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ABSTRACT

This report discusses outcomes of a Canadian initiative to assist in the deinstitutionalization of persons with intellectual disabilities in Newfoundland, Prince Edward Island, Ontario, Manitoba, Saskatchewan, and Alberta. The projects were managed through a partnership in each province including representatives from Human Resources Development Canada, the provincial government, the Canadian Association for Community Living, and the provincial Associations for Community Living. The projects included over 250 individuals with intellectual disabilities living in institutional facilities, and 15 individuals living without adequate supports in the community. Under the projects, the majority of those individuals who were supposed to move from institutional facilities did move; others are still receiving supports to assist them in making decisions with respect to their moving. As people became more included in their communities and were given greater status in decisions affecting them, enormous personal growth and development took place, opportunities for integration expanded, and their health status improved. The report discusses outcomes relating to self-determination, supportive personal relationships, educational and economic integration, community participation, and access to personal supports. The cost-effectiveness of the projects, mechanisms enabling community inclusion, policy factors, and future directions are also discussed. An appendix provides an overview of the initiative. (Author/CR)

Professional Report

Towards Inclusion:
National Evaluation of Deinstitutionalization Initiatives

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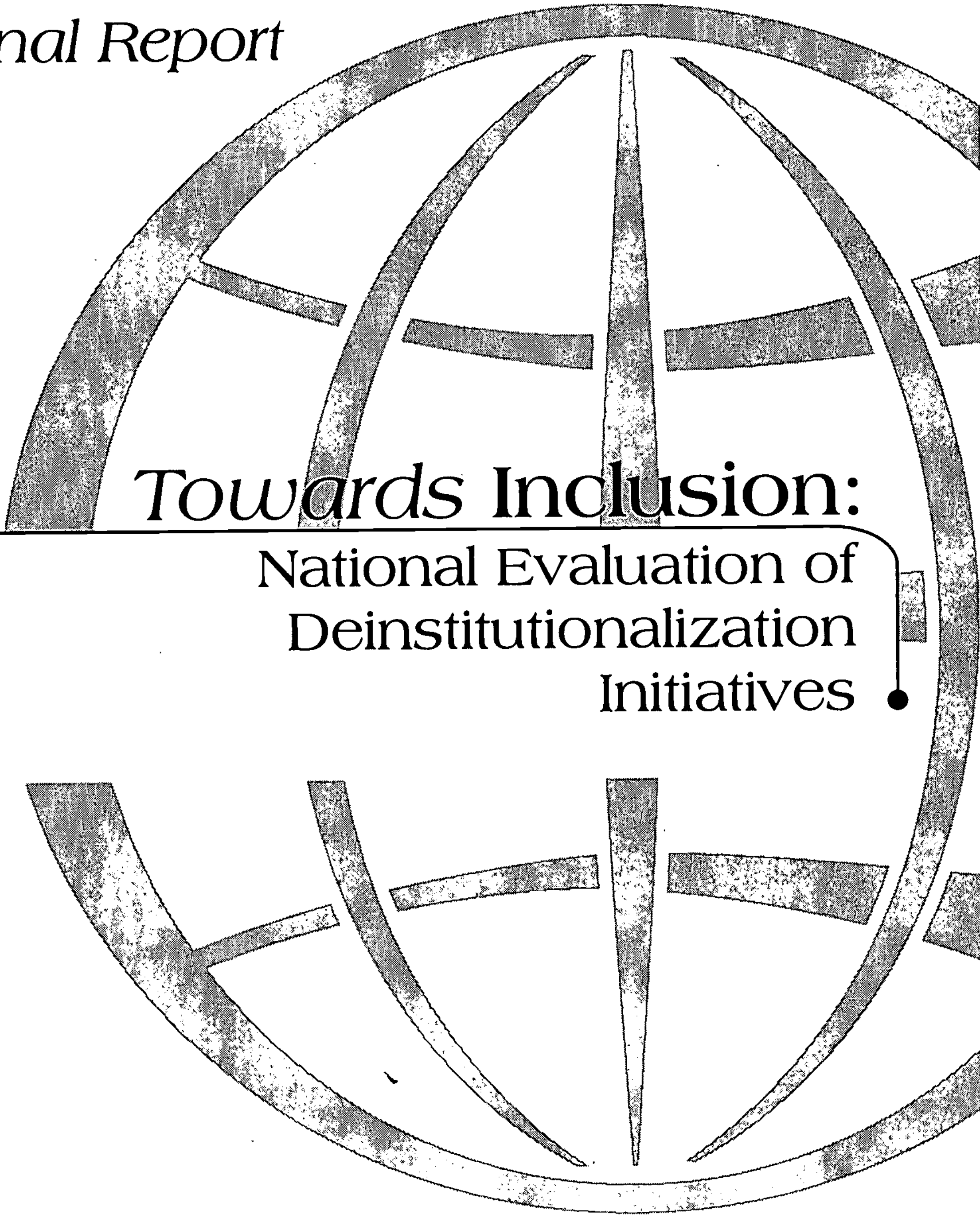

Towards Inclusion:
National Evaluation of Deinstitutionalization Initiatives

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About

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Canada's National Institute for the Study of Public Policy Affecting Persons with Intellectual and Other Disabilities

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"I want to move out, I've lived here for 14 years. I go out every Sunday, and home on weekends sometimes. I'd like to move and share an apartment with a friend. But they tell me that I have a long ways to go yet. The psychologist told me a little while ago I have a long way to go... Jim [staff on the ward] *tells me "no grabbin', pokin', pinchin', touchin' people," that's what's keepin' me from going out... People are on a point system see, the one's that does the right things get the checkmarks, the one's that does the wrong things gets the x's. Willie* [another man living on the ward] *wants the x's, he just doesn't like the checkmarks. They put the sheets up with the checkmarks and the x's, what certain things you are, and what things you aren't... They put the sheets for everyone on the bulletin board next to the office. I don't like it. If Willie sees that I get the checkmarks, and Peter gets them, and Chet gets them, Doug gets them, he's not in too good a humour then, and then he gets wound up, and sometimes if he has nothin' to do then he won't go back to the ward when he's told, and sometimes he just goes AWOL. Then they call the RCMP and when they bring him back they put him on* [another ward] *in the sideroom. He was tellin' one of them he wants out in May... Claude's back. First time he went out he was out for two years..."*

Quote from an interview with Ben, a man interviewed as part of the national evaluation of the National Strategy for the Integration of Persons with Disabilities Deinstitutionalization Initiatives, still living in an institution today.

CONTENTS

ACKNOWLEDGMENTS

This evaluation was undertaken by a research team including a number of individuals. Marcia Rioux provided overall direction to the project. Michael Bach coordinated the research process and drafted this final report in collaboration with the research team. At The Institute, the research team also included Cameron Crawford, Melanie Rock, and Leela Viswanathan. Ernie Lightman, economist with the School of Social Work at The University of Toronto provided extensive input into the development of the cost-effectiveness framework. The Roeher Institute contracted with Memorial University, School of Social Work, to participate in the field research in Newfoundland. On behalf of the school, Cheryl Hebert conducted a number of interviews for the case studies and coordinated the demographic survey and community attitude telephone survey in that province. Bill Rowe, former Director of the School assisted in the early stages of the research in Newfoundland. Elaine Wycreschuk and Laurie Cole conducted the telephone survey from St. John's. Melanie Rock assisted in initial interviews, prepared the databases for analysis of the surveys and completed much of the data entry and preliminary statistical analysis. Tom Martin worked on the statistical data analysis and the analysis for the cost-effectiveness framework.

