absence of the "Y" chromosome associated by some authorities with aggressive behaviour. The institute in 1970 has performed examinations on two hundred and fifty males at the Oak Ridge Section of the Penetang Psychiatric Hospital. This laboratory also has performed special examinations on many Downe's Syndrome children. Four unusual chromosome abnormalities were discovered in this group. The laboratory is involved in prenatal diagnosis of cytogenetic defects in conjunction with the University of Western Ontario Departments of Obstetrics and Pathology. Amniocentesis cultures were obtained from high risk mothers, to assist in genetic counselling.

The Biochemistry Research Laboratory has been responsible for a program of screening of all the institute's patients to detect metabolic errors. These specialized tests have furthered knowledge of the diseases of amnioacid metabolism and the mucopolysaccharide storage diseases, resulting in several papers being published by the staff of the institute.

The institute's commitment to education is one of its major functions as an affiliated teaching hospital of the University of Western Ontario. It has played a major role in the provision of clinical training for undergraduate physicians, postgraduate paediatricians and psychiatrists, child care workers, residential counsellors and has been affiliated with courses for public health nurses, social workers, general practitioners in the region. Children's Psychiatric Research Institute has provided a focal point for education of the general public, particularly those with special interests in handicapped children. The number of interested citizens visiting this institute continues to increase annually which gives further evidence of its major role in southwestern Ontario.

The institute has provided a focal point for service development throughout seventeen counties in southwestern Ontario. It has been a major influence in the changing attitudes of the community and community agencies toward the mentally retarded in its region. It is continuing to expand its delivery of services to the community and to increase the involvement of community agencies in their provision of services to both the retarded and the emotionally disturbed.

In connection with the institute, there are ninety-two persons who perform a regular voluntary service. They donate their time for patient service, fund raising and interpretation of the institute to the community. By their efforts, they have raised enough money to construct an outdoor swimming pool for the use of patients.

This institute, I say without qualification, is one of the greatest centres of its kind in the world.

(b) Mental Retardation Centre, Toronto

This centre provides diagnostic and counselling services for the mentally retarded of all ages. It also has twenty-four beds for short-term admission. This centre serves the Counties of Halton, Peel, York (including Metropolitan Toronto) and the southern part of Ontario County.

(c) Child Development Clinic, Ottawa

This clinic, which is affiliated with the University of Ottawa, Department of Paediatrics and Psychology, provides diagnostic and counselling services for retarded persons residing in the Ottawa-Carleton County area. It also provides a limited service to the five eastern counties of Russell, Prescott, Dundas, Stormont and Glengarry.

The clinic originated as a pilot project of the Ottawa Health Unit financed by the Mental Health grant. This year it has been taken over by the board of the Regional Children's Hospital. This could well be a good move if the clinic is given its own ward so that the patients can be looked after by personnel trained to deal with them. The clinic now has a part-time staff of three paediatricians, one psychologist, one medical doctor, one psychiatrist, two psychomatrists, two social workers, one speech therapist and one secretary-receptionist. The clinic is badly understaffed for the work it must do. Consequently, there is no travelling clinic.

7. Other Clinics which Assess the Mentally Retarded

(a) Community Psychiatric Hospital, Windsor

This private, board-operated regional centre provides assessment and counselling services for mentally retarded and their families in Windsor and Essex County to assist in home management or for placement in a mental retardation facility. There are no in-patient beds.

(b) Mental Retardation Clinic, Chedoke-McMaster Centre, Hamilton

This clinic established by the Department of Paediatrics, McMaster University, operates an out-patient program for diagnostic evaluation, assessment, counselling and continuing care in Hamilton and Wentworth County. It has four beds at The Dr. Rygiel's Home for Children.

(c) Whitby Psychiatric Hospital, Out-Patient Department

This facility provides diagnostic and counselling services for retarded persons and their families residing in Victoria and Durham Counties. It assists with placements in mental retardation facilities.

(d) Sudbury-Algoma Sanatorium, Child Health Centre, Sudbury

This centre, operated by a regional board, provides diagnostic and counselling services for retarded persons and their families residing in the Sudbury-Manitoulin area. It has an out-patient and in-patient clinic with twenty beds.

8. Approved Boarding Homes

(Mental Retardation Services Branch)

The approved home is a private family home where the members of the family are willing and able to care for patients who have been in a psychiatric facility. These homes are intended for interim care between institution and return to the home community. The main purpose of the home is to help in the rehabilitation of patients or residents. Residents are not discharged from the institution and may be returned at any time. While the resident is in an approved home, medical supervision is the responsibility of the institution. The home is paid \$5.25 a day for each resident plus clothing and incidental expenses. Because supervisors must be provided by the hospital school, these homes must necessarily be located in the vicinity of the institution. There are in Ontario only forty-three approved boarding homes for the mentally retarded, having one hundred and seventeen residents.

Children's Services Branch

The Children's Services Branch was established in September, 1969, as a new service within the Mental Health Division of the Ontario Department of Health to provide the administration, leadership and direction for the further development of the system of special services for children and adolescents. This Branch is responsible for the evaluation, supervision and support of existing provincial facilities and services for emotionally disturbed children and youth. Such facilities include eight regional centres for emotionally disturbed children and six special units for children and adolescents in Ontario Psychiatric hospitals.

The Branch administers The Children's Mental Health Centres Act, 1968-69, and the regulations made under the Act. It is the responsibility of the Branch to see that all special treatment programs for children shall be designated, licensed and appropriately funded by the Department of Health. At present, there are twenty-one residential and ten non-residential centres licensed under the Act.

The Children's Services Branch offers a consultation service to all organizations or persons interested in promoting better quality programs for

disturbed children. Through continuing surveys and analyses of the needs of children and the distribution of resources, the Children's Services Branch identifies areas of unmet needs, and plans for the establishment of new programs to meet these needs.

The Children's Services Branch serves as a focal point in the co-ordination of services for emotionally disturbed children and youth by providing for continuing contact and promoting close working relationships among representatives of all government departments and non-government organizations involved in the provision of services for children and adolescents with mental and emotional disorders.

B. PUBLIC HEALTH DIVISION

1. Special Health Services Branch

Homes for Special Care are licensed and supervised through the Chronic Care Section of the Public Health Division of the Department of Health. These homes are intended for long-term permanent care and are privately operated. The objective of the homes for special care is to relieve the institutions of caring for a large number of individuals by placing them in suitable residential homes in the community. Candidates for the homes for special care are residents who are chronically mentally disabled to the point where they are unable to be self-sufficient or self-supporting citizens of the community and where there are no medical reasons why they should be retained in the institution.

Residents placed in homes for special care are discharged patients and, if they are returned to the institutions, they must be re-admitted. The medical care of these residents is no longer the responsibility of the institution, but is taken up by a physician in the community. These homes take persons from either a mental hospital or Ontario Hospital School. No special record is kept of the mentally retarded residents except in the case of twelve homes designated for retarded children. There are two hundred and sixty-two nursing homes having a budgetary bed ceiling of five thousand, five hundred and fifty. There are two hundred and twenty-seven residential homes having a budgetary ceiling of one thousand, six hundred beds. The Department pays \$5.25 for residential care and \$11.00 a day for nursing care.

Residents of homes for special care who are under the age of sixty-five do not have any personal assets, receive no regular allowance to spend on the small comforts of life. While haircuts, bus tickets and tobacco may be provided by the operator of the facility and charged to the Province, I feel it is important that the individual be able to spend a few dollars as he or she chooses. I would

recommend that a comfort allowance for indigent residents of homes for special care be provided for each such resident.

2. Local Health Services Branch

The Province of Ontario is broken up into six Public Health regions. Each region is staffed by a regional medical officer who functions as the administrator. In addition, there are regional consultants in the areas of public health nursing, public health inspection and nutrition.

Within the six regions there is a total of forty-three health units and health districts. These are autonomous board-operated bodies funded, in the case of health districts, 75% by the Department of Health, and in the case of health units, 25% to 50% by the Department of Health. Each health unit or health district has a medical officer who is in charge of the district or unit. There are in addition seventeen associate medical officers of health. Operating within the health units and health districts there are one thousand, five hundred and seventeen qualified public health nurses, two hundred and seventy-eight registered nurses and one hundred and fifteen nursing assistants.

Public Health regions in the Province of Ontario are as follows:

Region	City	Areas Served
Southwestern	London	Essex, Kent, Lambton, Middlesex, Elgin, Huron, Perth
Midwestern	Hamilton	Welland, Lincoln, Wentworth, Waterloo, Wellington-Dufferin, Oxford, Brant, Norfolk, Haldimand
Central	Toronto	York, Peel, Halton, Ontario, Simcoe, Grey and Bruce, Metropolitan Toronto
Mideastern	Kingston	Northumberland, Durham, Victoria, Hali- burton, Peterborough, Hastings, Prince Edward, Lennox and Addington, Frontenac, Leeds, Grenville, Lanark
Eastern	Ottawa	Renfrew, Carleton, Prescott, Russell, Stormont, Glengarry, Dundas
Northern Ontario		Territorial Districts of Algoma, Cochrane, Kenora, Manitoulin, Muskoka, Nipissing, Parry Sound, Rainy River, Sudbury, Thunder Bay, Tamiskaming

For many years the Local Health Services Branch, through the public health nurses, has provided a multitude of services and has filled the gap in the programs for the mentally retarded persons. Areas in which the Local Health Services Branch plays a major role in relation to the mentally retarded persons include:

- (i) immunization against diseases known to contribute to the incidence of mental retardation;
- (ii) casefinding through visits to hospitals, homes, schools, etc.;
- (iii) care and management through supportive counselling, and home training in techniques for managing the retarded person;
- (iv) source of referral to mental retardation assessment clinics;
- (v) pre-admission screening by completing a detailed rating form for use in setting priorities of admission;
- (vi) follow-up services for retarded persons who have been assessed at a clinic or discharged from a mental retardation facility.

THE DEPARTMENT OF SOCIAL AND FAMILY SERVICES

A. CHILDREN'S SERVICES DIVISION

1. Child Welfare Branch

The Child Welfare Branch advises and supervises the fifty-one Children's Aid Societies which serve the needs of neglected or dependent children in Ontario and inspects the operation of the Societies.

Children's Aid Societies in Ontario are responsible for protection of children in the home, wardship of children with no proper or permanent home, help to unmarried mothers, adoption of children, and a general responsibility for children in the province. Each area in the province is covered by a Children's Aid Society operating under the terms of *The Child Welfare Act* under the supervision of the Child Welfare Branch. Each of the societies is governed by a board of directors and employs its own staff. Operating expenses are entirely financed from tax raised funds, the major portion being provided by the Province. Figures are not available for the whole of the province, but statistics from a survey made on behalf of the Metropolitan Toronto Children's Aid Society indicate that 18.7% of all children under its care are mentally retarded.

2. Children's and Youth Institutions Branch

(a) Children's Boarding Homes

The scope of the Branch includes the registration and supervision of institutions which care for homeless and handicapped children, retarded persons,

and young people with various problems. The institutions are planned and built by private individuals. They receive no subsidies from the Provincial Government. There are twelve such homes in Ontario for retarded children housing one hundred and seventy-three.

(b) Homes for Retarded Persons

The Ontario Government gives assistance to private non-profit organizations maintaining residences for the education and training of mentally retarded children and adults. The Province contributes eighty per cent of operation costs and provides \$5,000.00 for each bed, capital cost for construction, and \$1,200.00 per bed for renovations.

