MOVING TOWARDS DEINSTITUTIONALIZATION

A DISCUSSION PAPER

PROLOGUE

There has been a growing trend over the past twenty-five years away from institutional placement toward the development and delivery of community-based services to individuals who are mentally challenged and who require long-term, community-based living arrangements and program supports. In addition, there has been a recognition that there should be similar opportunities provided to those individuals who are currently residing in long-term care facilities.

Other jurisdictions have been criticized for developing deinstitutionalization policies which have provided for little more than the movement of people out of institutions with no plan or service structure in place regarding alternate services. To ensure this does not happen, the Department of Community Services is proposing a policy which will be used as the basis for a formalized service system for Nova Scotians who are mentally challenged and who require long-term supports. The following represents a synthesis of that policy:

> *Deinstitutionalization requires the development of community based services for those persons who are moving from institutions and for those who have similar needs but have remained in the community. These services must be comprehensive enough to provide an acceptable quality of life and allow full community inclusion.*

The Department of Community Services recognizes the value of key stakeholder input; Family members, advocates, consumers, municipalities, service providers, other government departments, all are seen as important partners in this process.

The department developed extensive opportunities for input in the area of deinstitutionalization as it applies to Children's services through the work of the "Advisory Committee on Services to Children with a Mental Handicap" and the "1994 Review of the Children's Training Centres in Nova Scotia". The reports of these committees have resulted in an intensive planning and consultation process. All of the key stakeholders are working to develop individualized community support services as alternatives to institutional living arrangements.

While extensive deinstitutionalization efforts have also been made in the area of adult services, (i.e., Officials Committee for regional service planning, Strategic Planning in Adult Residential & Regional Rehabilitation Centres), there has been no province wide consultation with the same focus as noted above for the children's program.

This brief discussion paper attempts to outline the policy directions the Department of Community Services feels should be pursued in order to effectively and responsibly replace adult institutional services with community living alternatives for persons with mental handicaps and mental disabilities.

The department is seeking the opinion of stakeholders with regard to these suggested policy directions through a variety of means starting with the "Invitation to Participate" form accompanying this paper.

HISTORICAL CONTEXT

There are five general time frames in Nova Scotia in which basic philosophical/legislative and/or service shifts and developments occurred in services to persons with a mental handicap or a mental disability.

A. **1759 - 1880**

The workhouse, poorhouse and orphanage were the first institutions established in the developing colonial society. These institutions responded to the needs of those individuals who were unable to look after their own needs, including persons with mental handicaps or mental disabilities. Conditions were appalling.

B. **1880 - 1958**

In 1886, an act was passed in the Legislature which enabled municipalities to build asylums for those deemed to be harmlessly mentally ill or mentally handicapped. Institutions sprung up across the Province, some initially deemed as poor houses and others as county mental hospitals. While some were well run, most would be judged harshly by any standards today. Joseph Howe in the late 19th century referred to them as "Mansions of Woe".

C. **1958 - 1970**

1958 represented a key turning point when the "Social Assistance Act" was passed ending a period of almost 200 years of Nova Scotia Statutes based on the Elizabethan Poor Law. The new legislation established policy directions to upgrade and improve the old poor houses or county homes, leading to the first separations of individuals with mental illnesses and mental handicaps from the elderly and the poor. The Canadian Association for the Mentally Retarded (now The Canadian Association for Community Living) organized and began to advocate for better services. Initial recognition was apparent in this period that the needs of individuals with mental handicaps were different from those with mental illnesses. The first small steps towards community services started with the development of recreation based sheltered workshops.

D. **1970 - 1990**

The past two decades have been a period of rapid philosophical change. The principle of normalization was the philosophical base for changes in service direction. (See Appendix I) This principle supports the belief that persons with mental handicaps should be able to enjoy patterns and conditions of everyday life which resemble, as closely as possible, the norms and patterns of mainstream society.

Many collaborative processes among the Province, municipalities, service providers and advocacy organizations were initiated during this time. The planned closure of Mountain View Home in the early 1980's, the closure of Gardiner Centre in the mid 1980's, and the Officials Committee processes for regional planning of the late 1980's are examples of initiatives which assumed the values of community living and provided real Nova Scotia experiences in the movement towards deinstitutionalization.

