# A STATE OF MUTUALISM: A POLITICAL STUDY OF ORGANIZATIONS WHICH REPRESENT MENTALLY RETARDED PERSONS IN THE PROVINCE OF MANITOBA.

by

CHRISTOPHER ADAMS

A thesis
presented to the University of Manitoba
in partial fulfillment of the
requirements for the degree of

MASTER OF ARTS

in the

Department of Political Studies
Winnipeg, Manitoba

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**CONTENTS**


| Chapter | | page |
|---|---|---|
| I. | **INTRODUCTION: THE STRUCTURE** | **1** |
| | Preliminary | 1 |
| | Setting the Stage | 7 |
| II. | **THE SOCIO-ECONOMIC SITUATION** | **17** |
| | Normalization: Integrating the Population | 17 |
| | Profile of a Stigmatized Population | 19 |
| | The Shift in Services | 26 |
| III. | **THE INTEREST GROUP: IN SEARCH OF MUTUALISM** | **29** |
| | Preliminary | 29 |
| | Interest Group Attributes | 30 |
| | Interest Group Developments | 31 |
| | Health to Welfare Interests | 33 |
| | The Federal Effect | 36 |
| | Conflicting Stakes | 37 |
| | The Position of the ACL | 43 |
| | The legitimate Position | 45 |
| | Party Politics | 49 |
| | Summation | 51 |
| IV. | **THE PARENT MOVEMENT AS ORGANIZATIONAL REPRESENTATIVE** | **52** |
| | Western Developments | 52 |
| | The Manitoba Organizations | 58 |
| V. | **DEINSTITUTIONALIZATION: THE SEARCH TO INTEGRATE MENTALLY RETARDED PEOPLE** | **69** |
| | Preliminary | 69 |
| | The Institution as Symbol of Past Models | 71 |
| | Identification and Segregation | 72 |
| | Institutionalization and Other Sectors | 75 |
| | The Financing of Two Models | 77 |
| | The Degree of Government Commitment | 81 |
| | A Need for a Community Support System | 86 |
| | A Balancing Act | 88 |
| | Inter-Departmental Rivalry? | 92 |
| | Group Homes | 93 |
| | Summation | 98 |

VI. MENTAL RETARDATION POLICY IN RURAL MANITOBA: AN ADDITIONAL CONSIDERATION . . . . . . . . . 101

Preliminary . . . . . . . . . . . . . . . . . 101
The Urban Nature of Social Welfare . . . . . . 102
Stretched Resources . . . . . . . . . . . . . 103
Proximity of Organizational Influence . . . . 108
Not All Rural Communities Are Alike . . . . . 109

VII. CONCLUSION: MANITOBA AND THE ACL . . . . . . . . . 112

Appendix page

A. . . . . . . . . . . . . . . . . . . . . . . . 119

BIBLIOGRAPHY . . . . . . . . . . . . . . . . . . . . . 120

# Chapter I

# INTRODUCTION: THE STRUCTURE

## 1.1 PRELIMINARY

In Canada, and throughout western industrialized society, there has been a change in direction concerning services and attitudes towards mentally retarded persons. Manitoba has not been excluded from these social shifts. This is becoming more apparent in the 1980s as many become aware that mental retardation can be seen within a social framework. The thesis will deal with North American trends in mental retardation policy and how Manitoba has been a part of these overall developments. Issues such as deinstitutionalization have arisen outside Manitoba but have influenced both the Provincial Government and the Association for Community Living. The local divisions have strong contact with their national organization hence influence, and are influenced by, them.

The development of attitudes toward, and treatment of mentally retarded people in Manitoba will be the focus of the examination. Because the patterns in Manitoba will be compared to those found in North America, the thesis is both

descriptive and comparative. It is aimed at the political nature of the developments through a description of those groups which represent the interests of mentally retarded people and an examinination of the means by which they have affected government policy.

Manitoba, it will be argued, has shown advances along the lines which the ACLs have wanted but this should not be seen as unique as it will be shown that throughout North America there has been a push for deinstitutionalization and community living. The ACLs are effective organizations and the government of late has shown a responsiveness in Manitoba but Manitoba should not be seen as the vanguard of community living. It has been progressive in some areas and slow to change in others. For example, the Manitoba Human Rights Act regards "mental Handicap" as a condition which is to be protected from discrimination while the Manitoba Mental Health Act is considered as one of the Province's most regressive pieces of legislation.

Therefore the thesis in each section deals with the following boundaries of service and policy direction:

1. North America (Canada + U.S.)
2. Canada
3. Manitoba

## Mental Retardation as a Category

The research will use the concept of mental retardation within the context established by the Prince Edward Island Task Force on Mental Retardation:

> The conception we utilized could best be called a sociological definition ; this definition focuses on the role performance of the individual in relation to the expectations of the community in which he/she lives. Simply put, if the community through its agencies, services or "community knowledgeables" ...identifies an individual as being "mentally retarded", then that individual is included in our target population. In this understanding, the glaring inadequacies of purely medical definition (i.e syndrome differentiation), or a psychometric assessment (I.Q. tests or other spurious constructs) are overcome.[1]

The label "mental retardation" has often been used to stigmatize or medically categorize members of our society. Regardless of modern attempts to replace terminology, in Manitoba both the community and the government continue to use the label. The terms mental retardation and mentally retarded are used simply for consistency in this report.

At the outset of this research project the subject was to be mentally retarded "citizens" however it was made clear from the research that the ACLs have had to work to show that these members of our society should be considered as citizens. A National Health and Welfare 1964 report makes this point very clear:

> The retarded person has not been thought of as a second-class citizen, but rather as no citizen

---

[1] Provincial Task Force on Mental Retardation, Final Report CAMR (P.E.I. Division), December, 1980, p. 9.

at all.[2]

Such rights as voting, marrying, owning property, and many others are often withheld even to this day.

## The Shift in Service and Policy Models

In the field of human service delivery and how it is applied to disabled people (including those with mental retardation), there are a number of models which the literature deals with. Among the many labels attached to these models are: community living, independent living, medical, segregational, professional, and institutional. The model supported by the ACl compresses a number of labels together under the model label of community living (hence the name Association for Community Living). This organization sees this as a replacement for the earlier established models which used custodial services (comprising the professional, medical, institutional, and segregational models) as a major means of service. As the earlier models had their beginnings in the 1800s it is not surprising that there has been a strong push for change since the Second World War.

Table 1 shows the attributes of the two major paradigms of service delivery and policy. In the custodial model there is little room for consensus and a heavy reliance on professionals for administration and policy. In the commu-

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[2] National Health and Welfare, Mental Retardation Activities of the Department of National Health and Welfare, (Ottawa, 1964), p. 13.

nity living model consensus is needed and control is open to

TABLE 1

CONTRASTING CHARACTERISTICS OF SERVICE MODELS

| Community Living | | Custodial |
|---|---|---|
| Integration of Individual | ------- | Segregation of Individual |
| Joint Policy Formation | ------- | Hierarchical Formation |
| Decentralized Services | ------- | Centralized Services |
| Small Group Residences | ------- | Large Institutions |
| Independent Living | ------- | Supervised Living |
| Integrated Employment | ------- | Sheltered Employment |
| Integrated Education | ------- | Separate Education |
| Social Services | ------- | Medical Services |

various social sectors.

The shift in model is important in that as community living is supported, government services, policies, and attitudes become subjected to major changes. Furthermore, there are socio-economic issues such as the effect which group homes and community programming may have on neighbourhoods throughout the province and, the ramifications of closing down long established services such as the institutions. These issues will be dealt with throughout the following chapters.

It will therefore be shown that mental retardation has become an issue of social welfare and community welfare under the government's umbrella. In Manitoba, services in the field which are not directly related to the physiological

aspects of the individual are to be found under the jurisdiction of the Minister of Community Services (in 1986 it is Muriel Smith).

The communication of ideas and developments in the movement of mental retardation interest group behaviour should be seen in the light of an international aspect. All of the organizations in this province related to this issue have contacts with outside organizations, especially the national body of the ACL. In turn the ACL is in contact with the international scene both through making its own contributions as well as receiving them. The National Institute on Mental Retardation acts as a research wing for the national ACL and is known throughout the world for its contributions towards the developments of community living writings and research. Furthermore, locals of the ACLs in Canada maintain strong links to the national ACL causing the ideas to be international throughout most regions in Canada. Also, the national organization plays a high profile in the media, conventions, government hearings, and, as mentioned before, publications. Therefore, it becomes necessary to discuss patterns outside Manitoba in order to evaluate the Manitoba ACLs. In each section there will be a discussion of the three levels of activity and development.

The following chapters will show that the Association for Community Living uses the same tools which other interest groups use when seeking to affect the political system. The

discussion in Chapter 3 will address the major themes of interest group theory. The ACL has all four of the attributes listed by A. Paul Pross in his definition of institutional interest groups. From this will be found that the ACL has been very successful both on a national and provincial level.

The chapters are layed out as follows:

1. The socio-economic situation of the mentally retarded person
2. Interest group behaviour (theoretical considerations)
3. The parent movement and its role as representative
4. Deinstitutionalization
5. Urban-rural variations

The above subject areas are relevant both to the Province of Manitoba as well as to the North American level.

## 1.2 SETTING THE STAGE

This thesis indicates that with the shifting of the attitudinal paradigm there has been a revolution concerning what is considered of importance to mentally retarded persons in Manitoba. The medical and segregation models should no longer be seen as the primary means of basing a region's services. Commenting on the attitudinal shifts of the 1970s, the Manitoba Task Force on Mental Retardation states:

> Gradually, mental retardation began to be viewed as a social problem rather than a medical prob-

lem.[3]

Furthermore, the impact of mental retardation on the pertinent content of public policy has in recent years progressed within this context. The research will therefore describe and assess the political impact which the Manitoba organizations representing mentally retarded people have had and continue to have on human service delivery approaches and patterns.

Research Considerations

A. The Population

Outside of institutional "head counts" there is a shortage of information pertaining to the mentally retarded portion of the total population. National estimates have error factors of hundreds of thousands of persons while specialized data, for example unemployment data on the mentally retarded population, remain non-existent.[4] The major data gathering agencies at the federal and provincial levels normally exclude mentally retarded persons from the populations from which economic or social data are gathered. In the case of Manitoba this was recognized by the 1982 task force. It saw that there was a need

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[3] Task Force on Mental Retardation, Challenges for Today, Opportunities for Tomorrow, Report to the Minister of Community Services and Corrections, (Manitoba, 1982), p. 2.

[4] Statistics Canada is unable to provide any statistics concerning mentally retarded people.

> ___to facilitate the pooling of existing information and the gathering, storage, retrieval and dissemination of additional information pertinent to the development of services for persons with mental retardation in Manitoba.[5]

While there is a shortage of information there is also a degree of confusion in the literature. While the 1982 report states that three per cent of Manitoba's population have "some level of mental retardation" a non-government report states:

> It has been estimated that persons with "mental retardation" comprise 2-3% of any population ...It is estimated that only 1% of the population is formally recognized as "mentally retarded".[6]

From the above, the population is defined by both incidence and service delivery. While the difference resides in the qualifier "formally recognized" the pin-pointing of the population remains to be clarified.

The 1982 report does not indicate that it has done primary research in determining the numbers in question but uses a 1979 survey of social agencies (the Hull Report). The report estimates that 30,000 Manitobans have "some level of mental retardation" which would be approximately 3 per cent of the province's population.[7] Table 2 shows that of this 30,000 figure the government believes that 10,000 require

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[5] Manitoba Task Force on Mental Retardation, op. cit., Recommendation B.4, 1., p. 74.

[6] ARC Industries Inc., "Background on the Human Service Focus of ARC Industries Inc.", (fact sheet), Winnipeg, 1984.

[7] Manitoba Task Force on Mental Retardation, op. cit., p. XXVIII.

special assistance. There is no indication that the 3 per cent figure has any empirical foundation other than being based upon outside estimations. One would suspect that it is merely drawn from the President's Panel on Mental Retar-

TABLE 2

POPULATION PROFILE: THOSE WITH MENTAL RETARDATION REQUIRING SPECIAL ASSISTANCE

| | |
|---|---|
| Mentally Retarded People Needing Occasional Assistance | 6,000 |
| Mentally Retarded People Needing Partial Assistance | 2,500 |
| Mentally Retarded People Needing Continuing Assistance | 1,500 |
| Total Mentally Retarded People In Manitoba Needing Special Assistance (approx. 1%) | 10,000 |

(Source: Manitoba Task Force on Mental Retardation, 1982.)

dation figure given for the United States in 1962.[8]

The 1982 Task Force might have been less certain in its estimates had it paid closer attention to an earlier Manitoba Government report which stated:

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[8] The President's Panel on Retardation, A Proposed Program for National Action to Combat Retardation, 1962, as cited by John A. Christianson, A Study of the Education of Handicapped Children in Manitoba, (Winnipeg, 1965), p. 10.

> Although it is commonly accepted, on the basis of the assumption that intelligence is normally distributed, that about 3% of the population are mentally retarded, the actual figures in various surveys have ranged from .68 percent to 8.83 percent depending on the population examined, the means of assessment employed, and the criteria of retardation utilized. In fact, it is apparent that the distribution of intelligence is skewed, with at least three times as many persons falling below an IQ of 50, as would be predicted by the normal curve.[9]

Although it is beyond the scope of this report to criticize the Task Force Report one would suspect that the basis from which it worked was not proven. One questions whether it fully understood the Manitoba situation in order to draw conclusions and make recommendations for service policy for the next twenty years.

B. Services and Data

It is very difficult to determine the extent and nature of all services in Manitoba. Purely from a facility size perspective, the options range from the large institution which underplays its negative aspects, to the tiny community service, which may be virtually invisible. Government itself is often unable to understand the system it directs or to obtain accurate data which would allow for informed policy direction. A shift by only 1 per cent of the total population in Manitoba would have a dramatic effect on the policy and programming outcome.

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[9] Manitoba Department of Health and Social Development, Mental Health and Mental Retardation Services: A Review and Preliminary Model, Government of Manitoba, 1972 , p. 39.

It is clear that Manitoba's dilemma is not unique in that it fits within a broader context of the problems facing social welfare research in Canada. Andrew Armitage comments that Canadian governments face the following problem:

> Since there are a great number of small programmes at the neighbourhood and community level (and this includes most that are of the self-help type) meaningful inquiry about their experiences is so fragmented as, for practical purposes, to be unavailable. Complete listings by such local institutions as churches and fraternal organizations do not exist.[10]

Furthermore, the data which exist usually consist of concrete measurements which may not be useful for qualitative analyses. For example, there is a heavy reliance in the Manitoba Government literature on budget levels and institutional population levels. While these measurements were not meant to be used for the purposes of assessment in relation to what Armitage is talking about, these measurements are used by the government for purposes other than merely showing budget commitments.

In spite of the lack of concrete social data in the field of mental retardation there is a basic understanding that mentally retarded people are stigmatized. The major factors affecting the individual are as follows:

1. low intelligence hence vulnerability;

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[10] Andrew Armitage, Social Welfare in Canada: Ideals and Realities, (Toronto, 1975), p. 182.

2. low expectations;

3. marginalization due to competitive society;

4. impoverishment of experience.

These factors will be developed in detail in Chapter Two.

C. The Association For Community Living

Because mentally retarded people traditionally hold low social status, groups such as those formed by parents of mentally retarded people have acted as advocates in order to obtain services and rights. Concerning disabled persons in general,

> Manitoba has been a centre for consumer activism for many years.[11]

Therefore, the combination of the activism of parents and the establishment of organizational headquarters in Winnipeg has provided an environment which has enhanced the potential of successful interest group activity. Along with the Canadian Association for the Mentally Retarded (which is now titled the Association for Community Living) which has established a Manitoba and a Winnipeg division, the national headquarters of the Coalition of Provincial Organizations of the Handicapped (COPOH) is located in the city. The World Congress on Rehabilitation International held its conference in Winnipeg which also added to this environment.

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[11] Health and Welfare Canada, Disabled Persons in Canada, Supply and Services Canada, (Ottawa, 1980), p. 34.