The following are community residences operated by local organizations for mildly and moderately retarded persons who can function in the community with a moderate amount of supervision:

Churchwood Residence	(Ontario Association for	
	the Mentally Retarded)	19
Charlestown		16
Daybreak		14
Glengarda		23
Good Shepherd Manor		28
Grand View	(Ontario Association for	
	the Mentally Retarded)	10
Hamilton and District	(Ontario Association for	
Association Residence	the Mentally Retarded)	11
Hawthorne Lodge	(Ontario Association for	
	the Mentally Retarded)	18
Harold R. Lawson	(Ontario Association for	
	the Mentally Retarded)	50
Sheppard Avenue	(Ontario Association for	
	the Mentally Retarded)	26
Rosedale	(Ontario Association for	
	the Mentally Retarded)	10
Margot E. Scott House	(Ontario Association for	
	the Mentally Retarded)	11
Silver Spring Farm	(Ontario Association for	
	the Mentally Retarded)	38
		274

Due to the high cost of land, Fire Marshall's Regulations, difficulty in raising the remaining capital funds, and the high interest rate on borrowed money, it is impossible for the local associations for the mentally retarded to raise enough money to build more than a fraction of the needed residences even with the assistance given under the legislation.

3. Day Nurseries Branch

This Branch has the responsibility of ensuring that both public and private group care is of a standard beneficent to children. This is carried out through a licensing procedure which establishes standards for premises, staff, equipment and furnishing and health supervision.

There are approximately eight hundred privately operated nurseries in Ontario. Eighty of these nurseries have one or more mentally retarded children under their care. Most of these are operated by local associations of the Ontario Association for the Mentally Retarded. The following table shows the percentage of nurseries in various types of accommodation:

Churches	48%
Public buildings	15%
Operator's own home	13%
Other houses	12%
Buildings built as nurseries	5%
Apartment buildings	4%
Schools	3%
	100%

The majority are financed by parents' fees. A few are partially financed under the United Community Fund.

Under The Day Nurseries Act, financial assistance may be provided by the Province in two ways:

- (a) Municipalities may recover from the Provincial Government eighty per cent of the operating, maintenance and renovation costs of day nurseries for which they have assumed responsibility. To date three such nurseries have been established for mentally retarded children.
- (b) A municipality may enter into an agreement with a private nursery to which the municipality will pay all or part of the fees for children whose parents are unable to meet the full cost. The municipality pays the balance between the actual per diem rate and the amount the parent is assessed. There is a subsidy given to the municipality for eighty per cent of these costs. Aid in paying fees is available to families who qualify under The General Welfare Assistance Act.

There are sixty-eight municipally operated nurseries, forty-four of them being all day and twenty-four half day.

The present legislation covering day nurseries has proved of little benefit to the mentally retarded. Lack of funds results in only a part-time operation for most of the nursery schools for these children. Experience has shown that with only a few exceptions municipalities are not prepared to sponsor specialized nursery schools. There are only five municipally operated day nurseries. They are at Kapuskasing, the Township of Plympton, St. Catharines, Strathroy, Wardsville, and these operate only for half days. There would seem to be no reason why the Act should not be amended to permit local associations to run nursery schools and be eligible for Provincial assistance on the same basis as the municipalities.

B. SOCIAL DEVELOPMENT SERVICES DIVISION

1. Family Benefits Branch

Family benefits provide for long term assistance. A disabled person at least eighteen years of age, who has a mental impairment likely to continue for a prolonged period of time and as a result is severely limited in the activities of normal living, is entitled to the maximum amount payable to a mentally retarded of \$105.00 per month. The benefit payable is based on need, which is determined under *The Family Benefits Act* by a consideration of the applicant's liquid assets. Limitations are \$1,000.00 for a single applicant plus \$200.00 for each dependent. If the mentally retarded earns more than \$24.00 per month, his allowance will be decreased accordingly. While it is impossible to ascertain the number of retarded adults who are in receipt of family benefits, it is known that 15.4% of applications for assistance received from disabled persons in 1969 were for mentally retarded adults. If this can be assumed to be the normal situation, then approximately three thousand, nine hundred and fifty mentally retarded adults receive assistance.

There are three serious limitations for the benefits which mentally retarded persons receive under this Act:

- (a) A means test is applied. The ordinary family cannot meet it.
- (b) No moneys are paid to the mentally retarded person until he reaches the age of eighteen. Actual need begins when the mental retardation is diagnosed.
- (c) The recipients are only allowed to earn up to \$24.00 per month without the allowance being reduced. This effectively means that any retarded person has a maximum income of \$129.00 per month.

2. Family Services Branch

The Family Services Branch provides counselling services to recipients of

workers in Ottawa, Thunder Bay, St. Catharines, Hamilton and Windsor. Because of lack of staff and very heavy caseloads, the staff cannot undertake responsibility for providing counselling and otherwise assisting the mentally retarded.

The Field Services Branch

The Field Services Branch provides twenty-one regional offices throughout the province for the purpose of co-ordinating the activities of the different branches and ensuring that the public has ready access to all the services of the department. The basic purpose of the branch program is to ensure that those persons who receive financial assistance under the family benefits allowance program also receive the social services they require.

4. Vocational and Rehabilitation Services Branch

The basic purpose of this branch is to restore and develop the working capacity of physically or emotionally handicapped persons, and to prepare and place them in safe and satisfying employment. To achieve this goal, the branch provides seven basic services: assessment, medical restoration, counselling, vocational training, travel and maintenance allowances, occupational tools and equipment and employment.

The key agent in administering this program is a field staff of vocational rehabilitation counsellors who are located in the department's regional offices throughout the province. These counsellors are responsible for locating and assessing handicapped persons and for purchasing and co-ordinating services leading to returning them to gainful employment.

Another important ingredient of the branch's program is in connection with the sheltered workshops, adult training centres and adult rehabilitation centres operated by boards. There are one hundred and eighteen registered workshops throughout the province serving all types of handicapped persons. Eighty-six of these are primarily for mentally retarded; they are all operated by the local associations of the Ontario Association for the Mentally Retarded. The branch provides a grant toward staff salary based on \$25.00 per trainee per month together with twenty-five per cent of capital cost of construction and equipment. The more advanced workshops are financed at a higher rate. The branch makes a grant toward the salaries of members of the Ontario Association for the Mentally Retarded who are consultants to or supervisors of workshop programs.

It also pays living allowances for persons who are engaged exclusively in retraining and rehabilitation programs and

The legislation is not adequate to fulfill the needs of the mentally retarded for workshops since the local associations must raise seventy-five per cent of the capital cost. The payment of \$25.00 per month for each trainee provides the training centre with only \$300.00 a year for the trainee. This is extremely low. The cost to keep a person in a training centre is approximately \$1,500.00 a year. This means the local association must raise \$1,200.00 per year for each trainee. This is a difficult burden for local associations and seriously limits the full training potential of many programs which are operated on a hand-to-mouth basis. The percentage of cost paid by the Province under this branch is considerably less than it pays for all other programs administered by the department.

5. Homes for the Aged Branch

Over the years, mentally retarded persons had been admitted to the homes for the aged in smaller communities where there was nowhere else to go. The practice was unfortunate from the point of view of the mentally retarded, who got no training, and was disturbing to relatives who visited their next-of-kin in the hospitals.

6. Municipal Welfare Administration Branch

(a) The Homemakers and Nurses Services

Municipalities may provide the assistance of trained homemakers and registered nurses under *The Homemakers and Nurses Services Act*, and claim an eighty per cent Federal-Provincial subsidy on these expenditures. Trained homemakers cope with the management of a home and family during the mother's absence or inability to perform her normal tasks. These homemakers offer a specialized kind of service which is designed to teach a mother in receipt of public assistance how she can improve her skills in housekeeping, budgeting, meal planning, shopping, cooking, sewing and to increase her understanding and acceptance of responsibility as a parent and community member.

Municipalities purchase homemaker services on a fee-for-service basis from three Visiting Homemaker Associations and thirty-two branches of The Canadian Red Cross Society. Visiting nurse service is purchased from thirty-six branches of the Victorian Order of Nurses and two branches of St. Elizabeth Visiting Nurse Association.

(b) General Welfare Assistance

The General Welfare Assistance Act provides help to needy persons and families to meet their ordinary living expenses, to supply their special necessities and care. The Municipal Welfare Administration Branch subsidizes and supervises

payments made by municipalities and Indian Bands to persons in need. In geographical areas without municipal government, the regional offices of this department administer this aid directly.

General welfare assistance has three component programs: general assistance, special assistance and supplementary aid to cover various short-term needs of people. General assistance is the payment of a maintenance allowance to a family or person in need to cover basic living costs.

Persons faced with emergencies caused through illness, unemployment or sudden distress, and who are in need of short-term aid, are assisted through local municipal welfare offices. Local authorities may grant a living allowance and special assistance items including the cost of nursing home care, dental services, prescribed drugs, funerals, travel allowances and vocational training.

The municipality is obliged to grant such aid to individuals and heads of families who come within the definition of a "person in need." Throughout the province, the municipality is subsidized eighty per cent for general assistance and fifty per cent for special assistance.

THE DEPARTMENT OF EDUCATION

1. Special Education Branch

Department of Social and Family Services

Opportunity classes for the educable retarded operate under local Boards of Education throughout the Province:

Primary classes	337
Junior classes	774
Intermediate classes	437
Senior classes	422
Classes not organized by age	196
•	2,166
Number of teachers	2,249
Number of pupils	27,431

Since January 1st, 1969, academic education for residents of mental retardation facilities operated by the Department of Health has been provided by the Department of Education. There are ten schools, having 182 teachers, and 1,635 pupils.

Under The Secondary Schools and Boards of Education Amendment Act, 1968, schools for trainable retarded were removed from local authority as of January 1st, 1969, and placed under the authority of Divisional Boards of Education for operation and financing. There are now 127 schools for trainable retarded, having 567 teachers and 5,057 pupils.

On July 16th, 1967, the Minister of Education announced that starting in September, 1972, the age for trainable retarded attending school would be the same as for other children, that is, from age five to age twenty-one. Attendance will be compulsory. This proposed legislation has been well accepted by those working with the mentally retarded.

2. The Youth and Recreation Branch

The Youth and Recreation Branch of the Department of Education governs grants to municipalities for recreational programs and grants to camps. The branch recently agreed to obtain a full-time consultant in the area of recreation for the handicapped. Although grants are available from this branch for certain non-profit camps, the eleven camps operated by local associations do not qualify because the camps for the retarded require more supervision. This results in a per diem cost which puts these camps in the same category as privately-run camps which are thereby disqualified.

THE DEPARTMENT OF PUBLIC WORKS

All Government property is owned by the Department of Public Works. It is responsible for all new construction, and all major and minor reconstruction or renovations over \$100.00 in value. Treasury Board must approve each new project for (1) sketch planning, (2) detailed plan preparation, and (3) tendering and construction.

INTERESTED COMMUNITY GROUPS

A. ONTARIO ASSOCIATION FOR THE MENTALLY RETARDED

The Ontario Association for the Mentally Retarded is an organization of concerned citizens interested in the welfare of retarded persons. It has been in existence for eighteen years. The Association is composed of 117 locals throughout the province. It is estimated that now only between 35 to 40% of the membership are parents of a mentally retarded person. Each local association is wholly independent. They are individually incorporated but obtain a charter

from the Provincial Association which, in turn, is governed by the local association through an elected board of directors. The associations and other public-spirited persons, by educating the public and exerting continued pressure on governments and agencies, have been the motivating force in removing lethargy and stimulating action in regard to mental retardation.

The Ontario Association for the Mentally Retarded has influenced the development of appropriate legislation and suggested amendments to legislation when required to better meet the needs of the retarded. Representatives of the Ontario Association for the Mentally Retarded had a voice in the preparation of the Blueprint for mental retardation services in 1965, the forerunner of several pieces of legislation to help provide services.