The views expressed in this report are those of The Roeher Institute and are not meant to represent the position of Human Resources Development Canada.

EXECUTIVE SUMMARY

The National Strategy for the Integration of Persons with Disabilities (NSIPD) was established by the federal government in 1992 to mark the end of the United Nations Decade of Disabled Persons. This cross-departmental strategy was designed to achieve the objectives of equal access, effective participation, and economic integration of people with disabilities. As part of the strategy a $15 million initiative was established to assist in the deinstitutionalization of persons with intellectual disabilities. Projects were mounted in six provinces. The largest project in terms of federal contribution was in Newfoundland, with smaller projects in Prince Edward Island, Ontario, Manitoba, Saskatchewan, and Alberta.

The projects were managed through a four-way partnership in each province including representatives from Human Resources Development Canada (representing the federal government), the respective provincial government (through the ministry or department responsible for supports to persons with disabilities), the Canadian Association for Community Living (CACL), and the respective provincial Associations for Community Living (ACLs).

The projects included over 250 individuals with intellectual disabilities living in institutional facilities, and 15 individuals living without adequate supports in the community. They also included the family members and others who were involved in individuals' lives. Under the projects, the majority of those individuals who were supposed to move from institutional facilities did, in fact, move; others are still receiving planning supports to assist them and their families in making decisions with respect to their moving.

Beginning as a loosely connected set of six projects, the deinstitutionalization initiative resulted in much more than moving individuals out of institutions. Through their activities, the projects spawned a process of community inclusion, the dynamics of which were made visible throughout this national evaluation. This process was sparked by an enabling environment which the projects were able, in different ways, and to varying degrees, to begin to construct. One legacy of the NSIPD initiative is the dramatic improvement in the quality of life of so many individuals, families, and communities. Another is that the initiative brought much greater clarity to the goal of community inclusion. It revealed what this process entails, and how to create a fertile ground—for its initiation and sustainability.

The Process of Community Inclusion

Quality of life was measured in this evaluation according to five commonly used outcomes or benchmarks: self-determination; supportive personal relationships; educational and economic integration; accessible communities; and, access to personal supports. The evaluation found that as these outcomes were put into place, they defined the process and the path to community inclusion. The process began to unfold as adult individuals, or families where younger children were involved, were given *the status and support to exercise self-determination*. The process gained momentum with the *building of supportive relationships for people* that accorded people value and respect; establishing *opportunities and support for educational and economic integration*; making *community services and structures accessible*; and ensuring the provision of *flexible, responsive and accountable personal supports* to meet disability-related needs.

These outcomes have not been realized for all participants in these projects, and indeed a few individuals remain isolated and without needed supports in their communities. Some family members are frustrated by what they perceive to be a lack of support, given the promises made. For the majority of participants, however, major strides have been made in realizing one or more of these elements of community inclusion. People's lives look much different than they did when they relied on institutional supports rather than on supports they now control in their own homes. As people became more included in their communities and were given greater status in decisions affecting them personally, enormous personal growth and development took place, opportunities for integration expanded, and the health status of individuals improved significantly.

Enabling Environment

The evaluation found that the process of community inclusion takes place where there is an enabling environment. A number of key mechanisms were found to be important levers of change in creating such an environment. First, there were mechanisms that helped to create a broad context for partnership, commitment, and accountability to the goals of deinstitutionalization and community living and to human rights principles. Federal-provincial fiscal arrangements for a transition fund for deinstitutionalisation, and individualized funding arrangements provided the fiscal framework to achieve the goals. These "macro-level" mechanisms proved key in shaping the policy, program, and organizational environment that made the large-scale changes possible. Second, there were mechanisms established at the "individual and personal level" that established the planning support, decision-making support and management structures that made community inclusion possible. Third, mechanisms were established at the "community level" to bring about needed changes in the social, economic, and political environments in which individuals lived, worked, and participated.

Creating an environment for community inclusion requires substantial investment, and re-investment of dollars currently allocated to provision of institutional supports. The evaluation developed a framework for cost-effectiveness to analyse the relationship between public investment, the extent of individual need, and effectiveness according to the established National Strategy objectives. The evaluation points to the long-term cost-effectiveness of investment in enabling individuals to participate in their communities. Investment in developing individual support networks, and involvement in activities and personal relationships in the community creates a system of support for individuals that can lead, for some, to an eventual reduction in the intensity of paid direct supports. The analysis found that underinvestment in specific employment-related supports has significant consequences for individuals and for the community. The evaluation also reveals the cost-effectiveness of individualized funding approaches to allocating public resources. The analysis found that individualized funding mechanisms did not inflate public expenditure. Investment in disability supports increased only as the extent of individual need increased.

Policy Factors to be Addressed

To a large degree, the NSIPD projects put into place many of the conditions favourable to beginning the process of community inclusion. The projects also encountered external policy factors that, if unaddressed, are likely to limit the prospects for building a sustainable environment for community inclusion. The legal status of individuals with intellectual disabilities is often undermined by current statutory provisions and administrative practice, and their self-determination is thereby threatened. Federal-provincial fiscal arrangements which made the NSIPD projects viable for provinces are not in place for fu-

Enabling Community Inclusion

ture efforts. There is a need to clarify a policy framework and investment strategy for community supports that recognizes the value of accountable planning supports to individuals and families, and that strengthens labour market policy for paid supports. A coherent investment strategy for community supports is likely to be a challenging venture with the increasing regionalization of health and social services within provincial jurisdictions. While these structures are bringing greater local accountability to some extent, it is local communities that have not been able to fully include people with intellectual disabilities in the past.

Future Directions

Five broad directions for future deinstitutionalization efforts emerge from this evaluation. First, government-community partnerships provided the leadership for the complex process of deinstitutionalization and community inclusion. Partnerships should be built and strengthened across the provinces and territories in order to continue the momentum for deinstitutionalization created to date. Second, projects created individualized models of support that effectively enabled community inclusion. These models should be more widely adopted and promoted. This will require attention to addressing support staff concerns, and concerns of many individuals, families, and Associations for Community Living over the impacts of unionization on their homes and their self-determination. Third, deinstitutionalization led to community inclusion for individuals when their legal, decision-making, and contractual status to make decisions about their lives and needed supports were strengthened. Additional provisions are needed to secure these forms of status. Fourth, the deinstitutionalizaton projects demonstrated that developing individual supports that lead to community inclusion requires both individualized planning and funding, and a community-level change process. A mandate and resources are needed to foster ongoing community development processes that strengthen capacity for inclusion. Finally, a comprehensive policy framework is needed to sustain and expand the successes realized through this initiative.

While the NSIPD projects revealed the possibilities for community inclusion, they also revealed the barriers to further inclusion that lie in the social, economic, and political fabric of communities. The evaluation points to the need for building the capacities of communities within a clearly articulated policy framework of common principles and direction, that cuts across communities and governmental departments, and that is national in scope. Without such a national framework, the inequities and exclusions may be exacerbated for people with disabilities, even within communities actively working to support and include them.

Based on the experience of these deinstitutionalization projects, the evaluation points to the importance of a set of common principles for a national framework for community inclusion, including: self-determination, citizenship, and equality of individuals; equity among regions; flexibility, responsiveness, and accountability in the funding and provision of community supports; and the principle of government-community partnership in guiding change of the scale required to achieve community inclusion.