The two divisions which the research will focus upon will be the Association for Community Living (ACL) - Manitoba, and the ACL - Winnipeg.[12] These two divisions of the ACL organization are not the only actors working for the benefit of mentally retarded Manitobans, but they are seen as the primary actors. In almost all of the interviews conducted with government administrators these two groups were the only ones mentioned although there are a number of local chapters of the ACL in Manitoba.

As a region for this study Manitoba should be understood in terms of certain characteristics. Manitoba maintains a steady population (just over 1 million) of which over half of the province's population resides in the capital, Winnipeg. Winnipeg is located in the southern region causing Manitoba's political structure to be awkwardly centralized.

All social decisions eventually result from Winnipeg where the provincial government is located. Furthermore, Winnipeg in the 1970s had 80 per cent of Manitoba's urban population.[13] Manitoba is therefore seen as being comprised of two halves, Winnipeg and the rest of the province. This is a misconception due to the fact that rural Manitoba de-

[12] The previous title, CAMR, was changed to ACL for the Manitoba division in 1984 and nationally and in Winnipeg in 1985.

[13] David E. Smith, "The Prairie Provinces", <u>The Provincial Political Systems: Comparative Essays</u>, D.J. Bellamy, et al, eds., (Toronto, 1976), p. 50.

fined in this way includes such cities as Brandon and Thompson. Nevertheless, rural Manitoba is lumped together by those in the government in Winnipeg. Nor is the problem one of simple labels. The current distribution of social services is also affected. Moreover, this has been the case for some time as the following quotation shows:

> In Manitoba the problem of providing services and classes for these children [with severe mental and physical handicaps] is complicated by the demographic fact.
>
> Only in Winnipeg is it possible for the school authorities to develop a complete range of specialized services. None of the other school divisions have enough children to warrant the development of a full program.[14]

Within both the Canadian and the Manitoba context it is evident that there are two dimensions to the activities of the Association for Community Living when it operates as an interest group. The first dimension concerns the formulation or provision of new policies. Examples of this are the pressures to alter the Manitoba Mental Health Act and the establishment of the Welcome Home Project. The second dimension is the attempt to affect existing policies. This would include: support for affected parents, ensuring that certain individuals are not abused or excluded from services, in short, safeguarding citizens. While the second category sometimes enters into the field of lobbying, in the strict sense of policy pressuring, the first dimension is

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[14] Christianson, op. cit., p.11.

the more important.

## Chapter II

## THE SOCIO-ECONOMIC SITUATION

### 2.1 NORMALIZATION: INTEGRATING THE POPULATION

The concept known as "normalization" is the practice of allowing mentally retarded people to enter the community and to partake in society's activities. If implemented it would act against a possible decline in society's actions and attitudes towards these people. Normalization plays a key role in conceiving modern human service delivery. The three main theorists have been Bank-Mikkelson of Denmark, Nirje of Sweden, and Wolfensberger of Canada. Bank-Mikkelson has defined normalization as "letting the mentally retarded obtain an existence as close to the normal as possible."[1] Nirje defines it as

> ___making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society.[2]

Wolfensberger stated it is the

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[1] As quoted by Wolf Wolfensberger, Normalization: The Principle of Normalization in Human Services, (Downsview, Ont., 1972), p. 27.

[2] Ibid.

> [u]tilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible.[3]

Concerning the trends in Canadian society, Michael Kendrick (Program Coordinator of the National Institute on Mental Retardation (NIMR)) stated in 1979 that despite

> ___some progress since the Second World War in terms of public support for normative community living for mentally handicapped citizens, substantial resistance still exists for the full-scale implementation of such a social policy. Judging by what has actually been implemented, we do not in Canada have a universal commitment to normalization. So in a historical sense, our society cannot be characterized as being entirely prepared to commit itself to viewing mentally retarded people as having unambiguously the same rights and responsibilities as other citizens.[4]

As indicated previously, the *per capita* population size of mentally retarded persons in Manitoba is seen as similar to that of other countries. Given that the Manitoba government estimates that 30,000 persons are deemed mentally retarded and that 10,000 of those need special assistance, it is not surprising that there are strong concerns being raised both privately and publicly about the present system.

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[3] *Ibid*., p. 28.

[4] Michael Kendrick, "The Response to the Community", *Sterilization and Mental Handicap*, (Downsview, Ont., 1980), p. 74.

## 2.2 PROFILE OF A STIGMATIZED POPULATION

A review of the literature reveals that mentally retarded persons need representation. The main reason for this is that they maintain low levels of legitimacy. Mental retardation is a stigmatized condition; more so than the average physical handicap. Western society places a high value on intellectual ability hence the mentally retarded person is vulnerable in as much as he or she is devalued.

The stigma arises largely from the view that mentally retarded people are suffering from a sickness or mental illness. The amalgamation of laws pertaining to mentally retarded people in Manitoba with mentally ill people under the Manitoba Mental Health Act is an indication of this philosophy. Whereas a person who is sick is temporarily vulnerable, the mentally retarded person finds no relief from his/her condition. Alfred and Maria Miller state:

> ___being a patient is usually not a continuous or primary role and does not serve as a basis for a person's ongoing identity. Being sick is ordinarily considered an episode or interruption of normal life activities. It is viewed as an undesirable, temporary status to be put aside as quickly as possible to return to one's normal roles. The sick role is actively rejected as a part of a person's identity. Thus the patient is *ipso facto* in an unstable, vulnerable position.[5]

Added to these effects of the medical model, in Manitoba the laws were framed in such a manner that they served as a support of possible abuses instead of being a protector against

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[5] Alfred E. Miller and Maria G. Miller, Options for Health and Health Care, (New York, 1981), p. 221.

abuse. The Clarkson report stated in 1973 that the Manitoba Mental Health Act was

> ___written in such a manner and with such language that it would seem to be dealing more with the imprisonment of offenders than with the protection and development of persons with limited intellect.[6]

Since the Clarkson report was written there has been no rectification of the problem. In a report to the Provincial Steering Committee, the ACL - Manitoba reported:

> ___the Manitoba Mental Health Act...is focussed entirely on institutionalization of persons with a mental handicap according to entirely inappropriate medical model criteria.[7]

The Mental Health Act does come into conflict with the Manitoba Human Rights Act which prohibits discrimination against those who have a "mental handicap".[8] The involuntary incarceration of what the Mental Health Act labels as "mental retardates" has yet to be fully challenged. The advent of the Canadian Charter of Rights however has provided the federal ACL with an important tool which will provide the provincial organizations a push to challenge their respective provincial legislation. At present the Manitoba ACL has been lobbying the government for a rectification of the

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[6] Dr. J. C. Clarkson, Mental Health and Retardation Services in Manitoba: A Report to the Minister of Health and Social Development, Province of Manitoba, (Manitoba, 1973), p.8.

[7] Moira Grahame, Legislation Involving Mentally Handicapped People of Manitoba, ACL - Manitoba report to the Provincial Steering Committee, 1985.

[8] Manitoba Human Rights Act, (Revised), August, 1982.

legal inconsistency.

Second, society in general has always had, and continues to have, low expectations for these individuals. This increases the disability.[9] This second factor has led many to concentrate on improving the education system for those with special needs. Those who are in the developing stage need to have educators who have high expectations instead of a defeatist attitude. For example, the I.Q. test has been criticized as a tool for the education system to weed out those who are perceived as being a nuisance. Joseph Agassi states that the I.Q. test has been used in the United States in order to resolve the following problem:

> It does not matter...what makes a half-wit a half-wit; what the teacher wishes to convey is, first and foremost, that there are pupils in his class who are not able to benefit from normal class situations, no matter how effective the teacher may be, and whose presence in the class is only a burden.[10]

Third, Canada and Manitoba's economic system promotes competition among groups and individuals thus causing the weaker (or less defensive) units to be marginalized. The mentally retarded person is the first to be placed in this situation. The mentally retarded person is often defended by his or her family which itself is becoming an increasing-

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[9] NIMR, Orientation Manual on Mental Retardation: Part 1, [Revised Edition], (Downsview, Ontario, 1977), pp. 75 - 77.

[10] Joseph Agassi, "The Twisting of the I.Q. Test", The Philosophical Forum: A Quarterly, Vol. 3, No. 2, Winter, 1972, p. 270.

ly vulnerable social unit. The family itself is also weakened as an economic unit by mental retardation in several ways. These include:

1. Institutional separation of the person from the rest of the family.
2. Treatment and care costs weaken the family's economic strength.
3. Less flexibility in terms of time for those responsible for family funding due to care of disabled individual.
4. Mobility of earning member(s) may be reduced by need to have close proximity to care and treatment facilities.

While there are no empirical data to support the claim that families in Manitoba with handicapped children are weakened there are a number of parents in Manitoba who support this claim.[11]

One parent, Liz Siemens, describes the difficulties of being the family bread-winner while supporting her mentally retarded child:

> I had to go on social assistance when my ex-husband took off. It wasn't the greatest thing for my self-esteem. It's horrible having people poking into your life all the time, and spending half your time filling out forms. So three years ago I suddenly said to hell with this garbage and took a job in a furniture factory down the road. For standing on a concrete floor from 8:00 till 4:30, spraying, sanding, and dodging the guys catching my boobs, I receive the princely sum of $5.78 an hour... It's also not much to keep three people [her family] on... It's a man's job and I work as hard as the men but I get paid less than them. I pretty well <u>have</u> to work at this factory because it's the closest job to home. I haven't

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[11] Personal communications.

> the time to spend hours on a bus twice a day, and I have to be able to run home in case of an emergency with Brenda.[12] [Siemens' Emphasis]

This parent also reports that there are strong constraints on free time which may affect the ability of family members to cope with stress: "My social life starts at midnight and usually ends a few minutes later."[13]

Finally, mentally retarded people suffer from an impoverishment of job skills and labour related experience. The problem is circular in nature due to the requirement that the person needs to have a job in order to obtain a new job. Social skills are often acquired through the work-place and if a person is unemployed there is less chance that he or she will be able to adapt to the community. While employment can provide economic independence it may also provide a chance for helpful role models.

The main reasons for the strong push for community living are found in the above assertions. The concept of "community" or "community living" is best understood when one looks at David Mechanic's definition:

> Community is both a social and a psychological construct. It refers to patterned relationships among persons and to a sense of being part of the pattern - a sense of identity.[14]

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[12] Liz Siemens, "Liz and Brenda Siemens", The Positive Path: Profiles of Disabled Manitobans The Council for Exceptional Children, (Winnipeg, 1981), p. 108.

[13] Ibid. p.109.

[14] David Mechanic, Future Issues in Health Care: Social

Behaviours which are suitable for community living should be seen therefore as related to environmental conditions.

There can be no doubt about the poor social positioning of mentally retarded people. Both the government and the private sector are aware of this. For example, the Special Parliamentary Committee on the Disabled and the Handicapped found that

> ___one of the areas of rather tragic neglect so far as human rights are concerned, was that of the mentally handicapped citizens...[15]

In a release, ARC Industries (a Winnipeg sheltered workshop) stated that the life experiences which are "commonly faced" include:

1. poverty of experience
2. material poverty
3. lack of control over personal decisions/destiny
4. limited personal friendships
5. lack of skills/lack of educational opportunities
6. rejection by other people
7. lack of opportunity to contribute meaningfully to society.[16]

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Policy and the Rationing of Medical Services, (New York, 1979), p. 73.

[15] As stated from Proceedings of the Special Parliamentary Committee on the Canadian Constitution, 21 November 1980.

[16] ARC Industries Inc., "Background on the Human Service Focus of ARC Industries Inc.", (fact sheet), Winnipeg, 1984.

The above points underscore the serious vulnerability being faced and suggest a personal sense of fragility and loneliness. While there is agreement concerning the personal situation there is also recognition that mentally retarded people are "in danger." Not only is it an issue of loneliness or the lack of material comforts but an issue of the need for protection from the institutions of our society. According to Paul McLaughlin, mentally retarded persons

> ___must cope with life in the face of an uncaring political system, a rigid, self-indulgent bureaucracy, a neglectful and exploitative economic system, a discriminatory legal system, a human delivery system that is more intent on labelling, segregating, institutionalizing, locking up and processing than on providing a truly human service, and a family system that is under extreme pressure itself. No wonder their lives are so filled with danger.[17]

In his terms, "less stigma means less danger."[18]

Concerning the current Manitoba situation a CAMR report[19] stated:

> ___adult lifestyles of the overwhelming majority of Manitoba's mentally retarded citizens are typified by experiences of impoverishment, underemployment, and near negligible opportunities for skill development.[20]

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[17] Paul McLaughlin, Guardianship of the Person, (Downsview, Ont., 1979), p. 7.

[18] Ibid. p. 29.

[19] This report was written when relations between the government and CAMR were at its lowest point. It was a result of a walk-out from the 1982 Manitoba Task Force on Mental Retardation by those representing the organizations.

[20] Helen Steinkopf, et al, Mental Retardation Services in Manitoba: "We Have Promises to Keep", CAMR, (WInnipeg,

## 2.3 THE SHIFT IN SERVICES

As the awareness increased as to the social problems so too did programming. Today almost all services in Manitoba come from the Department of Community Services. This is a change from what can be seen in a 1964 Federal Government report:

> Welfare Departments have concerned themselves to a quite limited extent with problems of the mentally retarded and usually indirectly through the normal child welfare services, public assistance, and other general programs.[21]

One of the potential disadvantages of moving mental retardation into the social sphere from the medical is that the popular support being counted upon may not grow. Looking at the very general area of health politics in the United States as compared to social welfare issues one can see the possible consequences to mental retardation policy. In an article on government and health, Theodor Litman comments that, in the United States, health politics

> ___is usually conducted in a favorable political climate. The notion of health is a popular one: the public, for good or ill, remains convinced of the efficacy of medicine in promoting and maintaining it and believes that future medical advances guarantee less sickness and longer life. This results in strong popular support for spending money in all fields of health...

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1982), p. 34.

[21] National Health and Welfare, Mental Retardation Activities of the Department of National Health and Welfare, (Ottawa, 1964), p. 13.

> Other fields are not so fortunate when they enter the political arena. Welfare spending, for example, is not merely opposed because of possible adverse tax or spending consequences, but there are important segments of the public that oppose welfare spending in principle. They believe that it is worse than doing nothing, because it encourages laziness and dependency on the part of those receiving welfare.[22]

In Manitoba with the new push for community living the ACLs will have to wait to see how the electorate perceives this new visible population. A dependent out of sight may be above public scrutiny but one in the community may be seen as just another "welfare bum". The stigma caused by marginality while being reduced may be shifted to a stigma caused by a social response to a perceived dependency upon taxpayers.

The direction which our society is taking regarding mentally retarded people is not yet clear. Some theorists as Wolf Wolfensberger claim that as we become more materialistic as opposed to community oriented we will ignore the weaker elements in society.[23] Many would argue that the opposite will occur, that is, as technology and awareness increases so too will the protection of those who are on the social fringe.

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[22] Theodor Litman, "Government and Health: The Political Aspects of Health Care - A Sociopolitical Overview", Health Politics and Policy, Litman and Robins, eds., (New York, 1984), p. 32.

[23] Wolf Wolfensberger, Voluntary Associations on behalf of Societally Devalued And/Or Handicapped People, (Downsview, Ontario, 1984), pp. 68 - 80.

The following chapter will first deal with the general behaviour of interest groups in order that a more detailed description of organizations involved in the field of mental retardation may be made.

## Chapter III

## THE INTEREST GROUP: IN SEARCH OF MUTUALISM

### 3.1 PRELIMINARY

In Manitoba, interest groups have played a major role in obtaining social advances for mentally retarded persons. While such individuals may lack personal social status, those who have acted as their advocates have often had high levels of social status as well as other resources. The volunteer sector has had an effect on government services and policies for a longer period than many would think. In a 1965 Manitoba Government report the following is found:

> The government authorities should not lightly dismiss the services of the voluntary groups. They should be encouraged to meet their changing roles, and, as traditional programs are taken over by government, actively encouraged to explore new areas of service. The active involvement of private citizens in these agencies provides access to knowledge not usually available and greatly enhances public understanding of social problems.[1]

In the past century Canadian voluntary associations, another name for interest groups in this field, have changed both in ideals and membership. The modern organizations began with parents who were concerned that their children were

[1] John A. Christianson, A Study of the Education of Handicapped Children in Manitoba, (Winnipeg, 1965), p. 13.

receiving inadequate care and that the service providers themselves were not getting acceptable levels of funding from their respective governments. The following questions arise: What are the ingredients of a successful interest group? What are the ingredients for such a group in Canada or Manitoba and what types of members of a group would be needed?