Through its constructive and dedicated efforts, the association has pioneered, developed and brought to a high standard of operation a whole variety of community services, such as education in home care, pre-school training, education, sheltered workshops for adult training, recreation and camping.

The first great thrust was to provide schools for trainable retarded because children with Intelligence Quotient measurements of under fifty were excluded from the public school system. In 1947, the first school for retarded children in Ontario was opened in Kirkland Lake, as an experimental project backed by parents, service clubs and the Community Chest. From this small beginning, the movement spread until the formation in 1949 of the Parents Council for Retarded Children in Toronto. In 1952, this group organized a daily class for retarded children in the basement of a church on Carlton Street. Parental associations sprang up across the country. The Ontario Association for the Mentally Retarded was incorporated in April, 1953.

Nine local organizations had sprung up prior to 1953 and each had plans for a local private school. Before the year was over, the association successfully persuaded the government to allocate \$250,000.00 for the operation of schools. This was doubled the following year. By 1961, the government became convinced that children over ten years should attend full-time and a grant was allocated to support this program. Two years later, capital grants up to fifty per cent to build the schools were announced by the Department of Education. By January 1st, 1965, the full operational costs were being paid for by the government through education authorities which were established. Fifty per cent of the capital costs were still the responsibility of the local association.

As early as 1954, the association began to train teachers for day schools by sponsoring a summer course for teachers for the trainable retarded in

conjunction with the Department of Education. This course has continued and improved and to date close to a thousand teachers have become qualified.

On January 1st, 1969, the 104 schools serving 4,500 trainable retarded were turned over to the County Boards of Education. Representatives of the Ontario Association for the Mentally Retarded worked closely with Department officials to achieve a smooth transfer.

The development of workshops and training centres for young adults grew moderately until 1967, when *The Vocational and Rehabilitation Services Act* became operational. Since then, the growth of workshops has been rapid and, by mid-1971, over eighty-six programs had been established.

These activities are instituted under the stimulation and guidance of the adult service committee of the Ontario Association for the Mentally Retarded and are administered by a similar committee at the local level. While this program was primarily established to accept graduates from the day school programs, it has since expanded to the point where it is accepting former opportunity class students, adults without any formal education and school dropouts who have been unable to secure employment and now realize that vocational training is a requirement for even the simplest of routine jobs.

Some of the adult programs work on a tri-level basis: offering an occupational program for the more severely retarded, sheltered employment for the trainable retarded and work training for the mildly retarded who showgood potential for obtaining competitive employment within the labour force. The Ontario program is now serving more than two thousand young retarded adults. The financial assistance available for this program from government is still limited and efforts to strengthen this support are part of the Ontario Association for the Mentally Retarded's request to government.

The development of pre-school nursery programs has been a major undertaking of the association and its locals. By the end of 1970, some ninety such programs were in operation in Ontario ranging from one-half day a week to a regular five-day week.

In recent years, the community residence concept has grown and today there are eight local associations for the mentally retarded operating community residences. These facilities will be offering both short- and long-term care and are designed to keep the retarded in his own community and thus allow him to continue attending other community programs in which he may already be enrolled. These facilities are being established under *The Homes for Retarded Persons Act* which provides financial assistance for both the construction and operation of such a service.

The Provincial Residential Care Committee works diligently in attempting to improve facilities, staff-patient ratios, staff working conditions and salaries in the hospital schools. The welfare of the patients is enhanced through volunteer services to the hospital schools.

The volunteer youth known as Youth Across Canada with the Mentally Retarded have eighty-four groups in the Province in Ontario, associated in most instances with a local association or sometimes with institutional facilities. Staff services to this vital group are provided by the association. They are most actively involved in social, recreational and camping activities and provide the youthful leadership and friendship that adds a new dimension to the lives of retarded persons. They play an ever-increasing role in getting younger people involved in the problems of their less fortunate peers.

In order to further the development of means of meeting the needs of the retarded, the association has undertaken several pilot projects. One of these includes the establishment of a Provincial residential camp which offers a co-educational camping experience for nearly two hundred retarded children and young adults each summer. The development of this program was made possible by an annual grant from the Ontario Lodges and Chapters of the Loyal Order of the Moose and the Guelph Kiwanis Club, which provided the site. The success of the Provincial camp, which has since become a regional project, has led to the establishment of nine additional local and regional camps which offer from one to nine weeks of summer recreation in a residential setting.

Courses to train the personnel of sheltered workshops and training centres have been run by the association since 1965 and are now in three levels. More recently, the association, in co-operation with the Canadian Association for the Mentally Retarded and the Day Nurseries Branch, started an in-service training and correspondence course to train pre-school teachers for retarded children's nurseries. This course is now administered by Humber College.

The 117 local associations sponsor or operate the following services:

86 Adult Workshops

90 Pre-school programs

12 Residence programs

11 Residential camps

3 Farm training programs are being instituted

A number of recreation, home care and public education programs.

Most of the services receive some government assistance while the remainder of the programs and that part of the funding for services not covered by government must be raised by each local association. They have the following methods:

- most local associations charge a membership fee, but this is normally only a token of perhaps \$2.00;
- (2) some of the associations raise funds through the "Flowers of Hope" program and the Christmas card program;
- (3) community events are also used to raise funds;
- (4) gifts from service clubs;
- (5) about thirty local associations are funded by United Appeal or United Community Fund.

B. THE CANADIAN ASSOCIATION FOR THE MENTALLY RETARDED

The Provincial associations have joined together in creating a national association. All of the Provinces in Canada, except Newfoundland, are members. The National Institute on Mental Retardation is the technical and professional arm of the Canadian Association for the Mentally Retarded. Its objectives include stimulating research, providing program development services, giving training through workshops, seminars, etc., to persons interested in working in the field of mental retardation.

C. OTHER ASSOCIATIONS FOR HANDICAPPED PERSONS

There are a number of parent-sponsored groups in Ontario for handicapped persons, including the Ontario Society for Crippled Children, the Ontario Association for Emotionally Disturbed Children, the Ontario Epilepsy Association, and associations for exceptional children, for the perceptually handicapped, and others. It sometimes happens that a child or adult may have multiple handicaps; the family of a retarded child with epilepsy, for instance, may find help and companionship in an association which focuses on this aspect of his disability.

D. SERVICE CLUBS

Kiwanis, Rotary and many other service clubs have interested themselves in the problems of retardation. Large contributions have been made to the construction of facilities for the retarded across Canada (including schools, clinics, hostels, workshops and other services) and to research in the field of mental retardation. Service clubs have assisted at the local level, as in financial contributions to the erection of many of the Ontario schools for the retarded and at the Provincial and National level, usually in close co-operation with the Ontario Association for the Mentally Retarded. A current outstanding example of this is the large contribution made by the Association of Kinsmen Clubs of Canada to the building cost of the National Institute on Mental Retardation.

PART III

Suggestions

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Suggestions

THE PHASING DOWN OF LARGE INSTITUTIONS FOR THE MENTALLY RETARDED

I recommend that the large hospital institutions for the mentally retarded be phased down as quickly as is feasible. The following is my indictment against present institutions:

- 1. The wards of these institutions are almost universally large, combining persons of different ages, degrees of retardation and varied handicaps. Living conditions tend to be dull, monotonous and impersonal. The wards are severely overcrowded; those which were designed to house 30 often accommodate over 50. The residents have few private possessions, and seldom is there space to store them. Any degree of personal attention or privacy is simply not possible. Generally, one immense building accommodates the residence, the hospital, and facilities for training, education and recreation. There is almost complete segregation of the sexes beginning in early childhood; co-educational activities are minimal. I have found that many of the wards are unnecessarily locked. In most cases males and females, even those who are only moderately retarded, must use lavatories without doors and often without toilet seats.
- 2. Traditionally, admission of a mentally retarded person to an institution was a life-long commitment and placement was considered to be an end solution to the problems of the child, his parents and society, the emphasis being on custody and not on training or rehabilitation.
- 3. Because the institutions are large, they draw residents from a very wide geographical area. The hospital may thus be hundreds of miles from the patient's home. Hence, visits from the family are both expensive and time-consuming. They tend to become infrequent. The retarded can seldom, if ever, go home for a week-end or a holiday. Many of the mentally retarded in these institutions cannot communicate by letter. Contacts between the retarded person and his family are weakened and often lost altogether. Today the majority of children in the large hospital schools in Ontario do not receive regular visits from parents or relatives.

- Because of the size of the institutions, their locations were usually dictated by economic and political considerations, i.e., low-priced land and the need to promote employment in a depressed area. As a consequence, such institutions are isolated from the rest of the community.
- There is understandably a dearth of highly trained individuals who are willing to spend their career lives in an institution located in a remote area of the Province.

There is always an insufficient number of physicians; psychiatrists; dentists; psychologists; occupational, physical and speech therapists; nurses; social workers and other skilled professionals available. The difficulty of interesting trained personnel in working with the retarded in isolated institutions is compounded by the comparatively low salaries and other restrictions professional persons feel are imposed by Governmental personnel practices.

- The institutions are usually so large and remote that professional assistance cannot be significantly obtained from those practising in small nearby communities. In addition, many specialists in mental retardation are not readily available to the general public because they are employed full-time in isolated institutions looking after custodial patients.
- The buildings which are too large, overcrowded and sometimes antiquated, constitute a serious fire hazard.
- These institutions are not an economical way of providing for custodial care. The capital cost of a new bed for one person in a new hospital school is estimated at approximately \$30,000.00. The daily cost for each resident ranges from \$15.00 to \$35.00 a day; this cost is increasing by about 10% a year. This daily cost does not include any allowance for capital or for maintenance of the buildings by the Department of Public Works. If a mentally retarded person is institutionalized for life, and if we assume a life expectancy of only fifty years, the expense to the Government at \$20.00 a day (without allowance for increase) would be \$365,000.00. Realistically, one can plan on spending \$500,000.00 for each resident who is to stay in an institution for life.

Present planning calls for:

Rebuilding of Aurora	300 beds
Rebuilding of Cobourg	300 beds
New facility for Sudbury	400 beds
New facility for Hamilton	300 beds
New facility on the Lakeshore	
Hospital Property up to	500 beds

To provide these 1,800 beds along traditional patterns, capital construction would be approximately \$50,000,000. Over the next fifty years, without any allowance for capital cost or maintenance of the buildings, it will take \$900,000,000 to maintain only 1,800 persons in an institutional way of life which has been almost universally condemned.

Phasing Down of Large Institutions

One reason for the very high cost is that the institutions have residents with multiple disorders and, as they are located away from centres of population, each must provide elaborate and expensive services to assist only these residents. These residential schools therefore usually have attached to them a hospital, a department of electroencephalography, x-ray facilities and a biochemical laboratory. This kind of equipment is a major item of expenditure, and technical progress is such that the equipment will rapidly become obsolete, needing to be replaced or supplemented by still more expensive equipment. The scientific and technical staff must be highly paid specialists if they are to give the best service to the residents.