The evaluation also points to the political viability of a national framework. The analysis of the data indicates that there *is* a shared national vision for community inclusion. This vision was found to be present in very diverse communities and jurisdictions across the country. Moreover, effective provincial partnerships were created with federal involvement. They demonstrated that the needed leadership can be mobilized to establish the mechanisms that are the condition of community inclusion.

INTRODUCTION

Research on human subjects and human conditions does not take place in a vacuum. It's context includes the prevailing social, political, economic and scientific conditions of the time and place. For the deinstitutionalization initiative of the National Strategy for the Integration of Persons with Disabilities (NSIPD) undertaken by the Government of Canada and six provincial governments, as well as the Canadian Association for Community Living (CACL) and six of its provincial affiliates, this was certainly the case. These projects were undertaken at a time of profound political change in the organization of social services and health care in Canada and in the means of fiscal transfers between the federal government and the provincial governments. It was also a time in which there continued to be shifts in the understanding of the nature of disability and its origins. It is important therefore to situate the evaluation of these projects and the findings of the evaluation within this context of change and to recognize the impact that this has for the findings.

In the design and development of the projects, several factors were taken into account. There was recognition that there had been a shift in the meaning and conceptualization of disability and that while there was not a universal consensus on this, it had significant influence on how the projects were constructed. Second, there was a recognition that the projects undertaken in the NSIPD initiative would be part of the 20 years of experience of deinstitutionalizing people with intellectual disabilities in Canada. Both of these factors provided the backdrop for the government infusion of funding to support the deinstitutionalization process. And both were influences on the lobbying efforts by the community living movement to encourage and pressure the government to take this step and to be involved in the overall initiative.

The two environmental shifts that have taken place over the past 20 years in Canada that provided the environment or the backdrop for the governments'/Associations' for Community Living (ACLs) initiatives are changes that also had to be accounted for in the design of the evaluation tools and the methodology for the evaluation. To understand the projects and the overall impact and to evaluate them, it is necessary to lay out this context.

The first change, a change in ideology, is the recasting of the condition of disability and its etiology. For much of this century, it has been assumed that disability was an individual pathology, a condition grounded in the physiological, biological, or cognitive impairment of the individual. The resulting incapacity was regarded as the consequence of that bio-medical or functional condition. More recent research has suggested that disability is also, or even principally, the result of the social, political and economic conditions in which people with disabilities live. According to this understanding systemic conditions often act as barriers to the participation and inclusion of people with disabilities in the institutional structure of Canadian society and limit the extent to which people exercise their citizenship.

This recognition that disability is more than the biomedical impairment has led to a shift in the expectations of people concerned with disability, not just in terms of the people served but the ways in which their needs have to be addressed. For example, if persons' disabilites are largely attributable to social conditions rather than a biological impairment, then providing rehabilitation services will not be sufficient to enable them to live inclusively in their community. If the goal (or outcome) of services is to enable people with disabilities to exercise citizenship, then providing services that do not lead to community inclusion will not ensure that outcome.

Increasingly over the past 10 to 15 years, recognition has been given to the concepts of citizenship, equality, equity and participation as the goals of disability programming and initiatives. The 1981 *Obsta-*

cles Report was the first federal document to suggest this direction. While the policy options being put forward in the late 1990s reflect more current thinking, the report contributed in important ways to the public and political shift in thinking about disability. Other evidence of the shift has followed including: the Abella Commission (1982) on Employment Equity (which included disability); the *Eve* decision of the Supreme Court of Canada (1986); the Canadian and provincial Human Rights Act amendments to include mental and physical disability as a prohibited ground of discrimination; the Mainstream 1992 report; and a number of Parliamentary Committee Reports over the past few years. [1] Besides the government recognition of this new direction, a good deal has been written by policy analysts and by disability advocates detailing the social model of disability, suggesting that disability is a condition resulting from the socio-political circumstances which impact on an individual. [2]

Second, there have been changes in what is considered standard or acceptable service practice and procedures. In the late 1960s, convention around best practice and service delivery was that institutions were outdated and needed to be modernized in terms of their refurbishment physically as well as by improving the rehabilitation services they provided and the way in which patients/residents were treated. In the ten years following that, it became standard professional practice to think about ways to move people out of the institutions altogether, that deinstitutionalization was not simply about improving the institutions but was about people moving out of large congregated settings. In other words, deinstitutionalization meant a physical relocation into more community-based institutions such as group homes and institutions with much smaller populations.

More recently, the conceptualization of deinstitutionalization has changed in more significant ways. Deinstitutionalization has come to incorporate, as fundamental to its meaning, the development of community. It involves the actual physical move out of the large full-service facility but it also involves several other shifts. It incorporates the notion that the move is into a residence in the community, with services that address the individual impairment and recognize, identify and address the social, economic and political conditions that are barriers to full inclusion. In terms of service provision, public policy and financial investment this has some commanding impacts. There is a means-end continuum that changes what is the means and what is the end. The end goal is no longer to simply ensure that the basic conditions of living and service for the individual with a disability are met (that is individual rehabilitation and comfort) but changes in the community itself so that the individual can be involved and can achieve citizenship status.

The NSIPD deinstitutionalization initiative was designed with the recognition of these shifts in mind. What was being attempted was to create the conditions both for individuals to leave institutions and for communities to develop the means to fully include them. The evaluation of the six projects that made up the initiative took the overall trends into account in the research framework, and was designed to examine the variety of ways in which the projects attempted to achieve their goals. Three overall objectives guided the evaluation:

1. To assess the extent to which the NSIPD deinstitutionalization initiative met the three overall objectives of the National Strategy: equal access, economic integration, and effective participation.
2. To determine how the projects contribute to a national framework that results in greater opportunities for individuals, communities, and governments to achieve the NSIPD objectives.
3. To develop a framework for assessing cost-effectiveness in achieving outcomes.

The evaluation had to take into account the complexity of issues that were being dealt with in the objectives outlined for the initiative, and the wide array of jurisdictions across which the initiative was implemented. It also had to include in the research design the cooperative nature of the initiative in terms of governments and non-profit organizations working together at the national, provincial, and local levels.

The research methodology included a number of strategies:

- A literature review on deinstitutionalization, and a review of project-related documents were undertaken.
- Sixty-six individuals who were involved in the projects, moving from institutions or living in the community, were selected for case studies and reviews, ensuring a representation based on gender, age, needs for support and province.
- A demographic survey of all of those who consented to participate in the research was conducted, once in Spring 1996 and once again in Spring 1997, for all projects except Alberta, where the focus was on children. This survey collected basic demographic information about an individual, information related to budgets, needs, and the three NSIPD objectives (Table 1 identifies the numbers surveyed).
- A community attitude survey was conducted in Newfoundland in Spring 1997 of 97 community members and 17 professionals who had had some contact with one of the individuals included in the case studies conducted in that province. A review of the community development process in each of the projects was undertaken. The review involved meeting with those involved in leading the process, attending meetings, facilitating focus groups and reviewing documents.
- Semi-structured interviews and focus group discussions were held with representatives of all of the project partners at various points in the research process, with staff at the institutions involved, community service providers, and with family members of some of those who were not included in the case studies.