## 3.2 INTEREST GROUP ATTRIBUTES

The term "interest group" is defined by Dell Hitchner and William Harbold as

> ___any collection of persons with common objectives who seek the realization of those objectives through political action to influence public policy.[2]

A. Paul Pross has found that the following attributes are essential to the make-up of a modern institutional[3] interest group:

1. Continuity
2. Organization
3. Articulation of Interest
4. Influence on power[4]

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[2] Dell Hitchner and William H. Harbold, Modern Government, (New York, 1972), p. 136.

[3] As opposed to an issue oriented interest group.

[4] A. Paul Pross, "Pressure Groups: Adaptive Instruments of Political Communication", Pressure Group Behaviour in Canadian Politics, Pross, ed., (Toronto, 1975), pp. 2 - 3.

The fact that the representatives are organized is a factor in itself. Peter Bernholz writes that an interest group's raison d'etre lies in demonstrating that it has more power by virtue of being organized than it would if its members were in disagreement or if the members of the group acted simply as individuals. Whether active or not, according to Bernholz, an organized body maintains political influence.[5]

One should qualify this by understanding that an organized body must exhibit at least the potential to act if it is to remain as an influential body. An organization may in fact be seriously weakened if its members rely too much on being part of an organization merely for effect.

## 3.3 INTEREST GROUP DEVELOPMENTS

With the rise of industrialism in Canada there has also been the rise of interest groups as functioning separate entities of influence. As B. Guy Peters states:

> One of the dominant features of postindustrial society is the return to pressure groups as a dominant input mechanism.[6]

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[5] Peter Bernholz, "Dominant Interest Groups and Powerless Parties", Kyklos, Vol. 30., No. 3, 1977, p. 412.

[6] B. Guy Peters, "Insiders and Outsiders: The Politics of Pressure Group Influence on Bureaucracy", Administration and Society, Vol. 9, No. 2, August, 1977, p. 215.

In the United States John Walker found that one half of all the groups operating in the 1980s were created after 1945.[7] Khayyam Paltiel states that this holds true in Canada and that the growth has been largely in what he calls the "citizens' group category."[8] One of the reasons is the increased size of the bureaucracy in both federal and provincial governments. As its size increases so too does its influence on public policy; the bureaucracy therefore is a means for policy input. Douglas G. Hartle states:

> It is true, of course, that the legislation usually requires that the minister 'decide.' In fact, as we all know, a minister's time is limited, and he is required, by and large, to accept the recommendations of his officials almost automatically.[9]

While Hartle is speaking of the Federal Government it is apparent that this is the case in the provinces as well. As John Kettle commented in the 1970s, "if you worry about the epidemic of bureaucrats, the provinces are the governments to watch."[10]

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[7] As cited by Khayyam Z. Paltiel, "The Changing Environment and Role of Special Interest Groups", Governing Under Pressure: The Special Interest Groups, A. P. Pross, ed., (Toronto, 1982), p. 205.

[8] Ibid.

[9] Douglas G. Hartle, "Techniques and Processes of Administration", Politics: Canada, 4th Edition, Paul W. Fox, ed., (Toronto, 1977), p. 498.

[10] John Kettle, "Bureaucracy Grows Apace in Provinces and Municipalities", Ibid., p. 506.

It is apparent that government administrators make use of the support and information provided by the group to defend any resulting policies which may be in the group's favour.[11] When the government believes that a specific interest group is a proper representative for a segment of society, the relationship between the group and the government will tend towards a state of mutualism. Peters describes this phenomenon:

> The descriptions of the interactions of interest groups and [governmental] administration in clientele politics leads to the characterization of these relationships as being symbiotic. As in biological symbioses, this relationship implies a mutual dependence of the two participants.[12]

The evidence in later chapters will show that such a characterization is increasingly accurate with respect to the ACL in Manitoba.

## 3.4 HEALTH TO WELFARE INTERESTS

The Canadian political system also contains many elements of welfare economics and the accompanying emphasis on the promotion of the public good. However, throughout Canada the welfare economy has come to be seen as a pie for which groups compete either with other groups or with the general populace for what they see as their fair share. This was highlighted at the First World Congress of Disabled Peoples'

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[11] Peters, op. cit., p. 192.

[12] *Ibid.*, p. 202.

International by Bengt Lindqvist:

> Disability policies...very often concern the distribution of resources in the society and are, more often than not, political issues.[13]

With the shift in the paradigm of how to serve mentally retarded people, conflicts arise concerning what issues are to be addressed by the interest groups concerned. Before the 1950s the question (or issue) was: where can society put this mentally retarded population? The issue now has become: what can we do _for_ these people.

In the move from the medical model for the treatment of mentally retarded people to the more general model of community living there can be seen a certain parallel with other changes in Canadian society. The overall health system and policy making have increasingly involved public pressure. In other words, public health is no longer a closed system above scrutiny. G. R. Weller comments on the parameters of the change:

> In the era of government regulation there began to develop a political-economy model of health resources distribution and an increasingly popular public model of health care: many governments began to feel that the allocation of health resources should be politically determined, and this coincided with a rising belief that health resources were a public good because of the importance of individual health to the economic and well-being of society.[14]

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[13] Bengt Lindqvist, "Disabled Peoples' International Manifesto", _A Voice of Our Own: Proceedings of the 1st World Congress of Disabled Peoples' International_, 30 Nov. - 4 Dec., 1981, Singapore, p. 54.

[14] G. R. Weller, "From 'Pressure Group Politics' to 'Medical

This has been of particular importance to disabled people.

As mental retardation moves from the medical sphere to the social sphere it is apparent that it imports with it some of the elements of health care. One can see that the rise of community involvement in public (physical) health in the United States grew at the same time as the push by the parent organizations for service monitoring and the heightening of quality.

Concerning transformations in health policy, as an example, Doman Lum writes:

> Problem identification in health policy leads to the formulation of social values and task roles, which can serve as guidelines for policy action. Values influence how policy problems are framed and interpreted and what policy goals are formulated. Task roles delineate potential policy areas for functions and assignments.[15]

The consumer movement in health care is similar to the movement for mentally retarded people. Participants in the health care sector in the United States realize that

> ___legitimacy and authority of these planning agencies increases with the representation of a cross section of social, economic, political, and professional interests within a region or one community.[16]

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Industrial Complex': The Development of Approaches to the Politics of Health Care", _Perspectives on Canadian Health and Social Services Policy: History and Emerging Trends_, C. A. Meilicke and J. L. Storch, eds., (Michigan, 1980), p. 317.

[15] Doman Lum, "Social Values and Task Roles in Health Policy", _Social Work and Health Care Policy_, D. Lum, ed., (New Jersey, 1982), p. 14.

[16] Christa Altenstetter, "Planning for Health Facilities in

Further, the organizational movement arose during a period in the western world when many different sectors of society were moving towards social activism and lobbying. G. A. Silver asserts that in

> ___the United States thus has arisen in part from social forces, such as the struggle for justice for the poor, the disadvantaged, and minority groups in aiding them to express their needs and end their powerlessness; from reassertion of some traditional values, like decentralization; and from professional reasons as well.[17]

## 3.5 THE FEDERAL EFFECT

Although governments appear to be more open to outside influences concerning public health and social welfare, the two tiered system of government, that is, the federal structure, in both the United States and Canada causes confusion as to the decision making areas for policy input. Therefore, the Manitoba organization representing the mentally retarded population must also deal with this added problem.

One area which indicates this problem is in vocational training. One could suppose that the Manitoba ACLs are not directly involved with the influencing of both the provincial and federal governments as related to the direct effect

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the United States and in Western Germany", Milbank Memorial Fund Quarterly, Vol. 53, No. 1, Winter, 1973, p. 57.

[17] G. A. Silver, "Community Participation and Health Resource Allocation", International Journal of Health Services, Vol. 3, No. 2, 1973, p. 129.

which VRDP (Vocational Rehabilitation of Disabled Persons Agreement) has upon Manitoba unemployment and handicapped people. Since VRDP is a federal-provincial agreement much is left in the federal association's hands.[18] Nevertheless, VRDP has major effects on mentally retarded Manitobans in that the vocational rehabilitation workshops fall largely under its jurisdiction.

The lack of progress concerning workshops may result from the fact that they do not belong completely in any one jurisdiction. The provinces wait for the Federal Government to introduce progressive changes and vice versa. Added to this complication, Keith Banting states:

> In keeping with the other forms of fragmentation of authority, divided jurisdiction raises the level of consensus required for innovation, and thereby complicates the process of introducing new programs...[19]

## 3.6 CONFLICTING STAKES

One of the major tasks facing the ACLs is to be found in the attempt to change the thinking and direction of government policy makers in order to instigate innovation. There is also the problem of being seen as the "true" representatives of those who are mentally retarded. Groups belonging

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[18] This was indicated by the low number of statements made by the Manitoba and Winnipeg ACL interviewees.

[19] Keith G. Banting, The Welfare State and Canadian Federalism, (Kingston, Ontario, 1982), p. 174.

to the institutional system defend both the old pattern of service delivery as well as their share of what the government spends on human service delivery. The conflict in Manitoba is highlighted in the Manitoba Task Force on Mental Retardation report:

> There is need for ongoing advanced planning to support a coordinated provincial direction in the mental retardation field. The changing social conscience, the ever-changing technologies, and changing expectations for more acceptance of responsibility for services to citizens with special needs, must be adequately addressed. Many stakeholders in the private sector see the present direction as a disincentive for some developmental programming and more community based options. The existing provincial directions, as perceived by some stakeholders, is the perpetuation of institutionally based residential care in its present form at the expense of developing an adequate continuum of services in the community.[20]

Further to this,

> [o]organizations are competing for the moral, physical and financial aid of the general public and the purse strings of government.[21]

The Task Force report is vague as to who the stakeholders may be concerning shifts in service delivery but it is obvious that interested stakeholders would include nursing unions, professionals, and certain communities, as well as the ACLs.

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[20] Task Force on Mental Retardation, Challenges for Today, Opportunities for Tomorrow, Report to the Minister of Community Services and Corrections, (Manitoba, 1982), p. 125.

[21] Ibid., p. 126.

The three main issues which the government will face concerning the phasing out of large institutions in Manitoba are outlined by a Manitoba mental health report in 1983:

1. the potential negative economic impact on the community in which the hospital is located and on the institution's staff;
2. potential difficulties in implementing effective community-based programming because transferred staff lack appropriate training;
3. lack of preparation of host communities.[22]

Therefore there are a number of stakeholders who may object to the community move.

In attempting to provide a new direction in the area of unemployment (which would be under the umbrella of community living) Robert McInnes, the past director of ARC Industries, cites the obstacles towards creating an affirmative industrial ideology. The Board of Directors of ARC use J. Durand and L. Durand's definition: "a non-profit organization whose primary goal is to provide employment to persons who are handicapped."[23] This ideology, because it differs from previous service modes, meets resistance from those who maintain vested interests in the established system. McInnes cites the following groups:

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[22] Canadian Mental Health Association - Manitoba Division, et al, Critical Issues in Mental Health: Community Based Mental Health Services, (Winnipeg, 1983).

[23] As cited by Robert J. McInnes, Affirmative Industries: A Silk Purse From a Sow's Ear?, Report to the CCRW National Conference, Montreal, 1984, p. 5.

1. parents
2. staff
3. the community
4. the rehabilitation system
5. some disabled people themselves[24]

McInnes is not clear on the similarity or distinctness of the groups' interest nor the intensity in which they hold their positions. One can say however that together these groups have obstructed the establishment of the new ideology.

Further to the above mentioned problems cited by McInnes is the threat of government restraint. The demand for resources is increasing and such observers as Burton Gummer raise the following point:

> Organizational domain...will be determined by an increasing concern with sheer survival...[25]

The demand for resources in Canada has paralleled the increases in resources since the Second World War, however there is nothing to indicate that these resources will continue to meet the demand. One federal report stated in 1980:

> In future, the spread between the continued rising consumer demand and the relative decline in resource availability will widen. Inflationary

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[24] Ibid., pp. 8 - 9.

[25] Burton Gummer, "...And Now For The Bad News: Organizational and Managerial Behavior Under Conditions of Declining Resources", Administration in Social Work, Vol. 4, No. 3, Fall, 1980, p. 93.

> conditions will exacerbate the problem.[26] This will have major implications for the human services field in general and help for disabled persons in particular.[27]

In a National Institute on Mental Retardation (NIMR) publication Pelletier and Richler support the federal report's statement concerning the Canadian trend:

> ___where money will gradually be less available to human services, competent management of highly cost-efficient and cost-beneficial services will become even more critical.[28]

As Canada emulates the progress made in the United States in relation to mentally retarded people it may also emulate a regression for those groups which seek innovative human service delivery. The concerns raised in Canada about the decline in social welfare resources are also to be found in other countries. Gregory O'Brian writes concerning social work in the United States:

> The first, and perhaps the most painful, challenge with which the social worker will be dealing in the 1980s is the discrepancy between the available resources and public expectations... In the 1960s Americans assumed that our seemingly unlimited resources coupled with American ingenuity could solve any problem. Today we find our resources limited... Human resources seem harder and harder to marshall for the common good as each

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[26] The inflationary problem appears to have declined in the past few years.

[27] Health and Welfare Canada, Disabled Persons in Canada, (Ottawa, 1980), p. 142.

[28] Jacques Pelletier and Diane Richler, Major Issues in Community Living for Mentally Handicapped Persons: Reflections on the Canadian Experience, (Downsview, Ont., 1982), p. 13.

individual group seeks its own best interest.[29]

Organizations other than the ACLs do have an impact at times. Although the ACLs would hesitate to form coalitions with such bodies as unions of professional workers or other institutional stakeholders, benefits accrue when such bodies react similarly to government policies, especially those pertaining to cut-backs in spending. For example, in a report of a client's injury at the Portage institution the Government's Employee's Association complained of staff cuts causing problems in adequate supervision.[30] Although the union would favour an expansion of staff for Portage (which would be of concern to the ACLs who worry about the expansion of an institutions's base) it also does have something to say about a declining quality of care for those in the institution (with which the ACLs would agree).

There is a tendency to group various interests into two distinct camps. Professionals are often seen as representing the institutions while parents and consumers represent the push for integration, that is, community living. This is not always the case, for example, in a 1964 statement to a federal-provincial conference the Canadian Psychiatric Association stated:

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[29] Gregory O'Brian, from Social Work and Health Care Policy, D. Lum, ed., (New Jersey, 1982), p. IX.

[30] The Winnipeg Free Press, 30 Oct. 1985.

> ___treatment and service programs must concern themselves with the emotional and social development of the retarded individual and...this can best be accomplished when the retarded child is being cared for in his home.[31]

## 3.7 THE POSITION OF THE ACL

While the government may seek to withdraw support for services and programmes endorsed by the interest groups it also realizes the benefits of existing organizations. As one person in the Manitoba government saw it, there has been a change in relations between the ACLs and the government in the past two years. She described it as previously being a situation of "them and us" and that it was now a "real partnership."[32] The shift was ascribed to a change in attitude of the executive of the Department of Community Services and to the increased willingness of organizations to respond.

The apparent strength of position which the ACLs hold in Manitoba and their perceived role as the major representative of the mentally retarded population is quite different from what happens in other parts of Canada concerning disabled people. For example, the Canadian Council of Rehabilitation and Work (CCRW),[33] largely represents sheltered work-

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[31] Submission by the Canadian Psychiatric Association to the Federal-Provincial Conference on Mental Retardation, October, 1964, p. 3.

[32] Personal communication, 9 July, 1985.

[33] Previously titled the Canadian Council of Rehabilitation

shops and their management while making statements to the government (such as the Judge Abella Report) as represen-tives of disabled unemployed people. The Coalition of Provincial Organizations of the Handicapped (COPOH) maintains a distance from CCRW due to the perception that their interests are in opposition to each other. Further to this confusion, both organizations receive Health and Welfare Canada funding and CCRW would be hesitant to form any type of coalition for fear that government would see this as a duplication of service.[34]

Another point of distinction between the federal disabled person's agencies and the Manitoba ACLs is a high level of confusion concerning what is progressive for disabled people. In addition, groups such as COPOH have questioned whether some of the other organizations are advocating change or the maintenance of the _status quo_. [35] Meanwhile it is clear that the ACLs are calling for a change in structures and types of service delivery. There is no confusion arising from this sector in Manitoba.