E.   **1990 - PRESENT**

While the principle of normalization dominated the past two decades, the concept of quality of life has become predominant in the 90's. The downsizing by fifty per cent of Harbourside Lodge in Yarmouth, the report of the Collaborative Strategic Planning process for Adult Residential Centres and Regional Rehabilitation Centres, the Report of the Minister's Advisory Committee on Services to Children with a Mental Handicap, the Review of Children's Training Centres, the closure processes successfully completed of the Digby and Pictou Children's Training Centers and presently underway at Mary's Hill Home in Mabou and at the Halifax County Rehabilitation Centre in Cole Harbour, the establishment of Early Intervention and In-home Support programs, as well as the Project Team established to develop community placement plans for residents leaving the Nova Scotia Youth Training Centre and the remaining two Children's Training Centres all provide evidence of the belief that quality of life is enhanced in the community .

While some believe the movement from an institutional-based service system to a community-based service system has been too rapid, others believe the opposite. Appendix I, however, illustrates that Nova Scotia has been moving in the direction of deinstitutionalization and towards the development and expansion of community-based services for the past two decades. There is a growing level of commitment at all levels of government, within the generic service community and amongst advocacy groups for "de-institutionalization". The questions appear to be how quickly and by what means should this process be accomplished.

PRINCIPLES

While not limited to the deinstitutionalization process, the following Statement of Principles (derived from the Mainstream process and other provincial consultations) provides the basis for the department's policy directions. The Mainstream 1992 process, a Review of Services to Canadians with Disabilities, was intended to bring together the different perspectives, views and experiences of a wide-range of Canadians. It included consultations with policy experts, with representatives of consumer, service and advocacy organizations, and with individual Canadians with disabilities.

RIGHTS AND RESPONSIBILITIES:

People with disabilities have the very same rights, and the same responsibilities, as other Canadians. They are entitled, as others are, to the equal protection and the equal benefit of the law and require measures for achieving equality.

EMPOWERMENT:

People with disabilities require the means to assume responsibility for their own lives and their own well being. Efforts are required to encourage them to take control, and to support and promote their own efforts in this regard.

PARTICIPATION:

People with disabilities require full access to the social, economic and physical infrastructure which supports our society so that they can participate fully and equally in their communities.

VISION

The Vision stated here reflects a society which values its citizens with disabilities, which understands the importance of empowering people, which recognizes the need to adapt the social and physical environment, and which acknowledges the rights and responsibilities of people with disabilities. It is consistent with international trends and the evolution of opportunities and services for persons with disabilities. The Vision is built on the Mainstream process and other provincial consultations and is based on the following tenets:

* *Inclusive Society*, persons with disabilities should be able to live in the community and to have access to community activities, opportunities and services.

* *Empowerment* is based on the concepts of individual responsibility and self-reliance. All ends of the political spectrum are increasingly rejecting paternalism and dependence upon government. Coupled with this is the growing recognition that solutions need to come from individuals, families and communities rather than from systems, government and professionals. Empowerment means equipping people with disabilities with the means to assume responsibility for their own lives and well being, encouraging them to take control, and supporting and promoting their efforts in this regard.

POLICY ISSUES

The following outlines some of the major areas where a policy approach is required and where the department is seeking stakeholder input into the deinstitutionalization process.

1. **HUMAN RIGHTS**

   Throughout Canada, people with disabilities are asserting a right to participate fully in their communities and to share in the full range of benefits available to other citizens in Canadian society.

   As stated in the "Principles" section of this paper, the department believes that people with disabilities have the same rights and the same responsibilities as other Canadians. They are entitled, as others are, to the equal protection and the equal benefit of the law and require measures for achieving equality.

2. **COMMUNITY ACCEPTANCE**

   These words are being used in the broad context. It is recognized that there are varying levels of acceptance of the philosophy of deinstitutionalization, from those who oppose the placement of persons who are mentally challenged in community-based settings, to those who believe it should have already occurred.

   The department believes that not only do all Nova Scotians have the right to live in the community, it believes the community is the natural setting for individual growth and fulfilment.

   The department accepts its responsibility to work with organizations in promoting real community acceptance of persons, who have mental handicaps or mental disabilities.

3. **REGIONAL/COMMUNITY INFRASTRUCTURE**

   In Nova Scotia, structures to support community-based services are developing at different rates. Some areas have well developed services which, with minimal enhancements, could readily respond to new clients leaving institutions. Other areas have fewer services and will require major planning and development before they are able to provide a range and quality of service comparable to, or superior to institutional services.