This final report is organized into the following sections. A brief overview of the NSIPD deinstitutionalization initiative is outlined in Section I. An examination of outcomes for individuals, families, services providers, and communities within a framework of community inclusion is provided in Section II. In Section III, a framework for cost-effectiveness analysis of the public investment for individual supports is presented. Section IV identifies those key mechanisms that have enabled successful community inclusion. Section V looks at policy factors external to the projects that have had an impact on the implementation and outcomes, and on the policy implications they raise. A summary of future policy directions, based on the evaluation's findings, are presented in Section VI. The conclusion looks toward the implications of the initiative for a national framework on deinstitutionalization and community inclusion.

The Appendix provides a background to the NSIPD deinstitutionalization initiative and an overview of the common elements of the six projects—goals, partnership structures, funding arrangements, etc. A separate document provides both appendices. Research instruments used in the evaluation are available from The Roeher Institute..

Each of the NSIPD projects, except for the one in PEI, had separate project evaluations completed, which are available through the respective provincial Associations for Community Living. These evaluations provide detailed information about each of the projects.

I. OVERVIEW OF THE NSIPD DEINSTITUTIONALISATION INITIATIVE

Deinstitutionalization projects were funded in six provinces under the federal National Strategy for the Integration of Persons with Disabilities (NSIPD). The projects were managed through a four-way partnership in each province including Human Resources Development Canada, representing the federal government, the respective provincial government through the ministry or department responsible for supports to persons with disabilities, the Canadian Association for Community Living, and the respective provincial Association for Community Living. Running from 1993 to 1997, the projects had the common aim to promote the human rights of individuals, support people to leave institutions, and to develop the community capacity to fully include them in communities. The projects were also guided by the broader NSIPD objectives of equal access, effective participation and economic integration.

A more detailed overview of the projects is provided in the Appendix of this report. In summary, "The Right Future Project" in Newfoundland focussed on assisting 120 individuals to move from the Waterford Hospital in St. John's to various communities in Newfoundland. This project received ten million dollars of the fifteen million dollar initiative, in order to demonstrate the full deinstitutionalization of individuals with intellectual disabilities in a province. The remaining five million dollars was distributed among five other provincial projects. In Prince Edward Island, "A Time of Change" was designed to provide planning supports to assist individuals living in the Hillsborough Hospital in Charlottetown to move to the community.

The "Opening New Doors" project in Ontario made community development its primary goal, working in four demonstration communities in the province. In the Saskatchewan "Coming Home—Staying Home" project, the second largest initiative in terms of the federal contribution, the aim was to assist 30 individuals to move from the Valley View Centre in Moose Jaw. The project in Alberta was designed to assist families with children who had disabilities and complex medical needs to find respite supports in community settings, to reduce the reliance on the Rosecrest Home, a facility in Edmonton.[3]

Individuals who participated in the NSIPD deinstitutionalization initiatives were a very diverse group. In 1996, when the projects were in full operation, participants ranged in age from 2 to 81 years old. The age range of participants in the projects focussing on adults, all except Alberta, ranged in age from 24 to 81 years old. Sixty-five percent of the adult participants were male, 35% were female. Some participants were living in institutions, some were living without adequate supports in urban and rural settings. Individuals had a wide range of disabilities and needs for support. It was reported in surveys for the study that about 95% of individuals have disabilities that affect their learning, and that just over 70% have disabilities that affect their speech. Between 40% and 50% have disabilities that affect either their mental health, and/or their mobility and agility. Individuals' needs for support vary, from those who have limited needs for personal supports, to those who have extensive needs, including complex medical needs. The group of participants is not as diverse in terms of their ethnicity and language. Surveys indicate that about 4% of individuals are of a visible minority, 81% speak English, 7% speak French, and 6% speak a language other than English. **Table 1** provides a numeric profile of participants in the projects, and those who were included in the surveys for this study.[4]

The demographics of individuals provide a broad overview of who was involved in the initiatives. But it only tells a small part of the story. Another way of drawing the picture of who was involved is the qualitative accounts of individuals and families whose lives were affected by their participation in the initiatives. These accounts are drawn upon throughout the study.[5]

TABLE 1*

Overview of Individual Participants by NSIPD Deinstitutionalization Initiative

Province	Total # of project participants	# of participants using institutional supports at outset of project	# of participants who gained community-based planning and direct supports through the project (as of August 1997)	# of participants using institutional supports as of August/97 who were receiving planning supports to move to the community	# of participants surveyed in Spring 1996	# of participants surveyed in Spring 1997	# of participants receiving community supports whose survey data (Spring/97) was included in statistical analysis
Newfoundland	118	118	85	13	73	72	65
PEI	26	26	14	12	26	26	10
Ontario	46	32 sheltered workshop 63 residential	33	3	8	24	1
Manitoba	15	8	15		15	15	15
Saskatchewan	27	27	27		24	18	13
Alberta	39	14 residential 75 respite	71 moved from Rosecrest 29 already in community	4			
TOTAL	271	306	274	32	146	155	104

*Figures in this Table have been revised as of October 1998, and should replace those figures presented in the first printing of the report.

II. THE OUTCOMES: ACHIEVING COMMUNITY INCLUSION[6]

The evaluation was designed to examine the impacts of the six deinstitutionalization projects on achieving the three objectives of the NSIPD: effective participation; equal access, and economic integration. These goals were measured by five benchmarks that are commonly used in quality of life research: self-determination; supportive personal relationships; educational and economic integration; accessible communities and access to needed personal supports.[7] The evaluation found that each of these outcomes made a unique contribution to the process of community inclusion, one that can chart a path from institutional care to community life.

First, the evaluation found that the process of community inclusion began as adult individuals with disabilities, and families with younger children, gained opportunities to ***exercise of self-determination***—to be involved in making decisions that affected their lives. With the status to make decisions about where to live, whom to live with, how to spend one's income, and what to do with one's life, a new kind of decision-making process was put into motion. Its effects rippled throughout the social, economic, and political environment of communities.

Second, ***supportive personal relationships*** were found to be an integral element of community inclusion because they provided a context in which individuals' and families' new-found status was promoted, valued, and respected. Such relationships created a context for personal growth, communication, linkage to the community, and a new source of knowledge about individuals. It was through these relationships that a person's human qualities could be illuminated, along with their personal interests, strengths and needs.

Third, it was found that communities became more inclusive when individuals had opportunities for ***educational and economic integration***. For participants in these projects, educational and economic integration provided a real connection to communities beyond individual's homes, an opportunity to learn, to gain economically, and to be recognized as contributing members.

Fourth, community inclusion was fuelled by an ongoing process to enable individuals' ***access to and participation in the community***. The daily work involved in assisting people to join a recreation programme, attend a community event, become part of a church group signalled successes for particular individuals and community members. The process also made clear the deeply entrenched barriers to inclusion that people still face.

Fifth, underlying each of these elements of inclusion was the provision of ***individuals' disability-related, personal supports***. Whether paid staff, aids and devices, or the accommodations provided at a workplace, the provision of a highly decentralized and flexible system of supports made possible the vastly diverse paths into communities that individuals took.

No one of these elements was found to be more important than another. When they were present in an individual's life, and they were not present for all, it was their interaction and interdependent impact that led to such profound changes—for individuals, families, and for communities. The evaluation turned its lens, therefore, not only toward the doors of institutions and who left, but more broadly to the reconstruction of communities that made the moving out possible, and the moving in preventable.