In a resolution adopted at the Annual General Meeting of the CAMR - Manitoba Division in 1984 the following statement was made:

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Workshops.

[34] Personal communication, Summer, 1983.

[35] Personal communication, Summer, 1983.

> ___[the] Manitoba Council of Rehabilitation Workshops Inc....during the course of the past two years in particular, has shown an inability to come to grips with the issues of financing, programs, policy, direction, etc. that have, and will continue to plague sheltered workshops, vocational training centres and occupational activity centres...[36]

The ACLs will speak on all aspects of a mentally retarded person's life even where other organizations have a mandate to represent specific aspects, such as the MCRW.

## 3.8 THE LEGITIMATE POSITION

In their search for change the ACLs face the choice of incremental or innovative change. Doman Lum draws the distinction between these two types:

> Incremental change involves minor adjustment to present policy, while innovative change results in unpredictable consequences.[37]

In changing the attitudinal paradigm, the ACLs are asking politicians and bureaucrats to take risks. While it is true that the environment is fertile for policy shifts, nevertheless it means that the ACL success is more difficult to obtain when compared with earlier demands which called for increases in funding for an already implemented system.

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[36] CAMR - Manitoba Division, Minutes of the 31st Annual General Meeting, 12 May 1984.

[37] Doman Lum, "Health Policymaking Framework", Social Work and Health Care Policy, op. cit., p. 27.

Interest groups can choose two directions in acting: illegitimate and legitimate activity. In Manitoba the successful group representing mentally retarded individuals or any other population has remained in the area of legitimate activity; that is, peaceful and legal pressuring.

Those interviewed in government positions stated that the ACLs act legitimately and support a cause which is deemed legitimate. This should however be qualified by the fact that the legitimacy is within a social welfare context. When asked why there was success occurring, one administrator responded by saying that both the parents and groups have "rightness" on their side and they are speaking to an issue which is considered humanitarian; that is, changing the present system in order to better serve those who are vulnerable.[38]

Another worker stated that the legitimacy element (which he categorized as being part of a "motherhood" issue) has been combined with a change in attitude in both the media and the general community. Events such as the Special Olympics have promoted this change. It was also stated that while the handicapped population was once feared or hidden away (due to fear and social embarrassment) they are seen as blameless for their disability. There are other low status segments of society, such as jail inmates, who have not received an equivalent level of public sympathy largely due to

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[38] Personal communication, 3 July, 1985.

a lack of social legitimacy.[39]

Although the ACLs are adamant that they are no longer parent organizations (stating they represent mentally retarded people not the parents of mentally retarded people) there is still the social perception that these organization are parent organizations. Therefore some of the legitimacy which is seen may be due to a misunderstanding.

When one looks from the understanding that it is the parents who represent the mentally retarded person through the organizations, members in the civil service have stated that due to the social image of the fragility and vulnerability of mentally retarded people there is something "right about parents representing them."[40]

The major area of partnership or convergence has been in the area of community living. There is a realization in the government that it must move in this direction as public demands and attitudes increase in favour of the mentally retarded person. The major activity of the Manitoba and Winnipeg ACL divisions has been the development of new community systems, that is, in the development of a living continuum.

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[39] Personal communication, 9 July 1985.

[40] Personal communication, 3 July 1985.

In pushing for new systems of community services and supports, the organizations have realized that the provincial government will not be the initiator. As do other interest groups in different fields, the interest group provides the ideas and proof of the value of changing policy direction. The government to date has held the purse strings while at present the organizations as a group resource hold the community support. In Table 3 the contrasting characteristics between government bureaucracies and groups such as the ACLs is drawn by Morton Warner. It is clear that the ACLs in Manitoba had much going against them in trying to converge with the government. One sign of its apparent success has been in the establishment of the "Welcome Home Project". This programme is aimed at returning a minimum of 220 people to the community from Manitoba institutions by 1987;

> The question of how to stimulate the development of community alternatives for people has not been a simple one. Government cannot easily bring about community services by its own initiative alone.[41]

Both government administrators and the group organizers believe that through cooperation they can unite their different resources. The government provides the money, support, and services while the group provides the initiative and community support.

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[41] The Welcome Home Project: Report of the National Comserv Panel Review, December, 1984, p. 3.

TABLE 3

THE CONTRASTING CHARACTERISTICS OF BUREAUCRACIES AND GOVERNMENT PARTICIPATION GROUPS

| Bureaucracies | | Community Participation Groups |
|---|---|---|
| Central Technical Purity | ------ | Local Vested Interest Participation |
| Bureaucratic Authority | ------ | Community Authority |
| Concentration of the Means of Administration | ------ | Community (Democratic [?]) Decision-Making |
| The Use of Technical Expertise | ------ | The Use of Local Knowledge |
| Social Responsibility (Universalistic) | ------ | Social Responsibility (Particularistic) |
| Slow Change | ------ | Fast Change |

(Source: Morton Warner, "The Rise of Community Participation: Its Impact on Health Professionals and Health Bureaucracy", Health and Canadian Society: Sociological Perspectives, op. cit., p. 364.)

## 3.9 PARTY POLITICS

In being politically active the group representing mentally retarded people in Manitoba stays largely outside party politics; however it maintains its link within the political system in its dealings with both government members and administrators. Although the New Democratic Party in Manitoba and its supporters feel that they have provided the fertile ground for what the ACLs see as progress this has not been proven as their doing alone. In fact, Nicola Schaefer in her book states how parents were disappointed with an earlier NDP government when they came to power over

a decade ago.[42]

While many short term benefits may be obtained through a direct attempt to affect party policy, for example, through policy conventions and constituency meetings, many expressed concern about being tied to a party which will not always be in power. There is however a slight sign that electoral politics may affect mental retardation policy. In the 1986 Manitoba Provincial Election the Progressive Conservative Party Leader, Gary Filmon, expressed support for construction plans for recreation facilities at the Portage institution. This would run counter to New Democratic plans concerning the institution. Although the ACLs have been quiet on the issue due to not wanting to be against recreation facilities for those who are institutionalized[43] there have been complaints by individual parents.[44] In spite of this the ACLs state that the PC Party will recognize them as innovators and will not dismantle such programmes as Welcome Home.[45] The reluctance to become involved in party issues and pressuring comes from the simple realization that the bureaucracy and not the party apparatus is the major contributor to government policy formulation and application.[46]

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[42] Nicola Schaefer, Does She Know She's There?, (Don Mills, Ontario, 1982), p. 231.

[43] Personal communication, 27 Feb. 1986.

[44] As expressed in a letter to the Winnipeg Free Press, 21 Feb. 1986.

[45] Personal communication, 27 Feb 1986.

## 3.10 SUMMATION

B. Guy Peters' concept of the symbiotic relationship between the interest group which is effective and the government, known as mutualism, is recognized by the ACLs in Manitoba. Both the government and the ACLs have resources which only they can provide for each other. The unique and valuable position of the Winnipeg ACL is stated by its President, Bob Manwaring:

> No other private or government agency is in a position to do the kind of "leading edge" development that the field requires: service providers are locked into ongoing service delivery responsibilities; government tends to follow, rather than lead, the development of innovative services; virtually all government funding flows into the operation of traditional services. The need for CAMR Winnipeg's services has been recently underlined by the Province's continued requests for involvement and technical support by the Branch, by similar requests from service providers, and by the sustained demand on the part of parents and advocates for assistance in planning, developing and evaluating services in the community.[47]

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[46] As Paltiel states: "The broadening role and scope of government public services at all levels has narrowed the sphere of party politics." (op. cit., p. 202.)

[47] Letter to the United Way from CAMR - Winnipeg, March, 1985.

# Chapter IV

## THE PARENT MOVEMENT AS ORGANIZATIONAL REPRESENTATIVE

### 4.1 WESTERN DEVELOPMENTS

As seen in the last chapter, the advent of the group representing mentally retarded people must be seen within the increasing trend of interest group activity following the Second World War. The progress made is best summed up by Harvey Simmons in his account of the history of services in Ontario:

> Unlike the organized working class, they have never made their own history, and it is only because they have been represented by interest groups since 1945, that their presence has been felt on the political scene.[1]

There can be no doubt that the mentally retarded person's low level of social status decreases the probability of having an effective impact on the political system. William Mishler states that in Canada,

> ___as elsewhere, the higher a citizen's social position the more likely the citizen will be to participate in politics.[2]

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[1] Harvey G. Simmons, From Asylum to Welfare, (Downsview, Ont., 1982), p. 261.

[2] William Mishler, "Political Participation and Democracy", Canadian Politics in the 1980's, (Toronto, 1981), p. 132.

Since mentally retarded people have low social status, parents and professionals, as well as any other interested citizens, act in their stead, as their advocates. What occurs therefore is a substitute system. In a sense, mentally retarded people borrow the social status of their advocates in a process of social "piggy-backing".

Two things concerning activity on behalf of mentally retarded people come into play when describing the historical patterns of these interest groups: a) participation and efficacy and b) the sense of necessity. Simmons writes that in Ontario between the years 1900 and 1920 the issues pertaining to mental retardation were virtually invisible within the political system. (By invisible it is meant that from a consumeristic standpoint and statements of policy by the government little was there.) Interest groups were active but the issues largely concerned social deviance. Also, these early twentieth century groups consisted of "socio-economic elites" such as doctors and professionals.[3]

Prior to the advent of the strong parent organization, which was the key factor in the development of the representation of mentally retarded people, the stigma of mental retardation caused the isolation of the afflicted population. In addition, the social weakness of the group exacerbated the degree of isolation. McLaughlin writes:

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[3] Simmons, op. cit., pp. 138 - 139.

> It was not very long ago that it was a great stigma to have a mentally retarded child. The medical profession looked upon the birth of a mentally retarded infant as a great tragedy from which the family needed protection. Typical advice stressed preventing mothers from seeing their children and early institutionalization. If kept, such children were later institutionalized or hidden away in shame. Mentally retarded persons were kept in vast, remote, dehumanizing warehouses where inferior care was provided in overcrowded conditions.[4]

In the 1950s the parent organization aimed itself mainly at overcoming the problem of isolation and stigma. Gunner and Rosemary Dybwad write:

> Mutual aid and self-help played an important role in the beginning of the movement initiated in the 1950s by parents of retarded children.[5]

From mutual aid and self-help arose a formal service delivery structure. The associations thus became primarily concerned with private service delivery. Services such as sheltered workshops and special schools were implemented.[6]

Wolf Wolfensberger comments that there is an established developmental pattern for these groups:

> VAs [voluntary associations - interest groups] in the area of human affliction are typically started by people who see an urgent unmet need, gross rejection and/or denial of rights, abuse, or lack of services, and who call on others to band together

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[4] Paul McLaughlin, Guardianship of the Person, (Downsview, Ont., 1979), p. 12.

[5] Gunner and Rosemary Dybwad, Severe Mental Retardation, (Downsview, Ont., 1982), p. 68.

[6] The parent movement and its growth follow similar patterns throughout the western world. Therefore, writings not originating in Manitoba are still useful for an understanding of developments in this province.

> to address this need and/or challenge society to address it.[7]

He states that they are usually parents of handicapped children and the organization starts out by offering developmental programming.

The second stage occurs when the organization seeks to find other bodies that will

> ___initiate and operate services, and/or take over the governance of at least some of the services started by the association.[8]

The move is to obtain services as opposed to providing services. Dybwad and Dybwad state that from the first stage, the 1950s, to the second stage, typical of the 1960s, there was a realization that being a major service agency has limitations:

> ___some of the associations had become major service agencies, owning extensive buildings and employing large staffs. It was at that point that some leaders in the parent movement recognized that what looked like a great success could become a great danger. Why should parents of retarded children have to become service providers when this was not necessary for parents of other children? From the ensuing discussions a leader in the parent movement coined the slogan: "Our task is to obtain, not to provide services".[9]

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[7] Wolf Wolfensberger, Voluntary Associations on Behalf of Societally Devalued and/or Handicapped People, (Downsview, Ont., 1984), p. 20.

[8] Ibid.

[9] Dybwad and Dybwad, op. cit., p. 80.

Concerning the United States, Roos points out that at anytime one is able to find groups at different stages at different places. Nevertheless in spite of differences throughout North America there are clear indications, as will be shown in the next section, that the present trends found in representational organizations are a western phenomenon as opposed to one which belongs merely to Manitoba. Variance does occur in Manitoba but this may largely be due to the urban-rural differences.

The third stage described by Wolfensberger occurs when the organization has obtained services for its constituents and devotes all its energy towards "a) self-renewal, and b) what has been called 'change agentry.'"[10] This includes public education, advocacy, and service monitoring.

Wetherow felt that ACL - Winnipeg has gone one step beyond Wolfensberger's third stage by pressing for services for handicapped people which will include non-handicapped persons. An example is found in the latest developments in housing. The establishment of integrated residences, Wetherow claims, increased the degree of permanence available to mentally retarded people.[11]

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[10] Wolfensberger, Voluntary Associations on Behalf of Societally Devalued and/or Handicapped People, op. cit., p. 21.

[11] Personal communication, 9 April 1985.

The beginning of the parent organization was different from other organizations. Philip Roos comments that the groups arose not from the social establishment (such as the professional elite in Ontario in the early part of the century) which supported medical professionals as the controllers of service but as a reaction to the elite;

> ___they developed as a result of what parents perceived as professional neglect.[12]

The fact that the representation of mentally retarded people has been supported largely by parents would explain a tendency in the literature to deal with those who are either children or young adults.[13] The push for community living has been supported by parents who are worried that when they become too old to care for their disabled son or daughter there will not be an alternative to institutional placement.

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[12] Philip Roos, "Advocate Groups", Handbook of Mental Retardation, Matson and Mulick, eds., (New York, 1983), p. 27.

[13] Only one study was found concerning elderly mentally retarded people (Betty Anglin, They Never Asked for Help: A Study of Needs of Elderly Retarded People in Metro Toronto).

## 4.2 THE MANITOBA ORGANIZATIONS

The typical advice of the professionals in the 1950s and 1960s was to physically separate the mentally retarded individual from the family, there was thus a weakening of the only link to persons who had some degree of social status, that is, the parents. Liz Siemens comments on the pressures she felt from the social service delivery system:

> I used to feel apologetic about Brenda's needs, mainly because I was constantly being told that all our problems would be solved if only I would put her in the institution permanently.[14]

Nicola Schaefer, another Winnipeg parent, reflected on her earlier discoveries in the 1960s when she became affiliated with a parents' organization:

> Meeting these parents made me realize several things. First, there were very few kids around as badly handicapped as Cath who were living at home. Second, apart from the meagre physiotherapy service at the children's hospital, there was absolutely nothing going in Winnipeg, and nothing in sight, for such children; except, of course, custodial care, and there was a huge waiting list even for that. Third, nobody in authority thought it was worthwhile trying to do anything at all with our children. My conclusion was that if one was daft enough to keep a child like Catherine one just coped as best one could.[15]

From the above, the problems facing parents can be summarized as follows: 1. there were strong pressures weakening

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[14] Liz Siemens, "Liz and Brenda Siemens", <u>The Positive Path: Profiles of Disabled Manitobans</u>, The Council for Exceptional Children, (Winnipeg, 1981), p. 111.

[15] Nicola Schaefer, <u>Does She Know She's There</u>?, (Don Mills, Ontario, 1982), pp. 53 - 54.

the family unit[16] and 2. a lack of services that would support home care. The ACL involvement with individual cases has brought members into the organization for what may appear as the individual's short-term goals only to find the new member staying and working towards the longer term interests of the organization (such as community living). This follows a trend typical of self-help organizations. In a Toronto study of 19 self-help groups (none related directly to mental retardation) the following was reported:

> The members indicated that on the average they devoted more than eight hours each week to various aspects of groups membership. Further, even those who were members of groups which have been characterized...as involving "Short-Term Crisis Resolution" did not anticipate terminating membership.[17]

The Manitoba Association for Retarded Children (ARC) began in 1951 with six parents of residents who were residing at the Portage La Prairie institution.[18] In the 1950s its role was to provide much needed services for their children.[19] The Winnipeg Association began in 1956 and by 1968 twenty-five other branches (otherwise known as "locals") had been established in Manitoba.[20] At present there are 25 lo-

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[16] See Chapter 2.