- Since the hospital institutions for the mentally retarded have featured a bucolic setting, they are usually too remote from universities or other centres of higher learning. Research into mental retardation is impeded by the isolation of the institutions. Distance also limits the ability of the universities and colleges to train personnel to work with the mentally retarded.
- 10. The mentally retarded person, on returning to his community, is beset by the additional problem of being stigmatized as a former resident of an Ontario Hospital School. The greater the number of mentally retarded persons taken out of the community, the more unfavourable community attitudes become towards those who remain at home, and the harder it becomes for a family to keep such a child.
- 11. Such an institution forces the retarded person to function far below his development possibilities. It inhibits rehabilitation as it does not provide the kind of social contacts to which, hopefully, the mentally retarded person will eventually need to adjust. The institutions can place little emphasis upon environmental enrichment as a means of fostering development. It is always more difficult to have a mentally retarded person accepted and integrated into community life after a period of institutionalization. In other words, to rehabilitate the retarded person who has lived the better part of his life in an institution is almost impossible since he will be ill-prepared to cope with the social requirements of normal community living. Many a retarded person comes from an urban community. For him to live for a long period in rural surroundings is poor preparation for his return to city life.

- 12. The residents are paid minimal and completely unrealistic wages for their work from 4ϕ to 8ϕ an hour. Their clothes and other necessities are supplied to them. They only have money to shop for incidentals. On leaving the institution they will have little, if any, appreciation of the value of money, having had no practice in its use.
- 13. The Ontario Hospital School system is divorced from the mainstream of health, education and social and family services. It thus cannot adequately establish and administer services which are responsive to community needs.
- 14. There are a number of significant inhibiting factors which militate against community involvement with the larger hospital institutions:
 - (a) The size and location prevents adequate integration. Transportation is the biggest stumbling block to getting more volunteer workers involved. Local community co-operation and involvement necessitates that the premises be small and located within the borders of population centres. The residential facilities for the retarded should ordinarily be for no larger a number of persons than can readily be assimilated by the surrounding neighbourhood in its everyday life.
 - (b) The institutions are located far from the major employment opportunities and thus usually have more residents who are able to work than can be absorbed in any nearby communities.
 - (c) The inertia of a large monolithic institution which has been functioning for an extended period of time does not stimulate community activity.
 - (d) Although the hospital tries to send out a small corps of social service workers, it is impossible for them to service the large area into which the residents are to be discharged.
 - (e) Since the institutions are owned and operated by Government, they do not tend to become identified with the community.
- 15. When we add to these arguments the fact that there is a profound psychological effect upon both staff and residents when there are hundreds of helpless and hopeless cases in one institution, the indictment becomes a formidable one to answer.
- 16. Lastly, I suggest that a century of failure and inhumanity in the large multi-purpose residential hospitals for the retarded should, in itself, be enough to warn of the inherent weakness in the system and inspire us to look for some better solution.

While I recommend that the use of large institutions for the mentally retarded in the province be phased down, I do not say that they should be

abolished in their entirety. In the first place, the large hospital school must not be dismantled without anything being put in its place. We cannot abolish the present facilities until the resources of the community have been mobilized to care for the mentally retarded in a better way. An increase in the load placed upon local health and social services without a great increase in their resources would inevitably worsen the plight of the handicapped. It would not be possible to empty a large number of the residents from the institutions and expect the public to instantaneously absorb them. Many parents who have become accustomed to having their problems stowed a long way away would now be shocked at the prospect of the return of their child. By now, many of the residents themselves have come to regard the institutions as their homes. Having been isolated for many years with little socialization with other members of the community, a mentally retarded person dramatically introduced to a world of few restraints would encounter almost insurmountable problems. These institutions have over the years acquired staff with special skills trained to deal with the mentally retarded. They should not now be entirely disbanded.

If, by severe restrictions on admissions and an intensive drive to rehabilitate those who could be absorbed into the community, the present institutions, after demolishing the more decrepit buildings, were cut down to, say, 40% of their present capacity, they might well play an important part in the whole system for some years to come for one or more of the following purposes:

(a) For nursing or medical care

A number of cases will always require nursing and medical care in an institution. Hospitalization may be necessary when the retardation is very severe or is accompanied by emotional damage or associated physical disabilities which necessitate long-term treatment or observation. It is too much to expect that a family can indefinitely look after a person who can never learn routine habits of daily living. It requires a 24-hour care which no mother can give and fulfill her obligations to the other members of the family.

(b) For behaviour modification or correctional purposes

The large institution may be useful as a temporary residence or place
of referral for retarded persons who have severe behavioural
problems which the family cannot deal with or need intensive care
by qualified experts for a short period of time. Intensive care may be
needed to break obnoxious habits.

(c) For crisis intervention

They may be used as a haven where parents who need short-term relief can place their children.

- (d) For training of parents and staff and persons who are to run residential facilities.
- (e) For purposes of research in co-operation with the universities.

THE REPLACEMENT OF THE INSTITUTION

A. KEEPING THE CHILD IN HIS HOME

The most favourable environment for the growth and development of the large majority of mentally retarded children is with their own families or in other residential facilities in the community. Every mentally retarded child should be with his own family until he reaches adulthood unless he imposes an undue burden on them.

In order to avoid the institutionalization of a mentally retarded child, the first step is to encourage and assist the parents to keep the child at home. Help should be offered where the problem begins in the home. It is the right and the primary responsibility of parents to care for their children. This equally applies if the child is handicapped, although the problems are infinitely more difficult and complex. The needs of every child, be he normal or handicapped, are basically the same. They are: family ties, love, emotional warmth, understanding and acceptance. There must be growth of his social, physical and emotional resources to prepare him for the future. The best place for the child to receive such essentials is in a healthy home environment. This statement, however, is subject to the following qualifications:

- The parents must be provided with the necessary support services. If
 these services are not provided and the child is forced to spend a
 large part of his time at home, he will in all likelihood suffer from
 overprotection and overnurturing, and other members of the family
 may lack proper attention.
- 2. There are certain homes where the environment is not satisfactory.
- In the case of the profoundly or severely or multiply handicapped, my personal opinion is that it is too much to ask the parents to keep the children at home except in unusual circumstances.
- In certain cases there may be behavioural or emotional problems which need expert care and assistance.

When a retarded child reaches adulthood, he should ordinarily be expected to leave home the same way as any other child. It is not good for the retarded person to live at home indefinitely where he will be consistently held in the attitude of a child. If he does not leave home when he reaches maturity, it can be very destructive to the family. The parents become increasingly anxious about what will happen to their child when they die or cannot keep him any longer. A moderately mentally retarded adult should be in a sheltered home close to a sheltered workshop. It is preferable that he makes his break while his parents are still alive so that they can give him the support he needs. The transition can be made without trauma to anybody. It will alleviate the financial and mental burden on the family if its members can see their mentally retarded relative is adjusting to society outside of the parental home. Thus the range of services in the community must be such that the family can be certain that their retarded member will be properly looked after when he leaves home. It becomes almost necessary that in the range of services there be some guardianship arrangement made with a trustworthy person or agency.

Reasons for Abolition of the Means Test

The effect a retarded child has on a family is complex and varied. The child is dependent to a large extent upon the attitudes and tolerance of social environment. The presence of a mentally retarded person can cause great strain on the family as a whole. The families which care for the mentally retarded are heavily penalized both materially and in their social life. The costs are often considerably higher than for normal children. There may be a sharp lowering of the standard of living due to many extra expenses in providing for a non-wage-earning member, greater overcrowding, and the mother's inability to go out and work. The parents' anxiety for the mentally retarded when he becomes older may necessitate the making of adequate provision for him for life. Social isolation and rejection may ensue as a result of the reduction in social contact. Other children may suffer when their parents are exhausted in dealing with the physical and emotional problems of the handicapped child. The stress on the family is usually severe and may, without assistance, result in the complete destruction of a family unit. Nor can we overlook the stress experienced by the retarded member himself, not the least of which is his limited ability to understand how and why he is different.

While it is generally agreed that the young mentally retarded persons are on the whole more likely than not to benefit by being at home rather than going into an institution, society offers poor recompense to those families who try to keep their child at home. In general, it is the parents of a young mentally handicapped child kept at home who have the most serious problems, and yet they get the least help in dealing with them. There is more adequate economic

provision for interventions that separate the child from his parents than for measures giving support to his own family in order for it to retain him.

Many children are today being inhumanely kept at home or sent to institutions because parents have or think they have no other alternative. At the present time parents who cannot keep their children at home because of physical or emotional problems or other family stresses have four choices:

- (a) They can have the child made a ward of the Children's Aid Society. Not only does this involve a stigma both to themselves and the child, but they lose control over their offspring.
- (b) Have the child placed in a hospital school which may be some five hundred miles from his community. There are large waiting lists to get into these institutions. While keeping a child in a foster home or an approved residence is not only more humane but is a fraction of the cost of institutionalizing him, a child must under our present legislation either be made a ward of the Children's Aid Society or be sent to an institution before he can thereafter be sent to an approved home or discharged into a home for special care.
- (c) Accept welfare as a matter of charity if they can get it.
- (d) Obtain the assistance of the Association for the Mentally Retarded and get him into a local residence. This association has a very limited budget and cannot, without much more financial assistance, be expected to accept the responsibility for a much larger number of inentally retarded. In a large number of communities throughout the province, the association does not and cannot operate residences or the supporting facilities.

Providing effective measures which will allow a handicapped child to be kept in his own community is not only humanitarian but economically viable, and could save heavy expenditures in other directions. The need for institutional care will be sharply reduced when more services are made available which are designed to help the handicapped and assist his family in looking after him. The unnecessary placing of children in an institution may be prevented if society is willing to make some effort in sharing the task with the parents of caring for handicapped children. The present system produces uneven standards, duplication and a reluctance on the part of some parents to seek help which they regard as stigmatizing their child because it is associated with social welfare.

The Implications of Social Care

True social care implies sharing in responsibility by the community in assisting parents in carrying out their part of looking after a child to the best of

their ability. There is need for acceptance of the idea that the responsibility of a community to help parents of handicapped children to bring up their children involves the providing of a totality of services. This concept is widely accepted in such fields as education, medicine, health, baby bonuses, old age pensions and Thalidomide children. In providing social care for handicapped children and their families (historically administered as an adjunct to the poor law), public concern has not until very recently been developed to the same extent. I suggest that we must soon spell the death knell to our poor law legacy as applied to handicapped persons and to the social attitudes and practices which stem from them.

The concept I strongly advocate is that it is far more economical and humanitarian to give to the handicapped the total care he needs in his own community than by providing for it in an institution. While the handicapped child remains at home, the parents should receive all the help they need to support him there whether it be material, financial, medical, dental, psychological or social. Total care for the handicapped must include adequate diagnostic facilities and appropriate treatment both for chronic conditions found frequently in association with retardation and for unrelated acute illness; genetic counselling to the families of the retarded persons; education; recreational opportunities; family support; employment; residential care, not only in long-term facilities but also in day care centres and in hostels established for parental relief.

The ability of the community to sustain its mentally retarded persons within its boundaries is dependent upon the quality and quantity of family support, crisis intervention, rehabilitation services, educational, vocational and recreational opportunities.

B. RESIDENCES IN THE COMMUNITY

It must be recognized that in many cases, because of other family obligations, financial or personal stresses, it may not be possible for parents to keep a mentally handicapped child at home. There will always be need for other residential provisions. The almost universal concensus of informed persons working in the field is that persons who do not have suitable homes and who need care, supervision and guidance should be provided for in small living units rather than in large institutions. In a small place the residents tend to come from a smaller catchment area and are therefore more likely to have common interests and to keep in touch with their families and friends. The customs and procedures of home and community life are more closely simulated. It is vital, regardless of the size and purpose, that the community residence be a home to those who reside within it.

There is a wide difference of opinion as to the optimum size of a community-based residence, but almost general agreement that, whether the facility is a small family dwelling or a complex, there should be individual units small enough to ensure privacy to the resident. His needs as an individual must be satisfactorily met. Smaller units can better serve the need for differentiation of specific programs for retarded of various ages and various levels of functioning, consequently better serving both the needs of the retarded as well as of society. More purpose and a higher efficiency will be found by taking the specific needs of a fairly limited homogeneous group into consideration in a more socially manageable context.