   While the department will continue to attempt to respond as equitably as possible to the needs of all individuals requiring assistance, extra effort and resources will be concentrated on those areas currently lacking a comprehensive community support services base.

4. **HUMAN RESOURCES**

The transition from an institutional-based service system to a community based system requires careful planning and management. Resources will need to be allocated to maintain the existing system and, at the same time, to support the development of a new system.

Additionally, there is a need to develop training programs which ensure that individuals currently working in institutions understand the shift in philosophy of service delivery and that all those providing community based service have appropriate knowledge, attitudes and skills to provide the required levels of support.

The Department of Community Services is committed to allocating additional staff to specific deinstitutionalization initiatives, to redeploying current fiscal and human resources from institutional programs to community based programs, and to the formalization of program standards for these programs.

5. **EMPLOYMENT**

The downsizing and closure of institutional beds may be viewed negatively from a community economic development perspective as institutions are the main employer in some communities. In other areas the process may be viewed as creating employment opportunities by diversifying services through a range of small community-based options.

While the department will make every effort to work with communities affected through this process, (as in #3 above), program decisions and directions will be primarily guided by the needs of individuals.

6. **IMPLEMENTATION**

Implementing the deinstitutionalization process does not rest with the Department of Community Services alone. The community must share responsibility with the Department of Community Services and other government departments for realizing the vision. For example, community organizations and government departments should ensure that their mainstream services are available to people with disabilities within their community, in order that they may participate fully in Nova Scotian life. The implementation process must recognize and accommodate the racial and cultural diversity of the individuals and communities being served.

The findings from consultations on the deinstitutionalization discussion paper and on other issues of concern to individuals with a mental handicap or disability will be used to establish a process that actively involves key stakeholders in the planning and implementation process.

7. **CO-ORDINATION**

A comprehensive range of services can only be assured by incorporating and coordinating the work of many departments, agencies, communities, municipalities, etc. The need to co-ordinate the activities of all these groups

is paramount in making the system function smoothly and effectively, with minimal duplication and maximum flexibility.

The department will seek clear agreements and commitments from other departments, agencies, municipalities and service providers to ensure that "effective" co-ordination and continuity of support becomes an integral part of this process.

8.   **FINANCES/ECONOMY**

The province's commitment to control government expenditures is a reality. Every program within the Department of Community Services and across government is being closely analyzed to ensure program dollars are being used to achieve maximum benefit. While completely closing institutions may eventually result in cost neutrality, there will be a period of increased costs during the downsizing process.

9.   **LEGISLATION**

The number of small unlicensed community-based settings has increased dramatically over the past several years. While the few homes exclusively serving children are governed by regulations under the Children and Family Services Act, many Nova Scotians have expressed concern over the absence of legislation, regulation, inspections, and standards for similar facilities serving adults. Others, however, caution against over regulating, as flexibility and the tailoring of services to meet individual needs may be lost.

As standards are developed, we will attempt to strike a balance between flexibility and responsibility, while specifically addressing the need for individuals of all ages to have the same, high standard of service.

APPENDIX I

INSTITUTIONAL VS. COMMUNITY BASED SERVICES

1976-1993

TABLE I   -   Adult Residential Programs - Mentally Handicapped/Mentally Disabled

TABLE II   -   Residential and Support Programs - Mentally Handicapped Children's Services

TABLE I

ADULT RESIDENTIAL PROGRAMS
MENTALLY HANDICAPPED/MENTALLY DISABLED

	1976	1990	1993
Adult Residential Centres/ Regional Rehabilitation Centres (Institutions)	1,620	1,110	1,050
Group Homes/Developmental Residences	32	300	283
Supervised Apartments Small Options	0	300*	811*
TOTALS	1,652	1,700*	2,144*

* Approximate - does not include some semi-supervised situations.

TABLE II

RESIDENTIAL AND SUPPORT PROGRAMS
MENTALLY HANDICAPPED CHILDREN'S SERVICES

Programs	1978	1988	1990	1994
Institutional (NSYTC & CTC's)	370	225	190	110
In-Home Support	0	170	195	400
Early Intervention Program*	107	125	134	164
Foster Care (Agency & Special)	50	50	50	50
Nursing Care	50	25	25	25
TOTAL	577	595	594	749

*Indicates full time equivalent spaces in Developmental and Mainstream Centres. The actual number of children served in these programs is closer top double that number.