[17] Andy Farquharson, "Self-Help Groups: A Health Resource", Health and Canadian Society: Sociological Perspectives, Coburn, et al, (Toronto, 1981), p. 315.

[18] Association for Retarded Children in Greater Winnipeg, Annual Report: 1968, p. 20.

[19] Ibid., pp. 20 - 21.

[20] Ibid., p. 22.

cals in Manitoba.[21] The idea for the Canadian Association arose at a meeting in Winnipeg in 1957 and a formal national organization was created in 1958.[22] At the beginning, the major activities of the Association in Manitoba were in the area of day training classes because, as stated by Christianson,

> As the membership grew, it became apparent that there were more moderately to severely retarded children residing at home than there were in the school [Portage].[23]

By the late 1950s the following activities were performed by ARC in Manitoba:

1. pre-school training classes
2. sheltered workshop training classes
3. adult occupational training activities
4. social, physical, and recreational activities
5. public relations for parents
6. public relations for staff and public
7. encouragement of research in professions.[24]

The late 1950s and the early 1960s saw a national growth of which Manitoba was only one of the participants. For example, in British Columbia the initial seven parent groups of

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[21] Personal communication, 20 April 1986.

[22] Association for Retarded Children in Greater Winnipeg, op. cit., pp. 20 - 21.

[23] John A. Christianson, A Study of the Education of Handicapped Children in Manitoba, (Winnipeg, 1965), p. 17.

[24] Ibid.

the Association which started in 1955 had bloomed to 58 locals by 1964.[25]

Table 4 shows the involvement of the Association for Retarded Children in direct education services for "trainable retardates" in the Canadian provinces for 1962 - 1963. As can be seen, the Manitoba ARC carried the sole burden of direct services in this field, not unlike some of the other provinces. Only in Nova Scotia and to some extent Saskatchewan was a non-ARC school board primarily responsible. The table reveals that ARC in Manitoba was acting in a similar vein in education services when compared to the other provinces. In the 1970s CAMR was still involved in services, although not directly in education, largely through the operation of workshops. In 1972, for example, sixteen workshops in Manitoba were operated under CAMR[26] and as of 1986 twelve locals in rural Manitoba were still operating workshops.[27]

Actual figures pertaining to government education expenditures in the 1980s are unavailable for providing any statement as to whether education expenses are increasing, decreasing, or stabilizing in Manitoba. Aside from pro-

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[25] F. S. Hatcher, A Spectrum of Mental Retardation Services: Province of British Columbia, Government of British Columbia Division of Rehabilitation, 1964, Section D, p. 1.

[26] Manitoba Department of Health and Social Development, Mental Health and Retardation Services: A Review and Preliminary Model, c. 1972, p. 44.

[27] Personal communication, 20 April 1986.

TABLE 4

SPECIAL SCHOOLING JURISDICTIONS (1962 - 1963)

| Province | ARC Classes | ARC Pupils | Regular School Board Classes | Regular School Board Pupils |
|---|---|---|---|---|
| Manitoba | 52 | 525 | -- | -- |
| B.C | 61 | 482 | 30 | 332 |
| Alberta | 43 | 448 | -- | -- |
| Sask. | -- | -- | 20 | 175 |
| Ontario | 310 | 2,497 | -- | -- |
| New Brun. | 22 | 197 | 2 | -- |
| Nova Sco. | -- | -- | 23 | 257 |
| P.E.I. | 6 | 44 | 1 | 10 |
| Totals | 494 | 4,193 | 76 | 802 |

| Province | Special Approved Board Classes | Special Approved Board Pupils | Totals Classes | Totals Pupils |
|---|---|---|---|---|
| Manitoba | -- | -- | 52 | 525 |
| B.C. | -- | -- | 91 | 814 |
| Alberta | -- | -- | 43 | 448 |
| Sask. | 22 | 175 | 42 | 350 |
| Ontario | -- | -- | 310 | 2,497 |
| New Brun. | -- | -- | 24 | 225 |
| Nova Scotia | -- | -- | 23 | 257 |
| P.E.I. | -- | -- | 7 | 54 |
| Totals | 22 | 175 | 592 | 5,170 |

(Source: Christianson, op. cit., p. 24.)

grammes meant for educating those with more severe handicaps in some school divisions, budgets amalgamate the mentally retarded school population with other sectors of society.[28] It is clear that integration has occurred to some extent, in

[28] Personal Communication, 20 May 1986.

that there are no separate education boards, parents seem to be happier, and some schools include both handicapped and non-handicapped children, however more research is needed to show whether or not the mentally retarded child is integrated with non-handicapped children through day-to-day social activity.

The financing of the Manitoba ARC until the mid-1960s came from the following sources:

1. The Department of Health of the Provincial Government
2. Local Municipal Government
3. Fees paid by parents
4. Public donations to local Associations
5. Capital funds raised by service and fraternal organizations.[29]

What is now titled the Association for Community Living was originally the Association for Retarded Children, and more recently, the Canadian Association for the Mentally Retarded. The name change to the ACL has been occurring in the locals throughout Canada in the past two years. Prior to being a group concerned with all mentally retarded people it has focussed on the concerns for mentally retarded children. This shift occurred towards the end of the 1960s. In the 1960s the organization in Winnipeg was titled the Association for Retarded Children in Greater Winnipeg.

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[29] Christianson, op. cit., p. 17.

In the 1960s, integration meant the integration of services for mentally retarded people with other handicapped people. The 1968 Annual CAMR (Winnipeg) meeting is a prime example for apparent signs of group transition. In his report to the Association, J. G. Keil, President of ARC - Winnipeg, discussed integrating services with the Society for Crippled Children and Adults of Manitoba.[30]

In 1968 there were slight indications that the Winnipeg Association was entering into the second stage, that is, seeking to divest itself of service management. It however maintained many other services including a nursery school, an activity centre, and transportation services for clients.[31] Thus, many of the concerns expressed at the time were about service efficiency as well as growth:

> It will be some years before we can expect to reach a plateau. There are some services that are urgently needed by the mentally retarded of our community and their families that we have not yet even started - notably, Community Residences [sic] and Guardianship [sic]. Existing programs require to be expanded yearly.[32]

In spite of the desire to expand operations there were signs that attitudes within the ARCs were changing. The Winnipeg ARC had been responsible for providing educational services up until 1967. Keil in his address to the Winnipeg

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[30] Association for Retarded Children in Greater Winnipeg, op. cit., pp. 2 - 3.

[31] <u>Ibid</u>., pp. 3 - 8.

[32] <u>ibid</u>., p. 5.

ARC stated that with the government taking over the responsibilities of education the associations were to reappraise their situation:

> School classes have more and more been transferred to the public school system across the country, with the result that, at least temporarily, many branches find themselves without any children's services. Also, we now recognize that our retarded adults are in truth adults, and must be recognized and treated as adults. As a result of these facts and this philosophy, last September, at the 1968 Annual Meeting of the Canadian Association [for Retarded Children], the name "Canadian Association for the Mentally Retarded" was adopted.[33]

Once again in the 1980s it is apparent that the associations across the country are in a period of transition. With the recent changing of the name, from the Canadian Association for the Mentally Retarded to the Association for Community Living, getting mentally retarded people into the community is the priority. In its 1985 statement of mission the Winnipeg Division stated:

> The aim of CAMR Winnipeg[34] is to initiate and support valued roles, experiences and relationships for people who are mentally retarded, and to assist the community in becoming an environment in which each person will experience maximum personal growth and enjoyment of life.[35]

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[33] Ibid., p. 8.

[34] This statement was made a few months prior to the name change for the Winnipeg local. The Manitoba Division had already changed its name.

[35] CAMR Winnipeg Branch, United Way Program and Budget Submission, 1986, 1 March 1985, p. 1.

The name change should not be construed as the agent of change but as a result of the changing attitudes within the organizations. The name change should be seen as an attempt by the organization to strengthen its already articulated goals.

According to David Wetherow, Executive Director of ACL - Winnipeg, the Winnipeg organization had been a major service provider but a desire arose from within the organization to change due to the following:

1. The quality of service provided was not at an acceptable level.
2. The organization was losing a lot of money in being a service provider.
3. Those involved with CAMR argued that the group should become advocacy rather than service oriented.[36]

Therefore, the decision arose to change the organization's character into one which could be considered "third stage".[37]

The name change shows the observer that the internal workings of the ACLs maintain an element of self-analysis. This falls into line with what the literature which deals with organizational renewal (that is, development) is calling for; especially such theorists of the advocacy movement as Wolf Wolfensberger.

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[36] Personal communication, 9 April 1985.

[37] Ibid.

The Winnipeg organization sees itself as having a different perspective from the government due to its different nature. The government had, and continues to have, a facility (institutional) approach to serving mentally retarded people by which is meant the provision of institutional and group home services. The Winnipeg group's approach instead pushed for a "supportive natural environment" which would not be based solely on facility services.[38]

In the promotion of the name change from much of the membership there occurred pressures for the addressing of the social stigma problem of the term "mental Retardation" and to move the issues towards the area of community responsibility. Furthermore, the membership within the organization is more willing to listen to mentally retarded people. With the rise of consumerism among the disabled there is now added pressure for associations such as disabled groups and the ACLs to show that they understand the issues facing their constituents. It should be noted that on the national level there was a fair amount of internal conflict concerning the name change. However, it is a sign of merit of the organization that they were able to contain it from the public and show a united front.[39]

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[38] Personal communication, 9 April 1985.

[39] Personal communication, October 1985.

The ACLs now do not consider themselves as a parent movement any longer. At present they are seeking to be more consumer oriented as they move towards more direct representation of the afflicted population and the awareness that more can be obtained when parents act as one part of the organization.[40]

The ACL - Winnipeg Division sees itself in 1986 as providing the following directions as their primary activities:

1. Service development and demonstration
2. Education of the public, members and caregivers
3. Class and individual advocacy.[41]

The major shift in Manitoba, particularly in Winnipeg, is the movement away from the management of major services (such as education) and where servicing is done it is in the area of promoting new forms that will eventually be serviced by the government. This is evident in a statement made by CAMR - Winnipeg President Bob Manwaring,

> ___the innovative nature of CAMR's projects has had a significant impact on Government funding and design for all services. Project Welcome Home, which will infuse millions of dollars into new community services over the next three years, was partly the result of demonstration and advocacy efforts on the part of CAMR Winnipeg over the past five years. Strategic use of core resources has meant that CAMR Winnipeg has not had to become a massive "service monolith"...[42]

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[40] Personal communication, 30 September 1985.

[41] CAMR - Winnipeg Branch, "United Way Program and Budget Submission, 1986", 1 March 1985.

# Chapter V

## DEINSTITUTIONALIZATION: THE SEARCH TO INTEGRATE MENTALLY RETARDED PEOPLE

> The same disabling condition between two different people does not predetermine that their medical social, vocational or recreational needs will be similar.[1]

### 5.1 PRELIMINARY

Much of the search for community living has contained attempts for deinstitutionalization. The term "deinstitutionalization" is used within the context used by David Mechanic:

> The term deinstitutionalization as it is most commonly used describes the movement of patient populations from large public institutions to other locations and the substitution of community treatment or short-term institutional care for long-term custody.[2]

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[42] Bob Manwaring, letter to United Way of Winnipeg, 1 March 1985.

[1] Alberta Committee of Action Groups of the Disabled, The Disabled Consumer Movement in Alberta, (Alberta, 1981), p. 28.

[2] David Mechanic, Future Issues in Health Care: Social Policy and the Rationing of Medical Services, (New York, 1979), p. 66.

In the United States there have been several court cases pertaining to the right of an individual to live in the community. Henry Beyer, concerning American litigation in the field of mental retardation, states:

> One right most Americans would probably support, at least in the abstract, is that of a citizen to live in the neighborhood of his or her choice, economic considerations permitting. A significant amount of litigation of the past decade has been devoted to converting that moral right into a legal right for mentally retarded citizens, in particular for individuals attempting to move from large institutions into the community.[3]

A review of the literature reveals that Americans have long been aware of the horrors which have occurred within institutional settings. An American report on behaviour modification, for example, commented on the application of aversive methods in institutions:

> The major reasons for challenging these techniques are that they are often punitive in nature...outrageous abuses (electric dog training collars, shackles, spending the night in a graveyard, etc.) have occurred under the guise of behaviour modification...[4]

Institutions have traditionally been placed in rural settings. There are many reasons for this. First, it is easier to acquire land for such operations; second, it may be placed in an area which needs to have employment boosted, hence political considerations are involved. Third, it has

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[3] Henry A Beyer, "Litigation with the Mentally Retarded", Handbook of Mental Retardation, Matson and Mulick, eds., (New York, 1983), p. 88.

[4] Seaside Education Associates, Behaviour Modification and the Law, (Massachusetts, circa 1975), p. 8.

been a way of isolating the mentally retarded population from the rest of the "normal" population. As isolation was increased so too did the risk for mentally retarded people. This was recognized by concerned individuals, especially parents who saw that their children had or bore signs of abuse, such as abnormal behaviour and scars.

## 5.2 THE INSTITUTION AS SYMBOL OF PAST MODELS

The institution was and remains the symbol of the medical model in human service delivery for disabled people. This model provides few expectations of a 'normal' life for retarded people. As one American analyst writes:

> The sick role is intended to be a temporary one. But for the long-term or permanently disabled person there is no immediate recovery in the sense of being restored...[5]

Two major historical models are found in relation to mentally retarded people, the medical and segregational. The two are often connected, especially under the umbrella of custodial care, that is, both orders of care contain a high level of supervision for a disabled person.

Even those who view the scene from within the medical model realize that limitations exist. Mechanic states:

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[5] Gerben DeJong, "Independent Living: From Social Movement to Analytic Paradigm", Archives of Physical Medicine and Rehabilitation, Vol. 60, October 1979, pp. 440 - 441.

> Our medical-care system is primarily organized around the treatment of acute episodic illness, and thus we have done badly in planning for longitudinal care for those with long-term illness...[6]

Due to this general fault the disabled population has suffered. Commenting on the results of the neglect in long-term care to develop proper socializing aspects, Mechanic writes:

> There is nothing more destructive to the elderly, the mental patient, the retarded, or the physically handicapped than to remain inactive, uninvolved, and totally dependent on program personnel. It contributes to diminished levels of coping, loss of affect, and the development of an apathy syndrome.[7]

## 5.3 IDENTIFICATION AND SEGREGATION

In the shift of paradigms, that is, custodial care to community living, there is a tendency in the literature to deal in absolutes. The observer is often left with the belief that all mentally retarded people were incarcerated. Harvey Simmons, concerning the history of mental retardation services in Ontario, writes:

> [t]oo often historians have implied that the late nineteenth and early twentieth century was completely dominated by the custodial movement and by custodial institutions, and that the movement toward community care only began after the Second World War. In fact, those associated with mental retardation policy always tried to distinguish between two groups of mentally retarded people:

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[6] Mechanic, op. cit., p. 52.

[7] *Ibid.*, pp. 53 - 54.

> those who needed institutional care because they were unable to cope with life in the community, or because they were a social menace; and those mentally retarded people who could be educated or trained to take their place in the community.[8]

While Simmons may be right in the sense that many did remain in the community, the literature concerning mental retardation prior to the 1960s is based on a custodial perspective. The introduction of the I.Q. test at the beginning of the century was used in order to weed out those who did exist in the community who may not have otherwise been noticed. The adaptability of the individual within the community was not the primary consideration but rather the identification of the mental handicap. Mental retardation was the basis for institutionalization. It is for this reason that the parent organizations formed to support mentally retarded people, not just those who could not adapt to the community.

The Manitoba institutional structure represents the old order of care for mentally retarded people. The main symbol of Manitoba institutionalization is the Portage School for Retardates (which now has been renamed as the Manitoba Developmental Centre) situated in Portage La Prairie just west of Winnipeg. The Portage School was reported as being "grossly overcrowded" by Clarkson.[9] Furthermore it was stat-

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[8] Harvey G. Simmons, From Asylum to Welfare, (Downsview, Ont., 1982), p. 108.