The following are among the desirable ingredients:

- 1. A large number of small facilities should be dispersed throughout the various population centres of the province so that they can be easily available to persons in all geographical districts. They should be easily accessible through public transportation. These units should be distributed geographically in keeping with the population characteristics so that the greatest number of residents can be as close to home as possible. This dispersal will entice rehabilitation and will permit the placement of residents close to employment and work opportunities.
- The residence should be placed in the midst of a community. They should be situated in or near population bases. A facility should never be for a larger number of persons than the surrounding neighbourhood can readily absorb and integrate in its everyday life.
- They should be situated in close proximity to the natural homes of the handicapped.
- 4. The residences should conform to other types of family accommodation found in the area. They must be as similar as possible to a typical house or apartment so that the residents will be educationally furnished with life conditions similar to the ones they will meet in the other parts of the community where they may visit or work.
- 5. There should be maximum socialization between staff and residents.
- 6. They must be integrated with and closely associated with the educational, recreational and commercial facilities in that particular area.

7. They should be able to draw on the professional resources of the communities in which they are centred.

It is important to keep in mind that the residential needs of the retarded will change the same way as in the rest of society and it may be that he should be given a variety of options from which he can choose the environment in which he wishes to live.

There are a number of different types of residences that could be successfully used:

- (a) Specialized foster homes, where foster parents have been screened and trained. Selection should be based upon their potential and willingness to receive training and supervision. They must be ordinary, kindly people, willing to accept the care of a child as a long-term responsibility.
- (b) Long-term residences for children who cannot be placed in foster homes or those who indicate inter-personal difficulties in a foster home but do not need the resources of a residential treatment centre. The basic requirement is that they be small and as home-like as possible. They should not be placed in the same building as a school. The residents should attend the same nurseries, schools, day care centres and training centres as the mentally retarded who stay at home. They should be located where these children can go to the same theatres, shops and use the same transportation as ordinary children. They should be differentiated according to age. Mentally retarded children should not be placed together with homes for adults. Sexes should not ordinarily be segregated.
- (c) Temporary specialized boarding houses for children where circumstances indicate either the child or the parent would benefit from a short-term stay of the retarded individual outside his home.
- (d) Residential treatment centres are relatively short-term residences for children who need special care and attention because of special handicaps or complicated emotional or learning disabilities. These groups of children need services and learning which can be provided by a multi-disciplinary team of specialists.
- (e) Supervised long-term residential houses for the adult. There will always be the need of sheltered residences for adults. They should be placed so that there is access to a sheltered workshop or sheltered employment. A parent who has a retarded child must not be always afraid as to what will happen in the event of his death. If these are provided, it will enable a number who cannot survive on their own to go to sheltered workshops or to sheltered employment in local undertakings.

- (f) Apartments and co-operative housing, where a small group of mentally retarded live with a minimum of supervision in a flat or villa and have their daily activities elsewhere usually in society. It should be assumed that this place is going to be their permanent home.
- (g) Half-way houses for mature men and women to prepare them for independent living in ordinary lodgings. The residents of these boarding houses would ordinarily go to some type of selected employment or sheltered workshop in the community. It can also be a place to which he can return if lonely or in need of advice or help. The club facilities of these hostels can at the same time serve as social centres to which other mentally retarded persons can go.
- (h) Chronic care facilities. Nursing homes for those with serious mental defects or complicating physical handicaps should be provided. It has been found that a large number of severely and profoundly retarded, even those not ambulatory, can be satisfactorily looked after in nursing homes. There should be special homes for the mentally retarded who could not live in a boarding house, but still can be looked after in a home if given special care and attention.

C. ADVANTAGES OF SMALLER RESIDENTIAL FACILITIES

The following are the advantages of looking after the mentally retarded person in the smaller type of residence rather than in an institution:

- 1. They are more humane.
- 2. The mentally retarded can much more easily be integrated into society.
- 3. It is very inexpensive as compared with an institution. The price currently paid for keeping the mentally retarded in an approved home or a home for special care is \$5.25 a day or \$11.00 a day if nursing care is provided. The cost of \$5.25 a day will be reduced if the mentally retarded person is trained for employment. There are, of course, additional expenses for administration and professional assistance, but it is still much cheaper than keeping the person in an institution.
- 4. There is no need to make major decisions involving the heavy capital expenditures such as are entailed in the building of a hospital school.
- 5. The system can be put into operation with great facility and speed. In the case of Cedar Springs and Palmerston particularly, the delay between the planning and the finished structure was such that the thinking behind them was obsolete before construction was finished.

- 6. Financial assistance can be obtained from the Federal Government. In or about 1967 in the Province of Quebec, a scheme was propounded to provide small residences for primarily the seriously and profoundly retarded. The scheme provided for:
 - (a) Centres d'Entrainement à la Vie:
 - (b) Centres de Formation Socio-Professionelle.

In the past two years seventeen small residences have opened in the various regions providing approximately eighty to one hundred and forty beds per residence. These facilities were constructed at an approximate capital cost per bed of \$10,000.00. Each of the seventeen residences is owned by a private, non-profit corporation.

The Centres d'Entrainement à la Vie were designed to provide residences for children and adolescents to the age of twenty-one years who are seriously and profoundly retarded. All residences provide out-patient programs.

There are presently two Centres de Formation Socio-Professionelle. These residences are again primarily designed for the seriously and profoundly retarded over the age of eighteen. The Centres provide occupational development training and social development training.

The capital cost of these seventeen new facilities was secured through loans from the Quebec Division of the Central Housing and Mortgage Corporation. After a proposed residence had the approval of the Minister of Social Affairs, a submission was made to the Quebec Division of the Central Housing and Mortgage Corporation requesting that the capital costs for the project be included in the Quebec budget. This technique secured 100% of the capital cost of the residence. In some cases it included the cost of the land. The loans are amortized over a fifty year period. The periodic repayment of the capital cost becomes part of the operational budget of the residence. The Quebec Government thus recoups 50% of the operational costs from the Federal Government pursuant to the provisions of *The Canada Assistance Act*.

D. SUPPORTING SERVICES

The greatest need today is for an intensification of the services within the community to enable a handicapped child to remain within it. In order for a retarded child to be kept within the community there must be supportive services provided as part of a continuum.

The following services should be provided in the local communities throughout the Province:

- (a) Home visiting and counselling services. Social workers and other trained personnel can give guidance and hope to the parents and other members of the community to overcome fear, superstition and ignorance, and assist them in accepting and keeping the child and in dealing effectively with personal and emotional reactions towards him. The parents need medical advice and counselling; practical assistance with housekeeping and shopping; and assistance in solving the various and special problems brought about by the child's handicap. The parents require as much help as the child. There is a great need to provide specialized programs for the parents confronted with the problem of raising the child to overcome their feelings of emotional conflict and insufficiency, and to acquaint them with present knowledge in the field of child growth and development.
- (b) Direct financial assistance to pay for additional expenses when incurred on behalf of the handicapped. When the retarded person reaches eighteen he will be entitled to receive a maximum governmental allowance of \$105.00 per month. If it would help to keep the child out of an institution, such a payment during the retarded person's infancy would be a small price to pay.
- (c) Short-term crisis relief. The institutionalization of a child or adult (which is long-term and a difficult option to reverse) is often all that is available to meet some need of short-termed duration. It may be prevented if the parents are given some relief often on a temporary basis. Many handicapped children would be maintained in their own homes if assistance could be rapidly mobilized where the situation becomes intolerable. A short-term removal of a child to residential care or otherwise, providing temporary help or accommodation, may be all the relief the parents require. On many occasions the institutionalization of a mentally retarded is completely unjustified except on the basis that he had nowhere else to go. I received many letters from parents outlining this need. The following is a typical one.

This is not just a letter, but a desperate cry for help. We are the unfortunate parents of a 2½ year old child stricken with the dreadful "Tay-Sack" sickness.

For almost 2 years we are trying to cope with this tragedy (watching our beautiful baby disintegrate). Since she is given to convulsions we can never leave her alone. The feeding is becoming extremely difficult.

The reason I mention these few details to give you some idea of the strain we are under. We have 2 other children who must suffer with us our sorrow.

We beg of you to help us in making possible that such a child should be accepted to the hospital from time to time for a period of a few weeks. Otherwise we will all collapse and not be able to go on with our work.

It is inconceivable that a society that prides itself with just and passionate feelings to every human being shouldn't have some form of relief to offer. And even from a pure economical point of view it makes more sense to have relief available rather than have a whole family breakdown and become a burden on society.

- (d) Day nurseries to develop basic self-help skills, socialization and group training. They offer an opportunity for parents to observe other children as well as their own. Lack of services for pre-school children is a major reason for the institutionalization of mentally retarded children.
- (e) Day care centres where the mentally retarded who are too disabled to attend training centres can be brought for a day or part of a day; they furnish respite for the parents, care for children of working mothers and promote self-care skills and social functions for the child, and assist him in attaining emotional maturity. Their function is to provide families in the neighbourhood an opportunity to leave their children in a situation that contributes to learning through proper guidance. They assist a mother who is sick and may enable her to go out to work.

The Mental Health Act, 1967 permits regional hospitals and hospital schools to operate day care centres for the retarded. The Children's Psychiatric Research Institute has recently undertaken this but none of the other facilities have. Day care centres should be in every large community and it is inappropriate that they should be run from an institution.

- (f) Special day care services for children who live at home but because of the gravity of their mental handicap and physical complications cannot be brought to or benefit from the day care centres.
- (g) Day care centres for retarded adults, providing physiotherapy, occupational therapy and speech therapy.
- (h) Specialized homemaker services to help the family in times of crisis such as illness, accident or temporary separation to remain intact without the utilization of foster homes. This serves as a means of relief for a family having only a single parent and generally assists parents to maintain a handicapped child at home.

- (i) Qualified baby-sitters who are familiar with the problems of the mentally retarded.
- (j) Foster grandparents. In the United States there is a program where elderly people are paid rather a small wage to work part-time in the institutions. The experiment has, by all accounts, been extremely successful both from the point of view of the residents and retired people. A child has the experience of having some person he can call his own visiting him regularly and the foster grandparent gets a new lease on life. It is inexpensive and humanitarian. An experiment along these lines has been conducted at the Lakehead Psychiatric Hospital. It appears to be equally successful. There is no reason why these foster grandparents could not be hired to visit children in their own homes.
- (k) A neighbourhood social work team. One of the most effective ways of delivery of social service work is by a team organized on a neighbourhood base. Social services are best provided through an office and staff visible and readily accessible to the client. The social work team should be comprised of a stable, integrated staff that assumes responsibility under a professional leader for a jointly carried case load. Each neighbourhood team should have responsibility for providing the full range of family counselling and child welfare services to families and children within a specific area. The team can consist of both professional and non-professional staff possessing various areas of training and skill and thus be able to efficiently serve a wide range of cases.
- (1) Guardianship services. Guardianship services for adult retarded persons are matters of concern for many parents of retarded children who wonder what will become of their retarded child when they themselves can no longer care for him. Formerly, such parents planned to admit young adults who could not manage on their own to the government institution for protection. To avoid institutionalization, assurance must be given to parents that, when they are no longer here, their children will be looked after in a manner that reflects the moral standards and aspirations of society. Most authorities in the field agree that such assurance can only be achieved when a suitable form of guardianship of the person is initiated and administered by an agency of government.

The following are the conclusions of the Stockholm Symposium of the International League of Societies for Mentally Handicapped: (June 11 - 16, 1967)

A retarded person, whether he is an adult or a child who is an orphan or abandoned, and who has a general inability to manage his life has a right to have a guardian who is legally and actually qualified to protect his interests and promote his personal welfare.