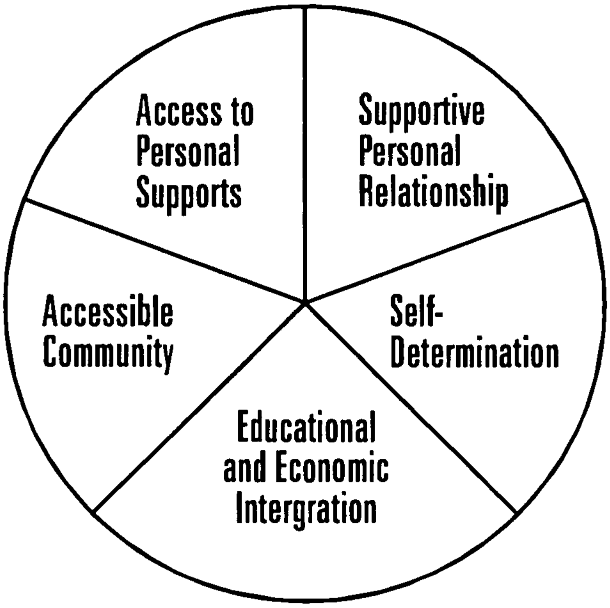
The following sections of the evaluation report examine changes in people's lives and support arrangements in each of these five areas. The changes were accomplished in a variety of ways; strategies varied from project to project, and from community to community. These are documented throughout the report. One challenge in a evaluation that cuts across so many different jurisdictions and sites is to see if any common themes emerge. In this evaluation, that challenge was made formidable by the sheer number of different communities in which individuals and families lived. Nonetheless, what became very clear through the evaluation, regardless of the particular project or community, was the centrality and interdependence of these elements in a process of community inclusion. The "whole" of an inclusive community was found to be much larger than the sum of these parts. The evaluation found, as well, that it was not possible to build such communities without the role that each part played in their foundation.

A. SELF-DETERMINATION

The process of community inclusion began with the establishment of decision-making processes in which adult individuals with disabilities, and families with children, were given the status and opportunity to exercise self-determination. Self-determination, as used in this evaluation, is understood to mean having personal autonomy respected; developing plans for the future and acting upon them; and having access to the social, cultural, economic, and political opportunities of one's community that help to define a person's possibilities.[8] The evaluation found that the process of making decisions in ways that kept the individual or family at the centre, and supported them to begin to direct their own lives, had far reaching impacts—at first in the institution and then in the communities in which they obtained support. Their sense of identity grew, accountability by others to assist them was established, opportunities opened up, personal capacities expanded, and health status improved.

Elements of Community Inclusion

(What is Community Inclusion?)



Self-determination was promoted through the development of individual planning processes, and the creation of support networks to assist in planning and in making decisions. In all the projects, a funding framework was established in which selection of disability-related supports was, to a significant degree, to be directed by the wishes and decisions of individuals and, in the case of the children in the Alberta project, by their families.

Evaluation Findings: Status and Opportunity for Self-Determination

The evaluation found that self-determination was most clearly realized for individuals and families where five distinct kinds of status and opportunity were secured:

- social status
- legal status
- decision-making status
- contractual status
- supported decision-making network

Social status

Analysis of the case study data across all the projects suggest that the possibilities for individuals and families to develop and exercise their self-determination relied to some extent on the belief by others that this is possible. Most individuals lost opportunities to exercise self-determination, in part, because they were considered by others to be incapable of doing so. However, that assumption either changed as individuals moved to the community and others got to know them personally, or is not as widespread as some may have assumed. The Newfoundland community attitude survey conducted in May/June 1997 indicates that to a large extent community members who knew people who had moved from the Waterford Hospital believed that individuals with intellectual disabilities have the "same hopes and dreams" as others (81%). This belief is one foundation to enable opportunities people with intellectual disabilities to make and pursue personal plans; it demonstrates the development of a cultural and social status supportive of individuals' self-determination. However, only 40% believe that individuals can make basic living decisions on their own. Other kinds of status were needed to secure a foundation for self-determination.

Legal status

One of the reasons individuals were not able to exercise their self-determination was because of restrictions on their legal right to make decisions. Legal status was removed from individuals included in the projects in a number of ways. The demographic survey reported that as of Spring 1997, 11% of individuals had court-appointed personal guardians for the purpose of managing their finances or personal affairs. Guardians have the legal power to make decisions within the decision-making areas authorized by the court.

In Newfoundland, many individuals had their legal status removed when they were committed to the Waterford Hospital. For persons who are committed, the Newfoundland Mentally Disabled Persons' Estates Act provides for guardianship of the estate of persons by the Registrar of the Supreme Court of Newfoundland.[9] In Prince Edward Island and in Manitoba, mechanisms such as "orders of supervision" were established for a number of individuals living in facilities.[10] In Saskatchewan, there was substantial concern by project partners that some parents or siblings might secure guardianship orders as a way of obtaining the decision-making authority to prevent an individual from leaving the institution, or to determine what community supports would be arranged.[11]

The consequences for those whose legal right to self-determination had in some way been restricted were clear: in a few instances they were not allowed to move from the facility despite their desire to do so; and, their ability to enter contracts for purchase of their disability-related supports was undermined.

Decision-making status

Regardless of individuals' formal legal status, all of the projects established a process to give to adult individuals—and in Alberta, families—status in the decisions to be made about where individuals would live, and the supports to be provided. The establishment of such a process was in marked contrast to the way decisions had been made in the past for many individuals. The account of one woman, who looked forward to moving from the facility where she was living, illuminates the many ways in which her decision-making status had been removed over the years:

> *I've lived here too many years. I went to [another institution] when I was 11 years old. My supervisor took me away from there because one of the staff was beatin' me up... I get really confused. I can't move out and get an apartment because my mother won't let me... I want to tell you something. One of the patients was giving me sex. I have to tell one of the supervisors. Mark [a person who was designated to plan for individuals to move to the community] won't talk to me on account of my mother. I'm going to tell the staff. I got my tubes tied last April.*

In the perception of one parent, loss of decision-making status has an impact on parents' ability and confidence to make decisions for their child:

Parents tend to lose their confidence after the professionals take over. They need to get it back by making decisions about where their child will live, the type and extent of intervention.

The primary mechanism for providing or restoring decision-making status was an individual planning process, which began with determining an individual's and family's hopes and vision for their future, identifying their particular needs, and putting into place the supports required. In the majority of situations, this process was most intense and focussed in the initial stages of an individual's or family's transition to new support arrangements. As individuals and support staff settled into new arrangements, the focus of the plan often became less clear. This is one indication that decision-making status was less secure for individuals than at the outset of the planning process.[12] Without a clear vision, the provision of decision-making assistance is without direction. The basis on which to resolve conflicts about strategies and plans to support an individual cannot be effectively resolved.

All individuals received a personal allowance, and all, including families in Alberta, received individualized funds (through various mechanisms) for their disability-related supports. However, only 40% of individuals who were surveyed are involved in making decisions about their own money. Most of this group manage their funds (usually their income through social assistance for personal comforts, as well as income for groceries, and household goods) with support from staff and their network. The research does show that the greater the extent of a person's disability (measured by the extent of their needs for support) the less likely they are to be involved in managing their funds, even with support from others.