[9] Dr. J. C. Clarkson, Mental Health and Retardation Services in Manitoba: A Report to the Minister of Health and Social Development, Province of Manitoba, (Manitoba, 1973), p. 10.

ed that it followed the style of the traditional facility:

> As is typical, there are no signs to direct interested persons from the main highway to the School. The design of the three large buildings has been aptly described as medical barracks... The older buildings are in poor condition. They are overcrowded and lack adequate plumbing. There is no provision for privacy while bathing or going to the toilet.[10]

Unlike the United States there is little indication in Manitoba of the problem of moving people from one institution to another in order to improve the institution statistics. The small number of Manitoban institutions prevent this sort of activity regardless of intentions.

The percentage of mentally retarded people placed in institutions across Canada has been smaller than what the public might think. This is not to say that the provinces have avoided institutionalization on purpose but more as a result of expense. Long waiting lists occurred in every province for entering into the institutions and there was overcrowding. The Ontario Association of Children's Aid Societies in the early 1960s called for 57 per cent of those children in their jurisdiction to be institutionalized.[11] Table 5 clearly shows that while the institution in Manitoba was the main means for servicing mentally retarded people relatively few were placed there. The 1972 Manitoba Government report (from which the table is derived) indicates that the per-

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[10] Ibid., pp. 26 - 27.

[11] As cited by the Minister of Health report, A Spectrum of Mental Retardation Services in Ontario, October, 1964, p. 49.

centage of mentally retarded people in institutions was 3.3.[12]

## 5.4 INSTITUTIONALIZATION AND OTHER SECTORS

The move towards community living should not be seen as only occurring in the area of mental retardation. Similar groups such as the elderly, physically disabled, and the mentally ill have been pressuring for this move. Institutional care affected a broad range of socially devalued people and any move to shift from this model has broad implications. Citing the elderly, as an example of a potentially powerful sector for political pressuring in the United States, Mechanic theorizes that there will be an informal coalition formed:

> Over the long range, these pressures will converge to create a climate in which experiments and innovations in financing of care become not only more feasible but also the appropriate political response.[13]

It has become increasingly apparent that this may occur in Manitoba and Canada as a whole. That is, the ACLs appear to be moving into a broader range of representation by becoming concerned with the issue of community living as a priority. Those who head the organizations have stated in

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[12] Manitoba Department of Health and Social Development, Mental Health and Mental Retardation Services: A Review and Preliminary Model, (Winnipeg, 1972), p. 40.

[13] Mechanic, op. cit., p. 55.

TABLE 5

PERSONS IN MANITOBAN INSTITUTIONS BY DEGREE OF RETARDATION (1972)*

| | Usual I.Q. Range | % of Man. Population in Category | Approx. # of Man. Residents in Category | % of Man. Residents Now Likely to be in an institution | # of Man. Residents in each Category Now Likely to be in Portage |
|---|---|---|---|---|---|
| Mildly Retarded | 50-69 | 2.5 | 25,000 | 1.0 | 250 |
| Moderately Retarded | 35-50 | 0.4 | 4,000 | 5.0 | 200 |
| Severely and Profoundly Retarded | 0-34 | 0.1 | 1,000 | 80.0 | 650 |
| Total Retarded | 0-69 | 3.0 | 30,000 | 3.3 | 1,100 |

* Government report category labels are used in this table.

(Source: Manitoba Department of Health and Social Development, Mental Health and Retardation Services: A Review and Preliminary Model, 1972, p. 40.)

interviews that while the mentally retarded population is the focus of concern with the name change there is also the change in direction since other sectors will also be represented insofar as they are without community support. This has been apparent also in the submission made to the City of Winnipeg Act Review Committee in 1984 which was from a "co-

alition of private non-profit agencies concerned with an acceptable quality of life for disabled persons and their living arrangements in the community."[14] This group has comprised Childrens' advocacy groups, CAMR, the Canadian Mental Health Association, and many other sectors of Winnipeg's society.

## 5.5 THE FINANCING OF TWO MODELS

In the United States between 1972 and 1982 there was a growth of 900 per cent of non-institutional spaces available.[15] In Canada the shift has not been as dramatic, yet, as stated earlier, it is growing in relation to the United States. McWhorter and Kappel state:

> Canada does have large institutions. In general, Canadians have institutionalized their fellow citizens about as frequently as our neighbours to the south. Historically, Canadian trends in human services often follow closely behind U.S. trends. If the pattern holds, and there are strong and public indications that it will, large scale deinstitutionalization efforts are not far in the future.[16]

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[14] Letter from Chairperson of Coalition, Canadian Mental Health Assoc. - Manitoba to Hon. Muriel Smith, Minister of Community Services and Corrections, 31 Oct. 1984.

[15] McWhorter and Kappel, "Mandate for Quality: Examining the Use of Public Authority to Redesign Mental Retardation Service Systems", The Canadian Journal on Mental Retardation, Vol. 34, No. 3, Summer 1984, p. 3.

[16] Ibid., p. 4.

It was believed a decade ago that the government listens to the cost-cutting argument but now it appears that this very position may undermine deinstitutionalization itself. DeJong comments that in the United States

> [t]he deinstitutionalization movement has been backed by the political argument that institutional care is expensive and that community care will save taxpayers money. Proof of this argument has been hard to establish, especially when studies overlook the present tendency of institutions to increase utilization to meet capacity.[17]

Furthermore, the money saving argument is

> ___beginning to wear thin with representatives of the tax paying public who have not witnessed any significant decrease in human service expenditures.[18]

A reason for the failure of governments (including that of Manitoba) to decrease costs is that instead of working with the previous single system of custodial care they are now working with a two-fold system; the custodial and community system. Pelletier and Richler comment:

> At present we Canadians are supporting two expensive systems: the institutional system and the community service system. We cannot go on living with the two, both for financial and moral reasons.[19]

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[17] DeJong, op. cit., p. 441.

[18] Ibid.

[19] Jacques Pelletier and Diane Richler, Major Issues in Community Living for Mentally Handicapped Persons: Reflections on the Canadian Experience, (Downsview, Ont., 1982), p. 29.

Table 6 shows that Manitoba has maintained a fairly stable level of spending in both institutional and community services for mentally retarded people. There is no indication that it is about to jump completely into the area of community services through the abandonment of institutions. A 1984 policy statement by Hon. Muriel Smith, Minister of Community Services, does not call for the closing of the Portage institution but the reduction of its population by 220 by 1987 and the enhancement of

> ___the quality of life for the mentally handicapped who must still live in an institutional setting.[20]

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[20] Hon. Muriel Smith, "Policy Statement: Services for the Mentally Handicapped in Manitoba", CAMR - Manitoba Annual Meeting, 11 May 1984.

TABLE 6

COMMUNITY SERVICES AND CORRECTIONS (SELECTED EXPENDITURES)

Community Mental Retardation: Administrative, including programme and funding of services, care, and accommodation for persons living in the community.

| | 31st March 1983 (Actual) | 31st March 1984 (Actual) | 31st March 1985 (Approved) |
|---|---|---|---|
| Salaries | $258,800 | $240,400 | $240,100 |
| Other Expenditures | $ 51,500 | $ 46,600 | $ 49,200 |
| Professional Training | $ 25,400 | $ 25,400 | $ 25,400 |
| Financial Assistance (clients) | $3,388,700 | $3,417,800 | $4,042,3000 |
| External Agencies | $352,800 | $225,200 | $226,700 |
| Total | $4,077,200 | $3,955,400 | $$4,583,700 |

Institutional Mental Retardation: Provides institutional care for the mentally retarded at the Manitoba School in Portage La Prairie (MDC), Pelican Lake Training Centre in Ninette, and the St. Amant Centre in Winnipeg.

| | 31st March 1983 (Actual) | 31st March 1984 (Actual) | 31st March 1985 (Approved) |
|---|---|---|---|
| Salaries | $14,329,100 | $17,258,100 | $17,064,100 |
| Other Expenditures | $2,518,200 | $2,358,300 | $2,420,500 |
| Professional Training | $140,000 | $140,000 | $140,000 |
| External Agencies | $10,715,300 | $11,708,500 | $12,074,200 |
| Total | $27,702,600 | $31,464,900 | $31,698,800 |

Rehabilitation Services to the Disabled: Provides rehabilitation services and assistance to the physically and mentally disabled.

| | 31st March 1983 (Actual) | 31st March 1984 (Actual) | 31st March 1985 (Approved) |
|---|---|---|---|
| Salaries | $271,500 | $242,100 | $245,700 |
| Other Expenditures | $108,000 | $28,400 | $79,800 |
| Financial Assistance (clients) | $3,435,700 | $3,897,600 | $4,176,600 |
| External Agencies | $5,884,100 | $6,583,100 | $6,489,800 |
| Total | $9,699,300 | $10,751,200 | $10,991,900 |

(Source: Government of Manitoba Approved Budgets, 1983 - 1985.)

## 5.6 THE DEGREE OF GOVERNMENT COMMITMENT

Not only has the institutional system isolated the person who is mentally retarded, both geographically and socially, it has also caused the isolation to affect the victim to the point of being unable to feel the power to climb socially; the effect is thus internalized. This is one of the reasons that the consumer movement,[21] that is, the mentally retarded people themselves, in the ACLs, has progressed more slowly than in disabled organizations in general. The lack of confidence in representing one's own interests has thus been hampered.

In the trend towards deinstitutionalization, Canada has followed the lead of the United States. While Canada has seen fewer cases of litigation in this area, its mentally retarded population has been moving gradually towards the community. An article in The Canadian Journal on Mental Retardation summarized this trend in Canada and the obstacles involved. It states:

> At this point in time, three facts are very clear:
>
> 1. The era of large-scale deinstitutionalization is fast arriving in Canada;
> 2. such a process requires a strong structural framework of community systems if it is going to improve the life chances of people with handicaps; and

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[21] The consumer movement in the literature dealing with disabled persons is understood as the interest group behaviour which is conducted only by the disabled people themselves (thus no use of advocates).

3. the current structural framework of community systems is weak and unlikely to be able to support large-scale efforts unless systematic and collaborative action is taken.[22]

While the ACL is in a period of transition the government rhetoric would have the public believe that it too wants to see institutionalism as an issue of the past, that is, that community living is the new central driving force for government policy. However, such statements as "there will always be a need for institutions for some mentally retarded people" still occur and appear as excuses for the continued use of the institutions.

Two examples from the media in 1985 support a claim that the move to the community is not occurring quickly enough for many and remains an issue both within the nation and Manitoba. A recent inquiry in Montreal concerning deaths in the Riviere-des-Prairies institution has brought to light the continuing dilemma. This will, according to the Canadian Press,

> ___likely spark a new public debate about what goes on inside mental institutions.[23]

In defence of the above mentioned institution, Dr. Augustin Roy, head of the Quebec Corporation of Professional Physicians, is quoted as saying:

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[22] Alan McWhorter and Bruce Kappel, op. cit., pp. 6 - 7.

[23] The Winnipeg Free Press, (CP), 22 July 1985.

> If you investigated...you could find similar incidents in all hospitals, even in the better ones. It's not surprising that there would be isolated incidents in those hospitals because the incidents are related to the very serious nature of the patients who are there. They can't go anywhere else. That's why those hospitals exist.[24]

While Clarkson reported overcrowding in Manitoba's Portage School and the response from the government indicates that it is a problem of the past nevertheless there are still reports of overcrowding in the media. Headlines such as "Patients Treated 'Like Cattle'" still occur in Winnipeg newspapers.[25] Clearly the issue of institutionalization is not an issue of the past in Canada nor in Manitoba.

The government in Manitoba has been trying in the past decade to create an image that it is returning the mentally retarded to the community. Clarkson in 1972 reported that from 1966 to 1972 the Portage institution's population had remained constant at approximately 1200.[26]

A Manitoba Government Health and Social Development report in 1975 stated that its intention was to reduce the Portage institution's population to 600 by 1980.[27] The re-

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[24] Ibid.

[25] The Winnipeg Sun, 26 July 1985.

[26] While data from the end of 1984 shows that Manitoba's largest institution has decreased its population since the early 1970s the decrease has not been significant nor consistent.

[27] Manitoba Department of Health and Social Development, Mental Retardation Programs in Manitoba, (Manitoba, Feb. 1975), p. 7.

port stated that this was to be in accordance with a new principle which was to "emphasize the assimilation of the mentally retarded into the mainstream of society."[28] indicating that the government was adopting attitudes in agreement with community living standards. The developments which have actually occurred are to be found in Table 7 [29]

TABLE 7

Manitoba School for Retardates (Manitoba Developmental Centre) - Populations

In-Patients at 31 December

| 1979 | 1980 | 1981 | 1982 | 1983 | 1984 |
|---|---|---|---|---|---|
| 854 | 829 | 832 | 830 | 797 | 774 |

Total Under Treatment

| 1979 | 1980 | 1981 | 1982 | 1983 | 1984 |
|---|---|---|---|---|---|
| 964 | 919 | 904 | 884 | 897 | 850 |

and in the accompanying graph.

From the table it is clear that the 1975 government target was not met. This is made even clearer in the graph below.[30] Table 8 shows that there has been a decrease of

[28] Ibid., p. 5.

[29] Province of Manitoba - Department of Community Services and Corrections, Annual Report: 1981, n.p., and Annual Report: 1984, p. 21.

[30] Ibid., and Department of Health and Social Development,

$365,300 in government budgeting for the Portage institu-

TABLE 8

COMMUNITY SERVICE EXPENDITURES - MDC

| | Year Ending 1985 (March 31st) | Year Ending 1986 (March 31st) (approved est.) |
|---|---|---|
| Manitoba Developmental Centre: | | |
| 1) Salaries | $16,639,100 | $16,263,400 |
| 2) Other Expenditures | $2,420.500 | $2,528,600 |
| 3) Professional Training | $140,000 | $42,300 |
| Total | $19,199,600 | $18,834,300 |

(Source: Government of Manitoba Approved Estimates, 1986.)

tion.

Currently the Provincial Government is sending out the same messages about reducing the in-patient population. In an address given to the CAMR Annual Meeting in 1984, Muriel Smith, the Manitoba Minister of Community Services, stated:

> We cannot overestimate the importance of community living as an opportunity for the mentally handicapped to integrate into society...[31]

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Annual Report: 1976, p. 103, and Department of Health and Department of Community Services and Corrections [Joint Report], Annual Report: 1979, n.p.

[31] Hon. Muriel Smith, "Policy Statement: Services for the Mentally Handicapped in Manitoba", CAMR - Manitoba Annual Meeting, 11 May 1984.

## 5.7 A NEED FOR A COMMUNITY SUPPORT SYSTEM

Although the ACLs and the government are discussing in detail the benefits of deinstitutionalization there are clear examples that dangers come with the territory. There is ample evidence in other parts of North America that mentally retarded people are dumped into the community without proper community support or preparation. Therefore, a negative effect has occurred as a result of this movement. A Canadian Health and Welfare report states:

> Many residents merely moved from one unsatisfactory setting to another one; if anything, this has added to skepticism about the merits of deinstitutionalization.[32]

Toronto's Parkdale area has been highlighted in Canada as an example of an area that many consider as a victim of dumping in the past decade due to poor policy planning in Ontario.[33] There are indications that Manitoba has had to avoid this problem. Administrators at the Portage institution have complained that many who had been placed in the community have returned due to the lack of community supports.[34] Such support would include employment, vocational

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[32] Health and Welfare Canada, Disabled Persons in Canada, (Ottawa, 1980), p. 145.

[33] Western Report, Vol. 1, No. 4, 17 Feb. 1986, p. 51. A personal tour of the Parkdale area (April 1986) revealed many mentally handicapped people walking the streets. All of those seen were walking by themselves along Queen Street and a few were seen causing a mild disturbance.

[34] "Program for Retarded Ready to Roll", The Winnipeg Free Press, 20 Feb. 1985.

preparation, and independent living training. The implementation coordinator of the Welcome Home Project, Ben Lewis (who was previously with the Manitoba Division of CAMR), stated that such supports are needed

> ___so that when people are moved to the community, we will be prepared to meet their needs there, instead of just shipping them back.[35]

It is for this reason that the Welcome Home Project was created.