The following points should be included in developing a system of guardianship for the mentally retarded:

- In the case of an adult there should be provision for having him declared a legal minor.
- b) The procedure should be as simple as is consistent with the proper weighing of the information concerning the actual and prospective intellectual and social competence of the retarded person and the qualifications of the prospective guardian.
- c) The procedure should be without cost to the retarded person or to his family.
- d) The guardian appointed should be one who will render conscientious service to the ward in the light of modern understanding of the nature of his condition; no person should be appointed who is responsible for rendering a direct service to the retarded person.
- e) There should be provision for continuity of the guardianship and in particular for the appointment of suitable successor guardians when no member of the family remains available. A representative or member of a parents' organisation or a parent may prove suitable.
- f) Guardians other than parents should be compensated for expenses incurred. In addition, they should receive fees for their services to the person. These should be in accordance with the actual duties performed, rather than based only on the income of the retarded person. Basic costs should be paid from public funds.
- g) Guardians should consider the wishes of their wards to the extent that these may be reasonable, having in mind the concept of an "extended minority."
- h) A guardian should, in general, be empowered to use his discretion on behalf of his ward to initiate and consent to any action which a competent adult might undertake for himself.

The Celdic Report recommended:

That guardianship responsibility be designated to a responsible individual or agency outside the residential centre in those instances where a child is not in the care of his own parents and that this person or agency be required to participate in a periodic review of the treatment planned for the child.

While there appears to be almost universal acceptance of the idea that there should be some form of guardianship, no state or country has a satisfactory system of guardianship for the mentally retarded adult. Neither is there agreement among experts in the field as to the most desirable form of legislation.

A three year study for the Canadian Association for the Mentally Retarded will soon be completed. I recommend that the findings receive careful consideration. A pilot project in Hamilton, funded by the Department of Social and Family Services, has placed a social worker in that community to explore guardianship needs as expressed by retarded persons and their families, and various agencies who come in contact with them. It will also be experimenting with the concept of citizen advocacy. This program should be watched and encouraged.

- (m) Citizen advocacy. This is a concept developed by Dr. Wolf Wolfensberger in Nebraska. He suggests that a retarded person be "paired up" with a normal volunteer who could act as a friend and advisor on a non-legal basis, with the support of a professional back-up person to whom the advocate could turn in a crisis. The Mental Retardation Service of Kingston Psychiatric Hospital is experimenting with this concept in co-operation with the Ontario Association for the Mentally Retarded. I suggest that this pilot project be closely observed with the possibility of duplication elsewhere, if successful. In this way, hopefully, the retarded person would be assisted to manage in the community.
- (n) Prenatal counselling. There are a number of obstetric factors that have been identified as being related to mental retardation:
 - Poor maternal nutrition, leading to prematurity and impaired fetal development, usually as a result of dietary deficiencies of such substances as calcium, iron, protein and vitamins.
 - Poor or inadequate prenatal care which may lead to premature or abnormal birth or leave undetected health problems in the mother which can adversely affect fetal development.
 - Premature birth. Infants born with a low birth weight frequently exhibit problems in later life related to learning and intellectual attainment.
 - 4. Maternal diseases. Certain diseases in a mother during pregnancy can permanently damage her unborn child. Examples are: syphilis, rubella (German measles), hyperthyroidism, toxoplasmosis. Such diseases may also result in prematurity, congenital malformations, cerebral palsy, deafness, blindness, mental retardation and learning and behavioural defects.
 - Drugs taken during pregnancy. Many drugs taken by the mother could have an adverse effect on the unborn child - some causing mental retardation. For example, excessive ingestion of Vitamin D during pregnancy.

- 6. Excessive exposure to radiation. Radiation, usually due to diagnostic x-ray examinations, can produce deleterious genetic changes which in some cases may be transmitted to future generations.
- (o) Dental service. There are many problems in dentistry for the mentally retarded person. He can be inarticulate and not able to explain his difficulties. On the other hand, a dentist cannot always communicate with such a patient and let him know that the inconvenience and pain are necessary and beneficial. Not understanding what is happening, it is hard for the mentally retarded to be co-operative; they tend to become hard to handle. It takes a dentist with special skills and training.

Parents are inclined to neglect dentistry in their mentally retarded children. They have so many other difficulties relating to them that they often overlook dental needs. The hospital schools are understaffed with dentists. Quite a large number of mentally retarded who enter the institutions are in serious need of dental work. It usually requires priority of treatment. In some of the institutions the emphasis has been on extraction rather than repair. This induces other complications as it is not always easy for a mentally retarded person to accept and use dentures.

When a mentally retarded person returns to the community from an institution, it is highly important that his teeth be attractive. Facing the stigmata of retardation, appearance is with him a high priority.

(p) Employment services. Mentally retarded persons are both vulnerable and inarticulate. Thus, there must always be some person in the community who will help them obtain employment, protect them from abuse and at all times act as an intermediary between the retarded person and his employer.

In America there has always been a tendency to underestimate the potential of the retarded person and this is reflected in the present training programs. The retarded child can have difficulties in some areas and be quite proficient in others. Some might have trouble working in the open market but could function well in a sheltered industry. The general public must be shown the capabilities of a mentally retarded person and employers assisted in handling the special problems, before mentally retarded persons will be accepted for employment in the community. It has been common practice to prepare the mentally retarded for simple, repetitious work. These jobs are not increasing. A heavy burden falls on the mentally retarded as unskilled jobs decline and higher education and adaptability is demanded. It is thus imperative to open up new fields by developing the potentialities of the mentally retarded.

For instance, in Holland there is an industrial workshop where bicycles are assembled by the *severely* retarded, and a sheltered workshop where a high number of *moderately* retarded are employed in an industry which makes high quality shoes.

Even though a person is mentally retarded he may have some special talents which can be used; a mongol with his liking for a stereotyped existence has a special ability to react as soon as he sees something different. Thus, he has been found to be very effective in industry as a controller or inspector at the end of an assembly line sorting and rejecting products which are not perfect. The fact that a mongol does not have a high imagination gives him the ability to concentrate on a job which others would find boring. Indeed, for him it is a rewarding challenge. For the same reason, in the Scandinavian countries, the mentally retarded are used extensively to keep gardens and parks clean and neat.

To ensure that the mentally retarded person functions to his full occupational potential, there need be:

- Vocational rehabilitation service agencies to provide counselling and placement for the mentally retarded person;
- b) Vocational training programs including industrial within the community;
- c) Sheltered workshops;
- d) Sheltered employment.

E. A COMPREHENSIVE CENTRE FOR RESEARCH, DIAGNOSIS, MEDICAL TREATMENT AND COUNSELLING

(a) Research

The numbers of the mentally retarded in the community will in all likelihood increase unless the problem is combatted by research which has application in the areas of early diagnosis, prevention and treatment. Modern medical treatment has enabled many to live who heretofore would have died at birth or soon after. Because of advances in science and medicine, the life expectancy of mentally retarded persons has vastly increased. This has been dramatically shown, for instance, in regard to persons with Downe's Syndrome (mongolism) who, until the antibiotic era, often died at much younger ages because of respiratory and other infections. More mentally retarded persons are being found and recognized in the community. Our complicated way of life is making it increasingly more difficult for the mentally retarded person to cope with the complexity of the problems. The demand for unskilled workers is not expected to increase.

Biomedical research in the fields of diagnosis, prevention and treatment, as well as sociological, psychologic and behavioural investigations, must be an integral part of the whole operation.

A province cannot afford to embark upon a program of services without including therein provision for research into the way it is working. A research centre could feed back to the Government the data which it has empirically collected so that future planning can be more meaningful. There must be a continuing evaluation as to the adequacy of services introduced to meet the problems. It is only in this way that it will be possible to monitor changes and anticipate future demands.

There must be extensive basic research into the causes of retardation; applied research into better methods of programming for nursery schools, day care centres, schools for trainable retarded, workshops and the various forms of residential care; training of staff for the various facilities throughout the province both intramurally and extramurally. The centre should provide for the training of students and attendees at postgraduate courses in medicine, dentistry, social work, nursing, occupational, physical and speech therapy, and allied disciplines.

Until recently, research into mental retardation as a separate subject rarely attracted the curiosity of the scientist. The "condition" does not always respond well to available methods of treatment. Thus there is often less interest in caring for retarded individuals than for persons physically impaired with whom professionals can anticipate success. However, there have been significant breakthroughs in relevant fields such as biochemistry, microbiology, cytogenetics and immunology which have had great significance in the field of mental retardation: for example, the discovery that rubella (German measles) can cause damage to the fetus; effective treatment of syphilis by the use of penicillin; and replacement transfusion when the Rh factor involves incompatibility between mother and fetus.

Prevention of specific forms of mental retardation is now a distinct reality. It is possible to diagnose some abnormalities in fetal life by x-ray, biochemical and chromosomal studies. The phenylketonuria (P.K.U.) testing program is a classic example. In P.K.U., the child lacks an enzyme in his liver. This deficiency does not allow him to metabolize phenylalanine, an essential amino acid found in many foods. This abnormal metabolism results in an accumulation of phenylalanine which has a relationship to brain damage. Diet low in phenylalanine is very helpful and can prevent retardation but diagnosis and treatment must start at a very early age. The Guthrie test is usually done on every live birth in a general hospital in Ontario, although the test is not required by regulation or

statute. Also a mother who has an overabundance of phenylalanine will, during her pregnancy, subject her unborn child to high levels of this chemical which can cause brain damage in the child before birth. A mother with an overabundance of phenylalanine may be quite normal intellectually but her unborn infant may be damaged by her abnormal metabolism. The testing of mothers is more complicated but, if she is tested and found abnormal, she can be treated with appropriate dietary therapy to prevent damage to the infant.

Another excellent example is the process called amniocentesis. Early in pregnancy, biochemical and cytogenetic examinations of amniotic fluid and fetal cells can provide a means of prenatal detection of infants afflicted with various metabolic and chromosome disorders.

It has been discovered that all persons with Downe's Syndrome have chromosomal abnormalities. Instances of this affliction increase markedly with advancing maternal age. By amniocentesis, cytogeneticists can diagnose whether a child will be born a mongol. These amniocentesis tests are not yet being carried out widely in any systematic fashion.

Research into the causes of mongolism could possibly have interesting applications in other fields. For example, leukemia is substantially more frequent in mongols than in the general population, and in both conditions chromosomal abnormalities are relevant.

Much meaningful research remains to be done in the area of perinatal hazards, such as asphyxia.

An alteration of the normal genetic information stored in the body's cells can have a profound effect on the development of the individual, causing, in some cases, "inborn errors of metabolism" in which the individual cannot utilize specific foods in a normal fashion. Examples are: phenylketonuria, cerebral lipoidosis and galactosemia. Many biochemical disorders are associated with retardation. It is highly likely that there are many more, as yet unrecognized. In order to do useful and functional investigation, the clinical personnel need not only access to the child but to his parents as well. The establishment of more laboratory facilities to carry out specialized studies in the areas mentioned is of paramount importance.

(b) Diagnosis and Assessment

Early diagnosis is also of utmost importance. Some conditions can be corrected if diagnosed at an early age. Mental damage produced by a thyroid deficiency (cretinism) can often be substantially eliminated if promptly detected. During infancy, a number of diseases can profoundly affect future

brain development and functioning. One important example is kernicterus, resulting from incompatibility between the blood cells of mother and child. Without sustained early help, mentally retarded children can develop behaviour and personality distortions that may remain with them throughout their lives. Many a child, because of difficulty in communication, has been wrongfully treated as mentally retarded when, in fact, he suffered from a visual, hearing or speech defect or had a minor brain dysfunction. It is important to identify the problem at an early age in order to help the child before he reaches school.