Health care decision-making appears to be one area where adult individuals have been specifically precluded from involvement. The Newfoundland attitude survey, and the review of individual cases, indicates that physicians tended mostly to consult other professionals rather than to involve individuals in the decision-making process.[13]

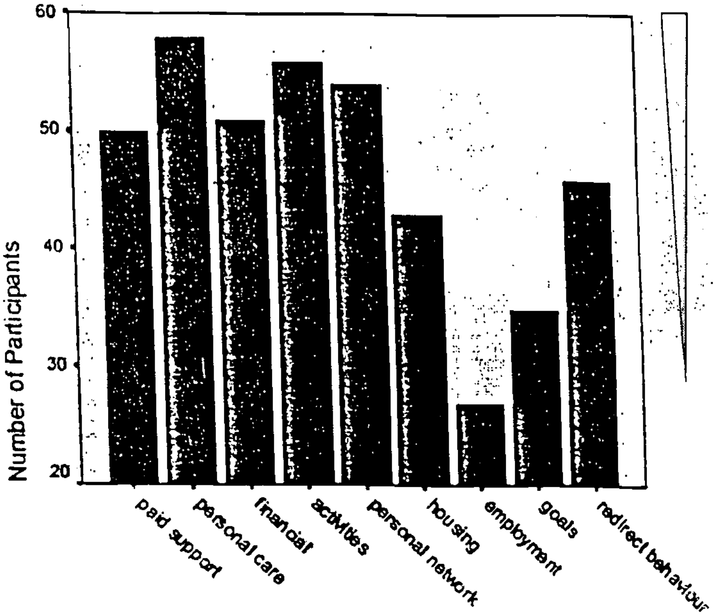
Contractual status

One of the measures of an individual's self-determination is whether or not he or she has status in the service contracts for funding and delivering their needed disability-related supports. In the vast majority of instances, individuals were not given contractual status. Most individuals did have decision-making status in the process for planning and hiring of staff, but they did not have contractual status—a signature on a formal agreement indicating what supports would be provided, by whom, and on what terms. Without contractual status, there is no formal accountability to the individual in provision of support arrangements.[14]

Supported decision-making network

About 65% of adult individuals had supported decision-making networks in place in Spring 1997. **Graph 1** shows the range of areas in which network members provided assistance in planning and decision-making: personal goals, personal care, financial assistance, and so on. This kind of support from family and other community members was essential to individuals in gaining the other forms of status, which together enabled self-determination. Networks helped to promote an individual's vision for his or her life, and helped to create one when it was unclear; and in this way helped to strengthen their social status in the community. The decision-making and legal status individuals had rested in part on an availability and willingness of support network members: to attend planning meetings; to assist a person in communicating; to help to make decisions; and to be recognized as a person's support network for the purpose of securing their legal status—as provided for, for example, in the Manitoba Vulnerable Persons legislation.

Graph 1—Areas of Planning and Decision-Making Support Provided



The research suggests that support networks tended to go through three phases in their development. These were related in part to the challenge of securing the ongoing decision-making status of individuals. In the *developmental* phase, members were involved in developing the new support arrangement. An external facilitator often facilitated the initial planning process. The network formed itself through the planning process and often social events. The decisions to be made were usually clearly laid out, if nonetheless complex and difficult (where to live, how to be supported). As plans and decisions were made, network members were involved in setting up the new arrangement for an individual. This was often an active stage, and very demanding in terms of time.

In a second phase, *managing community supports*, network members were confronted with the challenges of involving a person in their community, and assisting in managing a support arrangement. Demands of management were often enormous, with staff turnover, conflict management, and the day-to-day scheduling and organizing of supports. Time and energy was also required in finding community activities a person can be involved in, in assisting community groups and organizations to include someone, and in dealing with the negative attitudes individuals encountered. It is in this phase as well, that the complexity of providing support to individuals in making decisions became most acutely felt. Those who were interviewed indicated a range of difficulties: How should networks respond when they disagree with an individual? How should they deal with conflicts among themselves? What can be done when a network shifts from supporting the decision-making process to making decisions on behalf of a person? When does supported decision-making undermine independent and autonomous decisions that individuals might otherwise make? These complexities in decision-making were encountered in almost all support networks. This does not undermine the validity of providing support in making decisions; rather, it makes clear how difficult supporting people to make decisions really is. This difficulty was not as apparent when individuals were not able to exercise the decision-making status that the projects had granted to them.

A third phase can be termed *succession and renewal*, a phase that most networks appear to have the greatest difficulty in managing. The need to consider succession of the network often occurred with the sense of exhaustion, and sometimes failure, at not meeting expectations in the earlier two phases. As membership began to change, new people were needed, and networks found themselves defining and redefining who they were. In one instance, the marriage of a couple who had sat on the network together ended, and they felt decisions had to be made about which would continue to participate. Others decided they had other commitments, or short-term personal crises required they focus their attention elsewhere. Sometimes networks simply stopped meeting because the demands of providing planning, decision-making and management assistance were beyond the capacities of the group. In these situations, paid staff tended to manage the situation on their own, but without the input and accountability provided by the network.[15]

The importance of support networks in securing and supporting self-determination cannot be under-estimated. The research clearly identifies a need both to address the lack of a support network for about one-third of individuals, and how to sustain networks over the long term.[16]

The Place of Increased Self-Determination in Community Inclusion

As people gained decision-making status, and were supported by a network who were committed to the realization of their personal goals, a new place was carved out for them in their communities: people gained a stronger sense of personal direction; greater accountability to individuals by support staff was structured; the opportunity to make decisions led to greater participation, freedom, and respect from others; personal capacities expanded; and, health status improved.

The evaluation found that as individuals were supported to make decisions, a ***stronger personal direction emerged*** that guided their own involvements in the community and made clearer how others could support them to become more included. Individuals talked of a range of plans that were important to them as their decision-making status was respected and supported: for example, plans to visit parents some distance away, wanting to have a garden, plans to begin working or going to school, wanting to go on the annual trip into the country with members of his Innu community. One man expressed the importance of the achievement of his personal autonomy, being able to say "no" to how he was treated in the facility:

> *I was diapered every night at* [the facility]. *It was their decision. No, no more diapers, no more* [name of the facility]. *The doctor said I wasn't ready to move out...but I didn't think I'd be in for fifteen years. If I could, I'd like to go to bingo, would like to go to the spa, and I'd like a full-time job.*

One community member reflected that it wasn't until she got to know the individual that she began to recognize possibilities for him:

> *I learned he is a person, he has talent and characteristics. He's made me appreciate that those with disabilities—they want to be like everyone else. His personality has come through as I have come to know him. He has a unique personality.*

Emergence of a person's character and identity, on the basis of which a more authentic personal plan could be developed, sometimes took a good deal of time. When he first moved, Donald was in a wheelchair, could not walk, he showed very little emotion, and couldn't give a hug. The only word he said was "no" according to a staff person who had known him in the hospital. He made very little eye contact, stayed in bed, didn't want to be involved, and appeared to suffer from depression. His gums were infected, some teeth were broken, his skin was pale. By the time of the first interview (March 1995), he was walking, his complexion had improved, his teeth were fixed, he was communicating more, and giving hugs to people he cared about. By the time of the second interview (August 1996) his personality had become increasingly visible and according to his sister and support staff he was much more active and motivated. The live-in supervisor noted that he liked babies, was gentle when holding them and had a good memory. He was making phone calls, and "pitching in" with household chores. His sense of humour had begun to show; a few weeks prior to the interview he had turned the hose on the live-in supervisor when she was sunbathing, a prank that both he and the supervisor found amusing. He was also proud that he had learned to write his own name. He was increasingly surprising people with his expression of emotions—when at first there was so little, other than his frustrated aggression. By the time of the third interview (March 1997), he was talking in full sentences, his attention span increased from about two minutes to watching a full length movie. He still needed encouragement about bathing, but was starting to see a dietician and had started to lose weight.