The lack of community support can be easily found in the area of employment. While the last preference of a disabled person is to be placed in a sheltered workshop there is often not enough room even in there. What has occurred in Canada is that government programmes outside of Health and Welfare's vocational rehabilitation system tend to service only the physically disabled person.

Community living has so far meant partial social acceptance, not full integration into the social structure or the employment market. With a massive unemployment rate among mentally retarded people (the Director of ACL - Winnipeg estimated that 95-plus per cent were unemployed in Manitoba) the sheltered workshops are under severe demands. A report from New Brunswick stated that New Brunswick has "over 600 adults in workshops [and] hundreds more on waiting lists."[36]

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[35] Ibid.

[36] Bruce Kappel, et al, "Vocational Training and Employment: New Brunswick Perspectives", The Canadian Journal on Mental Retardation, Vol. 33, No. 2, Spring 1983, p. 6.

In Winnipeg one worker in the field estimated that there are approximately 600 people who could be serviced in workshops but are not.[37] According to the Canadian Council of Rehabilitation and Work it is estimated that there are 25,000 disabled Canadians in workshops.[38] Of that 25,000, 70 per cent are deemed as "intellectually handicapped" thus giving a population count of 17,500. Therefore if the CAMR statement cited at the beginning of this paper is correct that there are 500,000 mentally retarded Canadians then one is able to deduce that 96.5 per cent of Canadians who are mentally retarded are not to be found in the vocational rehabilitation structure.[39]

## 5.8 A BALANCING ACT

The Manitoba Government has not committed itself completely to the community living model. While those in the ACLs have consistently maintained that the institutions are a monster to be defeated the government has to perform a balancing act. It must contend with quality versus cost and should the institutions be closed down completely there is the added problem of dealing with the unemployment which

[37] Personal communication, Summer 1983.

[38] Canadian Council of Rehabilitation and Work, 1983 Fact Sheet (based on 1980 BIDS data).

[39] Christopher Adams, The Vocational Rehabilitation Workshop, the Disabled Worker, and the Canada Employment and Immigration Commission, CCRW, (unpublished), 1983, p. 36.

would result as well as negative sentiments from the institutional sector. In British Columbia, the government is in conflict with the unions over the ramifications of deinstitutionalization and the dumping of disabled people. The unions have cited the Parkdale case in their defence.[40]

The attempt to balance quality with cost is exhibited in the Manitoba Task Force on Mental Retardation report which called for the saving of "millions of dollars" and a system of quality "second to none in North America."[41] This 1982 Task Force also downplayed the deplorable conditions reported by others concerning the Portage institution. Citing such problems as the "drab appearance" of buildings and "hospital-like atmosphere" only revealed the report's willingness to ignore major faults and not to step on anybody's toes.[42]

While advances are being made by the ACLs and the government joining together in order to give priority to serving the mentally retarded population, the ACLs have toned down some of their idealism. The Welcome Home Project has been a result of many years of lobbying by the associations and now the Manitoba Government has established a formal regional

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[40] The B.C. case may be different due to cuts in social programme spending.

[41] Task Force on Mental Retardation, Challenges for Today, Opportunities for Tomorrow, Report to the Minister of Community Services and Corrections, (Manitoba, 1982), p. II.

[42] Ibid., p. 95.

committee structure which allows for joint planning and encourages consensus formation. This is revealed in a Winnipeg Free Press interview with Ben Lewis:

> "I think we moved towards a consensus on this. What it did was force people to sit and talk and work together."
>
> Admittedly, the plan won't please everyone, such as those who want all institutions shut down. "It won't satisfy people with extreme visions."[43]

Lewis goes on to say that the question of closure of Manitoba's three institutions for mentally retarded people[44] is avoided by both sides in order to get the joint committees working towards establishing community living environments through cooperative action. However, should the government change direction it would once again find itself in opposition to the ACLs.

The ACL position, although now tempered by the Welcome Home Project, is that institutions will have to close both for economic and moral reasons. Should a person need institutionalized care it should not be due to the identification of mental retardation but for reasons that other members of society may have (for example, hospital care for a broken limb). Such care should be generic; that is, a form of service which other members of society would need and use.

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[43] The Winnipeg Free Press, 20 Feb. 1985.

[44] The Manitoba Developmental Centre - Portage, St. Amant Centre - Winnipeg, and the Pelican Lake Training Centre.

The Welcome Home Project, while aimed at returning 220 persons to the community from institutions, is enough to satisfy those in the ACL until 1987. However, once the first stage is completed the ACL will be expecting further developments in community living. The present plan is seen as a launching towards further deinstitutionalization.

In Manitoba the pattern of obstacles on the long road to the financing and approval of long-term community support systems by the government can be seen through the following points set out by David Mechanic:

1. possible costs are unpredictable for providing proper care,
2. major developmental efforts have taken a backseat to the occasional demonstration programme,
3. uncertainties have led the government to take the "path of least resistance", that is, structures which the community is familiar with and that have maintained social legitimacy,
4. hard to replicate in different settings successful demonstration projects due to individual variables (eg., voluntary leadership, enthusiasm, etc.),
5. not a technical problem but one which (as in #4) maintains unpredictability due to unknown factors and difficulty in attempting to coordinate those factors which are known.[45]

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[45] Mechanic, op. cit., p. 55.

It is no wonder that with the above factors the Manitoba Government, when announcing plans towards community living, maintains a guardedness and often, as found in the 1975 report cited earlier, does not live up to its optimistic predictions.

## 5.9 INTER-DEPARTMENTAL RIVALRY?

Unfortunately this study is unable to review one variable which may have a large effect upon the shift from the facility approach to the community living approach. This variable is that of inter-departmental rivalry or even intra-departmental rivalry, which may have occurred or is occurring between the Provincial Department of Health and the Department of Community Services. While there is nothing to validate such a hypothesis at this time in Manitoba concerning policy affecting mentally retarded people, there are signs that it has happened elsewhere. Warner and Pallan in a 1976 study state:

> Directors for Human Resources have appeared quickly to see the advantages that can accrue from integrating health and social services. If anything, a move of this type tends to increase their domain and their bid for authority.[46]

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[46] as cited by Morton Warner, "The Rise of Community Participation: Its Impact on Health Professionals and Health Bureaucracy", Health and Canadian Society: Sociological Perspectives, Coburn, et al, eds., (Toronto (?), 1981), p. 364.

It was found in the interviews that the internal leadership in the Department of Community Services has, over the past three years, shifted towards personnel who are in more agreement with the ACL outlook as opposed to the medical model.

On the national level the Federal Government has refused to return the jurisdiction of services under VRDP back to the Canada Employment and Immigration Commission. Interest groups such as COPOH and CCRW have called for a move arguing that employment training programmes belong in the department which is in charge of employment. These groups view the reluctance for the change as a result of stakeholders in the Department of Health who are trying to maintain their departmental strength and resources.[47]

## 5.10 GROUP HOMES

The government response to the deinstitutionalization movement throughout North America, including Manitoba, has been to establish group homes. Problems have resulted from this when group homes were considered as the final or only solution to the problem. Problems such as overcrowding and poor support occur in group homes. Depersonalization tends to be duplicated in the group setting.

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[47] Personal communication, July 1983.

While services for disabled people often lump this population together there is also the problem of outright neglect.[48] A residential home of quality acceptable to ACL standards would follow the guidelines of the principle of normalization.[49] If the home is run in a suitable manner the person would receive social and personal benefits. Elizabeth Hong in Housing and Non-Traditional Family writes:

> The large aggregate of institutions housing 800 - 2000 inmates fostered unhealthy and asocial behaviour because of impersonal environment...plus isolation by distance, walls or secrecy from the inmate's own natural community. The smaller personal setting of the group home can provide and facilitate healing without the side effects of isolation and stigma.[50]

The most notable problem of group homes has been found in overcrowding. The Western Massachusetts Mental Health Region, for example, established in 1980 a standard that four was the maximum population for a proper group home for those arriving from institutions.[51] In a CAMR statement to a Federal Government Committee, David Vickers (Vice President - CAMR) stated in 1980:

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[48] One example faced by this writer was a young man who would be sent to his day programme from his group home with juice that had fermented.

[49] See chapter 2.

[50] As quoted by NIMR, Community Residences: A Zoning Issue, (Downsview, Ont., 1976), p. 3.

[51] John Lord, "Change Can Happen: 'Lessons from Ontario and Other Places'", Presentation to the Mental Health Association, 27 April 1984, p. 8.

> One of the problems...is the basic funding policies of provincial governments who will fund group homes of eight and ten people, and what we are talking about is a group home, a normal family environment so there is a basic funding problem and if we could talk about funding homes of four or five or even six people, then our argument that we were in fact living in community as a family would be more viable.[52]

In the Province of Manitoba the most significant response has been in the establishment of the Welcome Home Project which is designed to provide a community group home system for those who would otherwise be institutionalized.

In Manitoba, the ACLs and others have been successful in getting the government to alter its policy concerning the group homes and their size. The government has in the past year decided that new homes will have six or less residents.[53] Previously the government had established large homes such as the controversial Oxford Street house in one of Winnipeg's more affluent districts. In discussions concerning residence size those representing the interests of mentally retarded people have not been as cohesive as on other issues.

In the Oxford Street residence case, those in a representative role did not present a clear position to the public concerning the establishment of the eight resident home. At a Community Committee meeting (a Winnipeg civic regional

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[52] CAMR brief to the Special Parliamentary Committee on the Canadian Constitution, Proceedings, 21 Nov. 1980.

[53] Personal communication, 3 July 1985.

committee which reviews such matters as zoning variances) those who appeared voiced their support for both mentally retarded people and the establishment of the large home. In the belief that the government was not going far enough in establishing smaller residential facilities many people involved with CAMR, such as Nicola Schaefer, had negative sentiments. There was an element of confusion in the media and in government circles as to what the people with interests for mentally retarded people wanted. Both Winserv (the company establishing the home) and the CAMR claimed to represent mentally retarded people but did not agree as to what the proper size of home should be. Also many parents supported the home and its projected size. Winserv was able to mobilize the media before anyone else. The company combined the pragmatic rationale that the government was making progressive steps away from the institutions with the "motherhood" status of mental retardation issues. This strategy made all those who attacked the home appear to be prejudiced against disabled people.

The confusion highlights the position which every interest group must face, that is, how to show that the group represents the clientele in question. As the National Council of Welfare has accurately pointed out,

> The group which gets to the media first and which does an effective job of explaining its definition of an issue stands a good chance of having its definition be the one which gets lodged in the

public mind.[54]

Those who were against the larger group home but in favour of community living were caught in a difficult position. They could either support the establishment of the Oxford Street residence but give up certain standards pertaining to size (a bird in the hand...) or remain firm and object to the house. By remaining firm, as they did, the ACLs found themselves supporting those who objected on the grounds of property devaluation and community integrity. The house in the end was established as a residence with the ACLs being invisible in the press on the matter and handcuffed between the two camps.

The subsequent decision by the government to limit the size of future group homes cannot be attributed to the public or to the cohesive position of Manitoba parents. It was in spite of the recent confusion. The lowest point of public and private relations was in 1982 when the representatives of CAMR left the government established joint task force. Now there are clear indications that a basis for consultation and cooperation has been established, especially through such programmes as the Welcome Home Project. Regardless of the confusion, from an ACL standpoint the limit of six residents per home is a large improvement over the 1972 category of a Manitoba group residence which ranged

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[54] National Council of Welfare, Organizing for Social Action: Three Canadian Experiences, (Ottawa, April 1975), p. 73.

from 5 to 20 residents.[55]

## 5.11 SUMMATION

The institutions have been under severe attacks from the ACLs, not necessarily because all mentally retarded people were placed there but because all mentally retarded people were under the threat of being placed there. For example, someone who is mentally retarded may be in a safe position with a family. However, if for some reason, such as through death or poverty, that protective unit disappear, then the threat becomes reality.

Looking at just those who are in the institutions one finds the most severe cases of low social status. These members will lack social ties which would normally be found in a family, a job, or the community in general. Furthermore, the institutional environment will have exacerbated the disability and poor behavioural skill thus causing a lack of adaptability to occur.[56] It is here with these people that the ACLs are most concerned, their lack of defence and their isolation.

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[55] Manitoba Department of Health and Social Development, Mental Health and Retardation Services: A Review and Preliminary Model, (Manitoba, circa 1972), p. 45.

[56] Mechanic, op. cit., p. 66.

The community move has been attacked by those citing such reasons as those who are the most adaptable in behaviour and handicap will be the first to be introduced to the community. This would be due to providing a better chance for fewer programme problems and a higher level of community acceptance. There is however nothing to prove that this fact exists. Those who have been moved have ranged widely in type and severity of handicap.

One of the major factors which has caused the government to become more committed has simply been the power of the ACLs. The age and tradition of the ACLs from the 1950s attracts a certain amount of legitimacy. While the move to the community is a difficult one due to the major implications for governments, nevertheless it is being advocated by an organization, albeit renamed and restructured, which is stable both in membership and social legitimacy. Had mentally retarded people been represented by an organization that was newly formed in this drive the story would probably be different.

The duplication of services issue cited earlier, that is the use of both custodial and community services, involves the question of whether there is an option for complete deinstitutionalization; a complete shut-down of institutions. The ACLs state that no person should be in an institution[57] however the governments state that there will al-

[57] Personal communications, July, 1985.

ways be some who need institutional services. The duplication, from the ACL perspective, arises from the full-scale operation of both systems, especially that of custodial care. In the Manitoba case, as long as progress is made in the development of community services the duplication problem will not be the major issue.

## Chapter VI

## MENTAL RETARDATION POLICY IN RURAL MANITOBA: AN ADDITIONAL CONSIDERATION

### 6.1 PRELIMINARY

As an additional consideration, in the move to community living, there is a distinction to be made between urban and rural policy as it pertains to health and social welfare policy. One American report stated very bluntly that

> Health Care in rural areas is generally less available, less accessible and probably of lower quality than health care in the rest of the country.[1]

In Manitoba as well as Canada the dual nature is just as significant and long natured. A 1964 statement issued by the Canadian Welfare Council on mental retardation wrote that assembled studies

> ___reported disparity of resources for serving retarded persons from one region to another and from rural to urban areas... This inequality of resources and opportunities appeared to be one of the most deplorable aspects of the total problem.[2]

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[1] Richard F. H. Kirk, and Richard M. Spears, "Development of Rural Health Services: Problems Illustrated by a Nonprofit, Privately-Based Approach", Medical Care, Vol. 17, No. 2, Feb. 1979, p. 175.

[2] The Canadian Welfare Council, Report to the Federal-Provincial Conference on Mental Retardation, (Ottawa, 19 Oct. 1964), p. 9.

While this research has emphasized the Manitoba and Winnipeg ACL divisions, there are a number of groups and locals which are located outside the city which do play a role. In Manitoba the population is often seen to be split between those who live in Winnipeg and those who do not. The main task facing the government and the groups in the area of human service delivery is finding a way to provide the needed services. Such issues as service monitoring and advocacy play a much larger role in the city settings.

## 6.2 THE URBAN NATURE OF SOCIAL WELFARE

Because the issues surrounding mentally retarded people fall within the sphere of social welfare the patterns of policy and service will naturally be urban. Andrew Armitage states that social welfare services should be seen "as a response to the dislocation of community and family life caused by urbanization."[3] It is therefore not surprising that the issues surrounding mental retardation in Manitoba are largely dealt with by two ACL divisions that are centred in Winnipeg.

The main problems are in service delivery. The proximity of a community to the government service delivery agent was of concern to the government and the consumers. The govern-

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[3] Andrew Armitage, Social Welfare in Canada: Ideals and Realities, (Toronto, 1975), p. 5.

ment solution is to encourage the community to develop the help for mentally retarded people instead of relying on the distant agent. In one interview with a government coordinator it was stated that the issues surrounding mental retardation were not as intense in the rural areas as in the city.