A family must be encouraged to come to the centre as soon as they notice some slowness in the child's development or physical progress, for purposes of a comprehensive diagnosis, evaluation and counselling. No person should be considered for placement out of the home without a comprehensive evaluation not only of the afflicted person but also of the family and community resources. Ideally, such an evaluation is co-ordinated and multi-disciplinary and includes biomedical, psychological, social and educational studies. A final decision on placement out of the family home should not be made until the parents have been told of the variety of facilities and services available and have been given the maximum opportunity to consider the effects of separation for shorter or longer periods of time. There must be a multi-disciplinary assessment centre or clinic where the nature of the patient's problems is determined and considered. A medical history of child and parent should be completed. There should be a physical examination and a psychological and social evaluation made.

(c) Family Counselling Services

If research and diagnostic facilities are going to have a real purpose, then a continuing counselling service for parents and their advisors should be available. Diagnosis and assessment should be the beginning and not the end of the process. In the first place, parents will always need advice as to whether they should keep the handicapped child at home. The giving of this advice is not in the exclusive province of the doctor, nurse, clergyman or social worker. It is a duty for experts who have access to the records and conclusions of a diagnostic centre and know the appropriate available alternatives. They must be able to communicate to the parents and the rest of the family as to what the consequences of the decision are likely to be. The service should provide medical advice, genetic counselling, pre-school counselling, a directory of services, referral to appropriate services, and information about mental retardation. This centre should provide continuing contact with the family so that revaluation and changes in the plans for care and supervision can be made as the child gets older.

(d) Hospital

There should be a hospital ward available in connection with the centre to provide care, research and training. There must be facilities for acute medical

care, for observation and for diagnosis. It will enable the staff to keep up with new techniques in diagnosis and therapy and to disseminate this knowledge to those working with the handicapped. Mentally retarded persons can be restless, impulsive or destructive and must have individual treatment from trained personnel. In initial stages, special arrangements and facilities may be needed to protect the patient from himself. Profoundly retarded or the multi-handicapped may have feeding problems — for example, refusal to eat, habitual vomiting, difficulty in swallowing. They cannot always be toilet trained or learn to dress themselves. Thus a number will initially need hospital care. Most should at a later stage be placed in a nursing home or residential home or returned to their family. These hospitals should not be a place for chronic care.

(e) Location of the Centre

Identification, diagnosis and research require a large number of specialized skills in multi-disciplinary fields. Such personnel are only available in large hospitals and universities. It thus becomes essential that research be done at a centre attached to a hospital in a university town. It is not possible to do extensive testing and research in such places as Orillia, Smiths Falls, Cedar Springs or Palmerston. They have neither the facilities, the staff or the access to the families. If these centres were close to urban hospitals and universities, then, not only would research be stimulated, but there could be a correlation between the research concerning mentally retarded persons and that done in allied and overlapping fields.

F. DATA COLLECTING BANK

Today, most of our planning in the field of mental retardation is based on statistical guesswork, generalizations formulated on a few individual cases, studies done in other countries and other provinces, and speculative intuition. A researcher may spend countless hours locating relevant information that should rapidly be available to him. There is at present in Ontario no way of estimating the value of the data presently collected other than by the collective judgment of professional people using the information. At present there is no way of carrying out the analysis of the system other than by reading through one patient file at a time.

Many research projects are unnecessarily laborious, expensive and drawn out because time and other resources have to be devoted to gathering preliminary data not available in published sources and not brought together in any other way but which are in fact the elementary intelligence essential for the running of the service sensibly. Once a regular and reliable supply of information is available a stimulus and foundation for further inquiries into the efficiency and effectiveness of present programs will have been provided.

The State of Missouri in 1967 began a data processing program in collaboration with the Missouri Division of Mental Health. The intention was to develop a standard system of psychiatry for the State of Missouri, supported by a centralized computer facility with appropriate communication terminal devices located in all hospitals. The system is based upon the total in-patient file for all of their institutions. They collect and retain on their computer files all tests and results for each patient. Collection of out-patient data is now under implementation. The generalized objective of the project is to use the computer as a tool to:

- 1) reduce clerical effort of professional personnel;
- 2) monitor progress of patient treatment orders;
- 3) assist professionals in scheduling and performing duties;
- 4) store significant patient-related data for decision-making and research purposes.

The scope of the project encompasses over 50 major sub-systems, defined in terms of clinical applications, clinical research and development areas, administrative applications and basic accounting.

The Department of Public Health of the Province of Saskatchewan implemented a rudimentary data processing system in 1965 that was designed to maintain selected data on psychiatric patients. The system has since been expanded to include the mentally retarded. The Saskatchewan approach employs the medicare number as a means of patient identification. Each patient-physician contact (in-patient or out-patient) is recorded on this basis. Cumulative diagnostic data is captured and retained at the Government Computing Centre. Printouts of the Central File are available upon request. This system provides excellent control and has established meaningful feedback.

As services for the mentally retarded become more sophisticated in Ontario, the present recording system becomes inversely more awkward and archaic. In the past, with custodial care frequently being the eventual outcome of institutionalization, the existing methods of documentation may have been adequate. However, present techniques and methods for the training and treatment of the retarded are diverse and fast changing. To be most useful, a record system must fulfill demands for quick recovery of information and produce the information clearly and concisely.

My submission is that a centralized computer system is essential for meaningful planning, co-ordination of service, delivery of services, and research. Such a centralized system should have appropriate communication terminal devices located in each of the regional centres throughout the province.

There should be little objection from the point of view of privilege. No person is subject to the indignity of being required to be registered as retarded. Any person seeking the services of the facility will know that a record is being kept for his protection. Confidentiality as to the identity of patients can be assured by the use of a number for patient and physician.

UNIFIED CENTRAL PLANNING AND RESPONSIBILITY

The effectiveness of Government policy-making and its implementation as it affects handicapped persons is seriously impeded by the number of Departments and Branches which are independently trying to deal with one overall situation. This division of responsibility has had a deleterious effect upon policy, the use of resources, public accessibility, accountability, and coordination. Thus, Ontario may well miss the intended goal of being foremost in care for its most vulnerable citizens, not for lack of appropriate motivation or resources, but because there is an absence of centralized planning and responsibility.

While there have been undoubted improvements in Ontario in the last decade in the fields of health, education and social services, and in some areas new and exciting developments have taken place, still legislation, involving piecemeal social engineering, has resulted in a variety of services which are fragmented in terms of departmental responsibility and objectives. No one department or service has a clearly defined comprehensive responsibility towards handicapped persons. Yet their social needs today are so complex that each part cannot be satisfactorily dealt with by separate services acting independently.

The following departments are directly concerned:

THE DEPARTMENT OF HEALTH

Mental Health Division

Mental Retardation Services Branch
Psychiatric Services Branch
Children's Services Branch

Public Health Division

Special Health Services Branch

Local Health Services Branch

THE DEPARTMENT OF SOCIAL AND FAMILY SERVICES

Children's Services Division
Child Welfare Branch
Children and Youth Institutions Branch

Children's Boarding Homes Homes for Retarded Persons Day Nurseries Branch

Social Development Services Division
Family Benefits Branch
Family Services Branch
Field Services Branch
Vocational and Rehabilitation Services Branch
Homes for the Aged Branch
Municipal Welfare Administration Branch
The Homemakers and Nurses Branch
General Welfare Assistance

Financial and Administrative Services Division

THE DEPARTMENT OF EDUCATION

Special Education Branch
Youth and Recreation Branch

THE DEPARTMENT OF PUBLIC WORKS

THE DEPARTMENT OF CORRECTIONAL SERVICES

THE DEPARTMENT OF THE ATTORNEY GENERAL

The Public Trustee
The Official Guardian

Thus, complementary and alternative services are administered by separate departments with different policies and practices. The different departments and branches administered by different agencies are influenced by different outlooks and ideologies and thus a balanced comprehensive policy is impossible and the problems of the handicapped are being treated in a piecemeal fashion. As the agencies increase, the number of problems resulting from functioning in an unconnected fashion will multiply and become more acute.

The fantastically complicated array of problems in dealing with the handicapped can only be satisfactorily resolved by unified planning and co-ordination of services. In Ontario, no one person or department has the responsibility for overall planning for the handicapped or even for the mentally retarded. There is no overall planning and there is no centralized budgeting. Therefore, there can be no assurance that the total government expenditures on the mentally retarded will be applied in the most efficient and effective way to meet their needs. At the present time, each department requests funds

independently, vying with other departments for money to serve the same people. With divided responsibility, the staffs in the different departments are organized to achieve the specific objectives of those departments rather than to meet the full range of needs. This clearly militates against the prospects of helping a family or individual with multiple needs through close-knit professional treatment with comprehensive responsibility. The ill-defined and ambiguous boundaries generate friction between departments and their staffs. The setting of priorities and the planning of future developments is not in balance and does not have sufficient regard for the implications of the other departments concerned with similar problems and providing an alternative or supporting service. The prime need is for a more co-ordinated and comprehensive approach to the problems of handicapped persons and their families in order to develop a more cohesive pattern for their problems.

The lack of unity in command results in a fragmental delivery of services in the community. There is in the community no one authority or government agency dealing with the problems of the handicapped or even the mentally retarded. This creates duplications and gaps in service for those to whom it is directed. It dissipates money and manpower.

All forms of relevant help should be available to any handicapped child or family that needs them without the classification which the present system involves. There should be a point of fixed referral. A problem-ridden family with a retarded child who needs assistance may have, in the best of circumstances, a number of relevant options, i.e., institutionalization, visiting homemaker services, day nurseries, day care, among others. But an applicant for assistance cannot make his representations to a single appropriate body. He might be uncertain about the operation of services and confused about the division of responsibility between them. Sometimes the person seeking help may be bewildered or inarticulate and unable to make plain what particular help he requires. A parent may be pushed or led into making a wrong decision simply because he had no access to information which would have told him the entire range of alternatives in the care available to him in planning for his child. In such circumstances, it may be difficult for him to go directly to the appropriate service; the delay and further referral which this involves may be discouraging, particularly if the offices are a considerable distance apart.

The structuring of governmental patterns for the delivery of services is vertical when it should be horizontal.

Let me give you a few examples of the inefficiency and inefficacy of the symptom-centred approach which results from the split of responsibility for the care of the handicapped between departments.

It is a waste of money and of human resources when each department, and a number of branches or divisions in the department, operates its own after-care services. Two branches of the Department of Health seek out, inspect, approve and administer homes for retarded persons. Another branch of the same department looks after homes for special care and nursing homes. In the Department of Social and Family Services, the Children's Services Division and various agencies of the Social Development Services Division duplicate the same work. The Ontario Association for the Mentally Retarded is extensively involved in the field, especially in larger cities such as Toronto and Ottawa.

The shortage of social workers amounts almost to a crisis, and yet the various branches and agencies of the Department of Health, Department of Social and Family Services, and Department of Education, have their own hierarchy. Again, the Association for the Mentally Retarded has its own staff of social workers. Yet it is almost axiomatic that an individual or multi-problem family should, as far as possible, be the responsibility of a single social worker or team acting for the various departments and agencies. Responsibility should not be fragmented between several social workers. Decisions as to whether to involve other social workers with a family or individual should be taken by the social worker primarily responsible, in consultation with his supervisor, and not simply because the administrative structure requires more than one social worker to be involved.