Another man returned to his Innu community in Labrador after living in the Waterford Hospital for a number of years. After he moved, he began to speak in his native language again, his health improved, and he was drawn back into his culture. As this occurred, he also began to express his desire to participate in ways he not had the opportunity for in so long; for example, going with his family and community members "into the country" to set camp for an extended period, an annual event. This was a clear example of how important community and culture is to fostering capacities and opportunities for the exercise of self-determination.

Another individual began to make her wishes known as others came to understand her. One neighbour said,

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> *She's got her own mind. When she wants something she let's you know... She's well liked and she likes people and interactions. She's improved tremendously and has a large circle of friends... I've seen a big change. She was like a zombie when she came out.*

After getting over his initial anger and outbursts, one man became very active around his house and in the community. When asked to define the purpose of the project, he said,

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> *So I can have my own house, my own life. Thirty-two years in the* [institution]. *That's a long time. I'm forty-nine now.* [Live-in supervisor] *says I could live to be eighty. That's thirty-one more years. I hope I live to be eighty. I have plans... I've got it made.*

Having status in decision-making was closely associated with ***greater social, educational and economic participation, freedom, and value and respect from others***. The 40% of individuals who were involved in managing some or all of their funds with or without support were involved in making a variety of decisions about how their money would be spent, on what activities, with whom, and when. Those who were supported to manage some or all of their funds were perceived by those who knew them to have more freedom and choice, and more real opportunities to be involved in the community, than people who were not in control of their money. As well, the personal vision for an individual's life was clearer to those around him or her.[17] A very strong statistical relationship was found between those who are involved in managing their own funds, and involvement in integrated educational and/or employment-related activities.

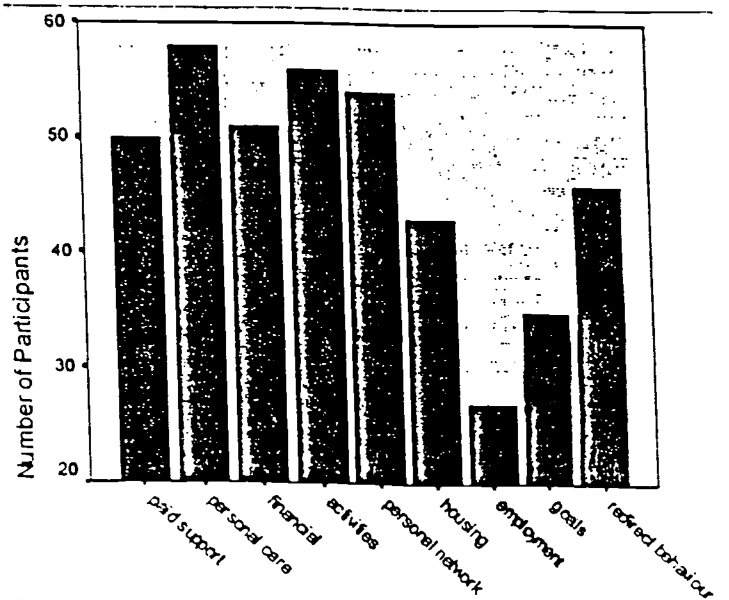
Undoubtedly, the extent of a person's needs and disability is an intervening factor in these relationships. However, the fact that such strong relationships exist between decision-making status and these positive outcomes, suggests the importance of the policy and program emphasis on securing decision-making status. Even when a person may not fully understand how to make decisions about his or her income, granting them decision-making status requires that others place the person at the centre of the process. This factor re-positions him or her in personal and community relationships, thereby leading to the positive outcomes associated with decision-making status.

In most situations, the creation of decision-making status created ***greater accountability between staff and individuals and families***. Staff at institutional facilities and in most community service agencies are not structurally accountable to individuals they support. Through these projects the structural relationship of support staff to individuals and families changed dramatically, except in Saskatchewan where an agency model for developing supports was used. There was a recognition that staff in some way were working for individuals and/or their support networks, and in the case of Alberta, for the individual and family. This accountability is one of the factors that has led to such positive outcomes for individuals; staff's role was to "follow the lead" of individuals, or to support individuals to "take the lead" where they had not done so in the past.

An ***improvement in health status, and an expansion of personal capacities*** (physical, communication, social) was observed for many individuals. The data pointed to significant changes in individuals' capacities after settling into their new arrangements. With regard to individual's health status, there is also substantial overall improvement. Health status was reported as "good," "very good," or "excellent" for 64% of participants at the outset of the project. By the time of Spring 1997, this outcome was reported for 84% of participants who had moved. In Spring 1996, 36% reported "poor" or "fair" health; a year later those reporting this way dropped to 16% (see **Graph 2**). Those had status in decisions about their personal income for basic and disability-related expenses, and were involved in managing these funds, were much more likely to have improved health status than those who did not.[18]

That individuals and families gained greater status—whether legally, in terms of the decision-making process, contractually, and/or through a support network—and that health status improved is consistent with other research. There is a substantial body of work indicating that as individuals gain greater control and decision-making status with regard to the conditions that affect their lives, their health status improves.[19]

Graph 2—Change in Health Status from Beginning of Project



B. SUPPORTIVE PERSONAL RELATIONSHIPS

Supportive personal relationships provided a context for building inclusive communities. They had a positive impact for individuals and families by strengthening the personal resources they needed to exercise self-determination. Relationships also changed others in communities by transforming their beliefs about the capacities and value of people with intellectual disabilities. It is on the groundwork laid by the exercise of self-determination and supportive personal relationships that broader community support for inclusion was built.

Study Findings: Nature and Extent of Personal Relationships

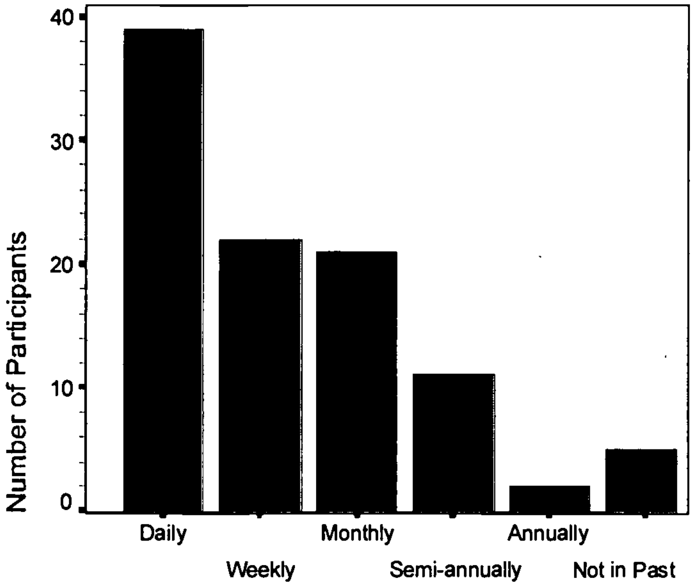
The study found that for individuals and families who were participants in the deinstitutionalization projects, "supportive" personal relationships evolved from within four groups of people:

- with family members and relatives
- with community members
- with paid staff
- within self-advocacy and family networks