In Winnipeg, quality level is the main focus of concern with integration as the main issue. One administrator for the government, having worked in Thompson, reported seeing little difference between the ACL local there and the Winnipeg Division in terms of group behaviour, ideology, and activity.[4] This however should be seen as a very general observation. Even if there is little difference between the larger communities outside Winnipeg, such as Thompson, and Winnipeg itself, there may exist sharp differences between the larger communities and smaller ones such as Steinbach.

## 6.3 STRETCHED RESOURCES

In a tour taken of small rural communities clear differences were found between Winnipeg and towns such as Beausejour in the area of sheltered workshops. For example, in Winnipeg those who are of a higher skill level may be able to find opportunities in places such as ARC, however in a smaller setting skills were mixed resulting in vocational

[4] Personal communication, 3 July 1985.

training not being suited for those at higher levels.[5] While the argument can be made that such practices are supported by rural traditional values, it largely results from the fact that a smaller population base provides fewer options for specialized services. The government sees some advantages in the rural areas in that family ties as well as general community attitudes provide a better system of support for mentally retarded individuals.[6] This should not be seen however as a proper solution to rely upon because it avoids the fundamental problems of lack of specialization and remoteness from government resources.

A 1965 Manitoba report found that a need was found for

> ___the development of better diagnostic facilities and health services particularly in rural Manitoba.[7]

The service delivery issue pertaining to rural Manitoba is one which is thus long-term. In a 1979 review of Manitoban health districts it is apparent that programme quality and service delivery is often dependent upon one person. Hospital District #1, situated approximately 500 kilometers northwest of Winnipeg which had a population of 13,716 in 1979 covering "an extremely large catchment area"[8] is a good

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[5] Personal observations, July, 1983.

[6] Personal communication, 31 July 1985.

[7] John A. Christianson, A Study of the Education of Handicapped Children in Manitoba, (Winnipeg, 1965), p. 10.

[8] Manitoba Health Organizations Incorporated, Community Health Systems Review: Hospital District #1, 1980, p. 7.

example. In 1979 this region had only one community service worker listed who was responsible for the following:

1. Direct Service - providing counselling and other social services to a caseload of 80 clients (as well as managing some elderly cases).

2. Liaison and Consultation - with a number of groups and agencies including CAMR on behalf of his/her clients and their families.

3. Programme Development - development of new services and programmes including the Apartment Support Program, Early Childhood Education Program, a dental programme, Respite Care, and a group home.

4. Public Education - public speaking and the showing of films to interested community groups.

5. Linkages - working closely with the Volunteer Coordinator to match volunteers with clients and the services required. Working closely with Income Security and Child Family Services. Access to a non-local Vocational Rehabilitation Counsellor.[9]

Further to the above duties, in 1979 the community service worker was also the treasurer of the local CAMR branch.

In another rural health district (#10) located in the southwestern part of Manitoba which maintains a population in excess of 10,000 there was found to be only one community service worker as well.[10] The duties of this worker were very similar to that of the previous case cited however he did not sit as an executive of the local CAMR branch. One cannot but wonder whether the separation of the duties of the ACLs and the government is possible in comparison to the

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[9] Ibid., pp. 66 - 68.

[10] Manitoba Health Organizations Incorporated, Community Health Systems Review: Hospital District #10, 1980.

City of Winnipeg due to levels of population.

When a government establishes or supports a service in a small rural community there are some certain considerations involved which may not be relevant in an urban environment. A small population will be granted a small service; hence, the number of staff is usually low. It would take only one staff member to threaten the quality of a service programme. In other words, the importance of staff quality is inversely related to programme size. In an investigation of a central Canadian arctic community John O'Neil found that if one individual (a public health nurse) acted according to personal principles as opposed to those established by the programme directives the goals of the entire programme would become denigrated.[11]

Another consideration has to do with differences between rural communities and the tendency on the part of government to formulate a service policy which will work in all communities. As one American researcher wrote following the failure of a cooperative health programme:

> ___a prospective innovator needs to focus on the social consequences of his proposals. The kinds of community interdependencies that exist and the way in which the intervention affects them may have more to do with successful implementation than the more detailed project planning.[12]

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[11] John D. O'Neil, "Health Care in a Central Canadian Arctic Community: Continuities and Change", Health and Canadian Society: Sociological Perspectives, Coburn, et al, eds., (Toronto(?), 1981), pp. 123 - 141.

[12] David Barton Smith, "A Cooperative Pharmacy Project: An

The availability of staff must also be considered in order to operate the community residences. In the United States some observers noted that the shifts in the 1960s Community Mental Health Centers from institutions produced a) decentralized power structures, and b) staff who lacked skills related to the new system. Concerning the first observation, James Osberg writes:

> With the emergence of the area programs, and the consequent decentralization of decision-making, both the deficiencies and the skills of mental health professionals who manage programs have become more apparent. Such matters can be obscured in an authoritarian and relatively static system, but not in... decentralized, constantly changing programs.[13]

Further to the levels of staff competence, Herbert Diamond and Anthony Santore (directors of the West Philadelphia Community Mental Health Consortium) found that:

> In its early phases, our centre was unable to rely on precedent and had no quidelines to suggest a reliable framework for binding together its multi-institution organization and large staff. The resulting process of trial and error, during a period of rapid growth, established an administrative system that relied on mental health professionals who lacked appropriate training for their new managerial roles.[14]

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Autopsy on a Community Health Intervention", Journal of Community Health, Vol. 2, No. 3, Spring 1977, p. 231.

[13] James W. Osberg, "Unifying State Hospital and Community Mental Health Systems Through Area Programs" Hospital and Community Psychiatry, Vol. 23, No. 4, April 1972, p. 108.

[14] Herbert Diamond and Anthony Santore, "Basic Tasks in Developing a Community Mental Health Center", Hospital and Community Psychiatry, Vol. 25, No. 4, April 1974, p. 232.

## 6.4 PROXIMITY OF ORGANIZATIONAL INFLUENCE

In maintaining the Manitoba Division in Winnipeg the ACL holds proximity to the provincial centre of power and exists in the geographic area which is the best suited in Manitoba to the social welfare system. Although other locals of the ACL, such as the Brandon and Thompson locals, would address urban social delivery problems they have neither the population nor the closeness to the political centre which both the Manitoba and Winnipeg divisions hold. One can see that in the larger communities there is a difference between the urban communities in Manitoba; this should however be seen within the context of welfare systems stemming from urban structures.

In Manitoba, laws which are designed for the population in general may not adapt easily to the rural areas. For example, building codes have been sometimes known to be waived without consideration for disabled people to their detriment in the rural areas. One report issued by the Manitoba League of the Physically Handicapped (MLPH) states:

> In rural Manitoba, these waivers are given almost as a matter of course. The reason for this is largely due to the relatively small and silent population of disabled persons in rural Manitoba.[15]

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[15] Michael Rice, Selected Manitoba Statutes and the Physically Disabled Person: Number Two, Prepared for MLPH and MARL, Aug. 1982, p. 3.

One of the main aims of the ACLs is programme and service monitoring and rural settings by their problems of distance inhibit such activities.

One should therefore question the government assumption that rural communities have a better environment for mentally retarded people. Family associations and community ties may be strong for some however there may be a clear lack of formal supports should the community not act within the government's expectations. There is no proof that mentally retarded people do not become stigmatized in rural settings. They are sent to institutions, suffer from the familiar urban problems of unemployment and lack independent living resources.

## 6.5 NOT ALL RURAL COMMUNITIES ARE ALIKE

If the policy makers in the government expect the communities in Manitoba's non-urban areas to be more accepting of mentally retarded persons there may be serious repercussions. The shift to community living while desirable must be seen in the light of being a major shift in services and policy which will affect the communities involved. In an analysis done on two Saskatchewan towns (Blackfoot an Deerville) concerning attitudes towards the mentally ill[16] it

[16] The mentally ill have also been part of a parallel drive to the community from institutions.

was found that people had not become more accepting between 1951 and 1974:

> These quantitative data indicate that public attitudes towards the mentally ill and recognition of psychiatric symptoms have changed little in the last quarter-century...the order of magnitude of the overall change was less than anticipated.[17]

From the above it is apparent that the move to the community, whether the population is mentally ill or retarded, demands more research than would be generally expected. While it may be true that community integration is needed for these individuals to become part of a society, it must be realized that the communities themselves may be hostile to new policies which will alter their towns or villages.

A study done on the Belgian town of Geel reveals a community which has maintained an integrated mentally retarded population for a number of centuries. While the handicapped people were integrated they also were by and large to be found in the lower social strata and not part of the more developed areas of their society (clubs and organizations). However, the report states:

> To bring normals in direct contact with mental patients in a "natural" environment seems to be the best, and probably the only efficient means of eliminating prejudices and promoting the integration of the patients. To put it bluntly: Most people tend to see many "crazy people" as crazier than they are, and by direct contact this tendency

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[17] Carl D'Arcy, "Opened Ranks? Blackfoot Revisited", Health and Canadian Society: Sociological Perspectives, op. cit., p. 104.

is corrected in favour of the mental patients.[18]

The study also drew a distinction between the varying types of towns. Some will accept integration while others will not:

> Everything depends on what the community involved wants. If it demands that its environment be as "hygienic" and "esthetic" as possible so as to be able to enjoy its prosperity in an ideal (utopian) fashion, it should not adopt such patients.[19]

While this is not to say that the move to the community should be given up it is a warning that the government should treat every community as distinct in its stages of operation and planning. The government should not rely simply on assumed community values based on rural environment. Treating each town or village as unique will help prevent such failures as have occurred elsewhere in other community projects in North America.

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[18] Eugeen Roosens, Mental Patients in Town Life: Geel - Europe's First Therapeutic Community, (London, Eng., 1979), pp. 189 - 190.

[19] Ibid., pp. 188 - 189.

## Chapter VII

## CONCLUSION: MANITOBA AND THE ACL

The previous chapters have reviewed the issues pertaining to mentally retarded people in Manitoba. While certain areas were not covered in detail, such as the smaller organizations in the province or the locals outside of Winnipeg, the research has dealt largely with the issues as they have arisen in North America and how Manitoba has followed those trends.

As an interest group the ACL and its divisions have taken advantage of the trends which have occurred in North America. The four attributes listed by Pross in Chapter 4 can be found in the ACLs. The first attribute, continuity, is apparent in that the ACLs began in the 1950s and exhibited an influence on government policy from the beginning as was shown both in the Canadian and Manitoba government literature in the early 1960s. Second, organization has played a role in that they have annual meetings, a strong and committed membership, organizational literature and a national structure which maintains provincial and regional divisions. The articulation of interest, the third attribute, appears also on the national and provincial level. Reports to the government supported by research facts and statistics have

been used time and time again. The consensus reached in the 1980s between the ACLs and the Manitoba Government in establishing a supportive community service system is proof that the articulation of the ACL interests has played no small role in Manitoba. This has been to the extent that they participate in the planning and implementation of new policies. The fact that the ACLs have not relied on the press for affecting policy since the rift over the 1982 government report is an indication of its utilization of more backroom pressuring. Issues do come up in the media but they usually result from individuals making contact and not the group. When the group has gone to the press in the past three years it has been concerning specific issues and not as full frontal attacks on government policy. The final attribute, the influence of power, comes with the first three factors. Some of the administrators, such as Ben Lewis who is with the government, were once with the ACL. Also, the interviews revealed that government administrators saw the ACLs as their major source of information and political support for new programmes. Without their support the government knows that government programming would meet strong resistance.

The above indications of the ACL's ability to act as an interest group show that the ACL should not be considered as a single issue interest group but as an institutional interest group. they have the capacity to act in the same manner as other traditionally understood interest groups such as

those arising from business and labour. Chapter 4 described the patterns found in interest group behaviour in modern post-industrial society and the ACLs have proven that they have been able to operate in this area with effect.

The above, although simplistic in its "pigeon hole" approach, shows that the ACL should no longer be considered as a mere service or social agency but as an organization which behaves as an interest group. Dividing interest groups as institutional or single-issue is usefull in that it provides an understanding of an organization's tendencies. An institutional group may occasionally behave like an issue group by using tools such as public protests (such as the Ontario Medical Association in 1986 concerning extra-billing).

Further, other categories may be used, for example, the ACL may be labelled as a legal advocacy group or a social welfare group. Regardless of the various categories or labels, the ACL in the 1980s stands out with one highly visible element, institutional interest group behaviour.

It is true that the present government of Manitoba has shown a strong commitment to the social service sector but there is little to prove that a change in government would be detrimental to the aims of the ACLs. In interviews with both those in government and the ACLs it was repeatedly stated that relations are very good between the government and the interest groups. The question arises as to whether programmes such as the Welcome Home Project have been estab-

lished as a result of changes in Manitoba or general trends in today's society. The government would assert the former but the latter is born out by this report.

Accounts arising from other provinces, such as Harvey Simmons' review of Ontario history in this field, support the assertion that Manitoba is not unique nor distinct in its progress pertaining to mentally retarded people in attempts to move into the community. However, certain particular successes have occurred such as the present government's willingness to establish joint regional planning committees in the development of the Welcome Home Project. As elsewhere, the Manitoba ACL has strong parent support both in its membership and activities. Parents, for reasons of self interest, awareness of mental retardation issues, and concern for their family members, play a strong role in pushing for community support systems.

There was found a strong flavour of openness in Manitoba between the government and the ACLs. Representatives of the government and the ACLs were willing to speak to anyone interested in order to prove that their efforts have given fruit. Likewise, the national organization has proven useful in its openness to the local organizations who have needed to see how other communities have dealt with problems in mental retardation.

Activists in Winnipeg are constantly aware of developments both nationally and internationally in programming and ideas. The convention network and publications have served no small part in Manitoba's ACL development. It is easier for an interest group to persuade a government if it is able to support itself with research and the ACLs have developed this ability to a fine point. One example is the Welcome Home Project where the national body did a review of the developments to see if they followed the national goals of the ACL.[1] Keeping up on outside developments has enabled the ACL divisions to be progressive in regions which may normally not be considered as geographically proximate to the national and international flow of ideas.

Manitoba has also had its share of contributions to developments outside its boundaries. As stated in Chapter 6, governments are slow in bringing about long-term changes and a programme's failure in one province will affect the possibilities for future services in another. There is a feeling in the ACLs that while they do not see the Welcome Home Project as being under a microscope the success of the programme will have effects elsewhere in as much as it serves as a national model. There is a sense therefore that any new development, regardless of which region in Canada it arises, will have national ramifications. This has helped push the locals into being modern and has provided the re-

[1] The Welcome Home Project: Report of the National Comserv Panel Review, 1984.

sources for such transitions as described by Wolfensberger in his earlier cited work on association renewal.

The push for community integration and normalization is a relatively recent phenomenon. If one considers that in North America community integration theory and practice has only been implemented structurally since the 1960s, the question arises as to the permanence of the trend. Arthur Schafer, Director of the Centre for Professional and Applied Ethics at the University of Manitoba, states:

> Western culture tends to over-value high intelligence and stigmatize low intelligence. Even the ancient Greeks put to death mentally or physically defective children and our treatment of the retarded has been far from admirable. They have been systematically devalued and treated as less than fully human - frequently subjected to punitive confinement, dangerous experiments and gross violations of their basic rights.[2]

Although the non-western trends are beyond the scope of this report it would be appropriate to state that whether this is a universal or western long-term problem the fact remains that while laudable trends have emerged vis-a-vis the policy approach to this population there is still the serious question regarding the degree of permanence that has been implemented.

The interest group activity of the ACLs does follow with the trends of other groups in the Canadian and Manitoba political systems. They seek to affect those who are close to

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[2] Arthur Schafer, The Globe and Mail 29 July 1985, p. 7.

policy making, use the media extensively, maintain strong community links through its parent membership, and understand that changes in policy come from establishing one's legitimacy.

## Appendix A

The following are the organizations and government offices which were contacted for information, publications, and interviews:

1. The Association for Community Living - Manitoba Division
2. The Association for Community Living - Winnipeg Division
3. The Canadian Council on Rehabilitation and Work
4. The Coalition of Provincial Organizations of the Handicapped
5. Department of Education, Research and Planning Division, Government of Manitoba
6. Social Resources Committee, Executive Council, Government of Manitoba
7. Manitoba Department of Community Services - Research and Planning
8. Manitoba Department of Community Services - Progamming and Services
9. Manitoba League of the Physically Handicapped
10. The National Institute on Mental Retardation

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