The present distribution of social workers in the field of mental health entails about 90% working within the hospitals and only about 10% in the communities. It is not the most effective or economical way of using this important and relatively large group of highly trained workers. Such a pattern fails to provide continuity of care and it is not well placed to help with the repercussions of illness on the family or to contribute fully to the community care of the handicapped. The vital core of social workers should not be stationed at the Ontario Hospital Schools where they tend to become "locked-in" institutional workers. They should be based in the communities which they serve. The development of new resources and the co-ordination of services would be immeasurably enhanced by having the social working staff based locally. This would enable problems to be tackled before they reach crisis level.

A new policy must be envisioned so that the person requiring help is no longer to be perceived as an applicant for a specific service request but as an individual who has a problem to be solved. The applicant must be visualized as a person having a problem requiring relief. He must be able to go to a person or agency who will help him determine the ways in which he best could be assisted. It would be almost ideal if this person also had the power to implement the decision.

There should be a combined effort for the training of staff instead of having a number of separate streams. A unified service will increase the ability to recruit and train appropriate staff and to deploy them in a more realistic way. A mutual understanding, respect and sympathy for the work of colleagues would be encouraged by the establishment of a common basic training for staff.

The problem of co-ordinating the work of various branches in the Department of Education, the Department of Social and Family Services, and the Department of Health, in respect to retardation, was alleviated by the establishment of an inter-departmental committee on mental retardation in 1966. Dr. D. E. Zarfas acts as Co-Ordinator for services to the mentally retarded supported in all branches of Government. This was a major step towards improved co-ordination of services as it brought together some of the personnel directly concerned with the retarded in various Government departments which no longer operate in complete isolation. But the problem has not yet been solved. There are the following weaknesses in the system:

- The co-ordinating body lacks authority to make its decisions effective. The effectiveness of co-ordination depends upon agreement between departments. Co-ordinated policy, even if agreed upon by the Committee, must be taken back for implementation through the chain of command in several different departments. The Committee thus lacks the power to implement policies mutually agreed upon.
- The officer responsible for co-ordination is not the chief officer of a unified department or group of departments reporting immediately to a person with direct responsibility to the cabinet.
- The co-ordinated policy may not be effective due to lack of a centralized budgeting system.

A prime need in Ontario today is a co-ordinated and comprehensive approach to services for handicapped persons, to join fragmented services, eliminate duplication and produce services where none exist. There must, above all, be unity of command.

It is essential to the continuing improvement of services that there be a permanent centralized planning office through which the various services to the handicapped can be conducted. That this has not yet been achieved reflects the rapid growth of the various programs and the inevitable loose ends which are unavoidable side effects of such expansion.

To accomplish this objective, there have been a number of suggestions. In my opinion, the least complicated and most effective way would be to have one department responsible for services to all handicapped persons and their families. The planning and programming of the services and facilities for the handicapped should be co-ordinated and supervised by one department of Government, say, the "Department of Human Resources," having jurisdiction over the planning, co-ordination and implementation of a complete and comprehensive province-wide program for handicapped persons. This department, call it what you will, would have responsibility for:

- (a) standards of services, personnel and programs through legislation or regulation;
- (b) evaluating and recommending the disposal of funds and how all moneys which the Government decides will be devoted to facilities for handicapped persons can be employed in the most useful and economical way (central budgeting, but not necessarily total financing);
- (c) implementation of standards, with inspections and other safeguards to ensure the maintenance of standards;
- (d) co-ordinating the planning and service delivery in the different zones;
- (e) development of technical personnel to assist in planning, operation and evaluation;
- (f) co-ordination of mental retardation services and research, including: program valuation, studies of the prevalence of the various types of mental retardation, and development of experimental programs.

I wish to make it clear that I am not recommending one mammoth department to take over all of the functions relating to the handicapped, of the Department of Health, Department of Social and Family Services and Department of Education. I am suggesting the establishment of a department headed by a person with cabinet authority to take over the planning, co-ordination and centralized budgeting to fulfill the needs of all those members of society who, by reason of their handicaps, must have special care.

Even if the Government does not fully accept my proposal that there be a new department to deal with the problems of the handicapped, I suggest that at the very least there be appointed one Senior Minister with the duty of co-ordinating all departmental responsibilities in this field.

Since the main function of this department would be overall planning, programming, budgeting, financing and the co-ordination of services, there must necessarily be a greater degree of decentralization to enable the services to be made readily available at the point of need.

REGIONAL SELF-SUFFICIENCY IN THE DELIVERY OF THE SERVICES

Centralized planning at Government level must, in my opinion, be implemented through regional centres whose orientation is directed towards the community. Only in this way would it be possible to ensure provision of services without fragmentation, duplication and unnecessary expenditures. It is fundamental to my recommendation that there be regional self-sufficiency so that the needs of all mentally retarded persons can be met within their locality. Implicit in the idea is that there be a community-orientated family service which would involve participation of individuals and groups in the community in the planning, organization and delivery of the services. Only through the development of a network of services within the community which are co-ordinated with education, health and social and family services, will the needs of the mentally retarded be adequately fulfilled.

For the purposes of the Department of Health, Mental Retardation Services in Ontario are at present divided into six planning areas:

> Northwestern Northeastern

Thunder Bay

Southwestern

Sudbury London, Cedar Springs and Palmerston

Central Lake Ontario Orillia Picton

Southeastern

Smiths Falls

A major difficulty is that the planning areas are unbalanced. The divisions or regions are determined not by population, geographical area, communicational resources or need, but have their boundaries delineated by the presence of a hospital school or mental health facility. There is no relationship to any zoning in the province by any other department or branches within the departments. The Department of Social and Family Services, the Department of Treasury and Economics, the Department of Municipal Affairs, the Department of Labour all have regions with their own geographic boundaries.

I suggest that the province be divided into a number of zones, say, for example, 15, which effectively divide the province into regions on the basis of area and of population. Ideally, the centre should be in a populous area and placed so that no person (except in areas of sparse population) need go more than 100 miles to reach the centre. It would be highly advantageous if the centre were located in a university town so that the facilities of the university could be used for research and the training of staff. Suggestions for the centres would be Toronto, Ottawa, Kingston, Peterborough, Orillia, Kitchener-Waterloo, Hamilton, St. Catherines, London, Windsor, Sudbury, Sault Ste. Marie, Timmins,

At the headquarters or centre of each zone, I would suggest:

- An advisory board or social planning council composed primarily of citizens residing within the zone who would be responsible for the total planning of services for the mentally retarded throughout the zone. It would have the duty of approving and controlling the use of Government funds.
- (b) An executive officer and staff.

Regional Self-Sufficiency

- (c) A diagnostic centre, affiliated to a hospital, including a comprehensive health clinic and a travelling unit.
- (d) A data collecting service on a computerized basis which would maintain the records of all the mentally retarded persons in the area. Each computer should be connected with a central computer.
- (e) An advisory or referral service to counsel parents and the handicapped for the purpose of recommending the services available to them,

Initially, the centre might be set up to deal only with the problems of the mentally retarded. Once organized it would not be difficult for it, at a later date, to take over the problems of all of the handicapped and thus avoid duplication of facilities.

Dispersed throughout the zones there must be the following:

Domiciliary facilities small community residences foster homes group homes apartments hostels - short-term and drop-in centres nursing homes half-way houses boarding houses

Community care facilities nurseries day care centres (for children and adults) vocational training, sheltered workshops clubs recreational facilities and opportunities camps sheltered employment vocational rehabilitation agency for training placement Community services
social and family counselling advisory services for both the retarded person and his family
home care and nursing services
home visiting services
guardianship services
programs for activity and recreation

The management and delivery of services as planned for the total zone must be provided by units located within the zones. Almost all the facilities under the Department of Health and the Department of Social and Family Services can be used, but they must be co-ordinated and, in certain cases, amalgamated. At the present time, since the Ontario Association for the Mentally Retarded has the expertise, the knowledge and experience, it is reasonable to give them a major share in the responsibility for the management and delivery of the services. To do this, it might have to re-organize and co-ordinate local associations within the zone into one association with a series of local units.

It is unnecessary for the Government to build or operate residences, workshops or leisure facilities in the communities. It would be more appropriate for the Government to give more economic support to organizations which are providing these services.

PART IV

Method of Proceeding and Acknowledgements

PART IV

Method of Proceeding and Acknowledgements

My assistant, Mr. Paul Green, and I went through all of the residential facilities and hospital units of the following institutions: Ontario Hospital School, Orillia; Rideau Regional Hospital School, Smiths Falls; Ontario Hospital School, Cedar Springs; Midwestern Regional Children's Centre, Palmerston; Adult Occupational Centre, Edgar; Prince Edward Heights, Picton; Mental Retardation Section, Kingston Psychiatric Hospital, Kingston; Mental Retardation Section, Lakehead Psychiatric Hospital, Thunder Bay; Oxford Mental Health Centre, Woodstock; Ontario Hospital, Aurora; Ontario Hospital, Cobourg; Lincoln State School, Lincoln, Illinois; Children's Psychiatric Research Institute, London; The Mental Retardation Centre, Toronto; The Child Development Clinic, Ottawa.

Mr. Green or I visited the following Residences, Sheltered Industries and Schools: Harold R. Lawson Residence; Lorimer Lodge; Sheppard Avenue Residence; Mrs. Dorothy Simpson's Half Way House, Kingston, and a number of other approved homes and homes for special care; A.R.C. Industries at Etobicoke, Barrie, North York, and Beverley Street, Toronto; Sault Ste. Marie; Thunder Bay; Kenora; The Harry E. Foster Employees Training Centre; Haney Avenue School, Toronto; Seneco School, Toronto; Harold Lawson School, Toronto; and the School Section for the Mentally Retarded in the Ontario Crippled Children's Centre.

I am very grateful to the staff and personnel of these institutions, residences and industries for their kindness and thoughtfulness in showing Mr. Green and myself through the buildings and for the many courtesies extended to us.

I examined all of the Hospital Records and Police Reports relating to Frederick Elijah Sanderson and Jean Marie Martel. I read the transcript of the evidence taken at the Coroner's inquest into the death of Sanderson and examined the exhibits, including photographs. I interviewed at length Roger Hughes, M.D., the Coroner, and two newspaper reporters who were concerned with the cases, Michael Gillespie and David McKay. I express gratitude for the

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time and assistance they gave. Where the evidence of a witness appeared clear from the transcripts or statements given to the police, I did not re-examine such witness, but when there was uncertainty as to the evidence, Mr. Green visited the witness and obtained a new statement. He interviewed Jean Martel and his mother and two medical doctors who had seen him. He also visited the Paauw Farm.

The following Associations presented written briefs: The Fort Frances and District of Rainy River Association for the Mentally Retarded; the Kenora-Keewatin Association for the Mentally Retarded; The Ontario Association for the Mentally Retarded; The Metropolitan Toronto Association for the Mentally Retarded; Roger Hughes, M.D., on behalf of 50 Parents of Retarded Pre-School Children.

We heard oral presentations made on behalf of: The Canadian Association for the Mentally Retarded; The Ontario Association for the Mentally Retarded; The Kenora Association for the Mentally Retarded; The Fort Frances and District of Rainy River Association for the Mentally Retarded; The Sault Ste. Marie Association for the Mentally Retarded; The Ottawa Association for the Mentally Retarded; The Kingston Association for the Mentally Retarded.

I am extremely grateful to the personnel of these associations for giving me their time.

I received many private letters and spoke to numerous individuals in their personal capacities. I do not mention their names lest I cause embarrassment. Nevertheless, I am very much indebted to all persons who saw or wrote to me.

I relied heavily upon the following reports, papers, books and articles:

ONE MILLION CHILDREN

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111

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