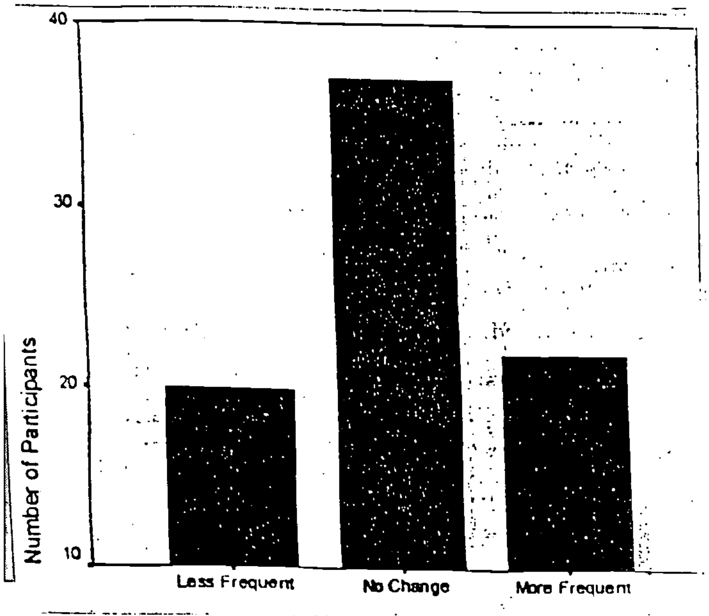
Relationships with family members and relatives

A history of the decision to place a child or an adult in an institutional facility was recounted by many families as a painfully difficult one. They made that decision for a variety of reasons: a recommendation by a physician that no other option was suitable; from an incapacity on the family's part to provide all the needed support; from a concern to protect the individual, or to protect others from the individual; or from a failure on the part of the community to provide adequate supports. A couple of the parents interviewed had placed their child in the institution because of a fear that he or she could be mistreated by community agencies, seeing in an institution a refuge for a vulnerable child.

Graph 3 — Frequency of Contact with any Relatives



Graph 4 — Change in Contact with Relatives



With the prospect of establishing community supports, a new way of viewing a family member and his or her possibilities, had to be created—within the family, within the culture of the institutional staff, and within the broader community. This began to happen as relationships with family members were strengthened. **Graph 3** shows that, after their new arrangements were put in place, the majority of individuals had daily or weekly contact with relatives, usually mothers and sisters.

Over the period Spring 1996 to Spring1997 contact with relatives increased for about a quarter of individuals, declined for about a quarter, and remained constant for approximately 50% of individuals.[20]

Families observed a number of changes as they had the opportunity to become more involved with their family member. They spoke of the personal growth in individuals; of the opportunity to become a family again; of a potential they did not realize an individual had; and of a new or renewed sense that an individual was a real person.

There remain approximately 20% of individuals who have little or no contact with family members. In a few situations, individuals have no known relatives. In the majority of situations for this group, efforts by paid staff and others to develop relationships has not proven successful; energy invested in doing so has tended to wane after repeated attempts. Moreover, mere contact with family members and other relatives is a necessary, but not sufficient, condition of a supportive relationship with one's family. In a few instances, it was reported that parents were continually trying to control the decision-making process for an individual, in ways that conflicted with what an individual wanted to do (where to live, who to spend time with, what activities to be involved in). This had two consequences in these situations: decline in the involvement of other members of an individual's network; and an increase in an individual's outbursts of anger.

Relationships with community members

Relationships were fostered with friends, neighbours, and the wider community through invitation to them to become members of individuals' support networks, and as individuals were introduced to neighbours and others in their communities.

Graph 5 indicates frequency of contact between individuals and these community members. Over 50% had daily or weekly contact, primarily with friends, and secondly with neighbours. To a lesser extent, individuals had daily or weekly contact with members of the broader community, through organizations they became a part of church communities, and recreation clubs. Overall, those community members surveyed in the Newfoundland community attitude survey reported a high degree of personal contact with individuals who had moved under the project; over 60% indicated they visit the participant in his or her home. Change in contact between individuals and friends and neighbours over the period Spring 1996 to Spring 1997 follows patterns similar to that of change in contact with relatives: contact decreased for about one-third of individuals, increased for about one-third, and remained constant for one-third.[21]

Generally, increased personal contact with community members meant that individuals became more widely known in their communities, and often more included as a result. There are many examples that demonstrate this finding. One man moved to a community where he had not grown up because his family was concerned about past issues his return might raise. Very soon upon arrival in his new community he got to know neighbours and community members. People in the local restaurant now greet him warmly, he goes dancing and to dinner, he visits friends from the institution where he once lived, and he is becoming well-known and well-liked in his community. One community member said of him:

He knows me more now, he is more friendly, he will come over to greet me and shake my hand when he sees me out and about, that is a change from at first.”

Another stated,

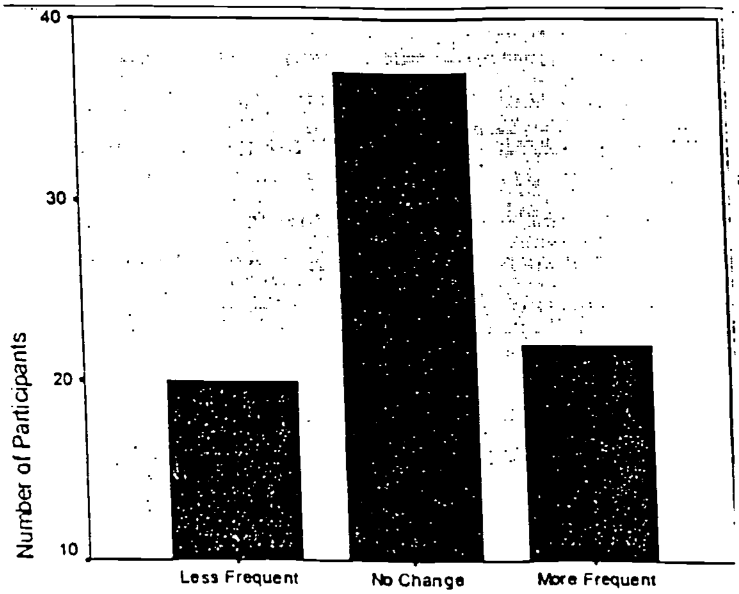
He is welcomed in many homes because of his good nature. We wonder why he went to the institution in the first place. He didn't need to be institutionalized even though his family could not provide him support.

And another told the story,

How we had our first visit was through selling Avon... I was making a delivery to one of his workers and he invited me in for a cup of tea and we hit it off from day one.

Another individual decided to move back to the community where he had originally lived. Attitudes of many community members were quite negative towards him after he moved from the institution, and eventually it was decided that he would move to a new community. Inclusion was not going to take place without the personal relationships by which he would come to be known in valued ways. By the third round of interviews for the evaluation, his support staff indicated a significant change in his life, because in his new community he was able to develop a number of supportive relationships. He was "dropping in" on neighbours

Graph 5 — Frequency of Contact with Community Members



for tea, attending community events, going to church, and visiting friends who worked at the local garage. Many people in the town had come to know him, and valued his presence among them.

Not all encounters with community members were positive ones for individuals. Most of those individuals included in the case studies and reviews, had experienced a negative encounter. Both individuals and paid staff reported a range of what they considered harmful actions by others: a comment to one woman who was attending church in her community, about why she was even at the church; refusal by an adult education program to include a person, on the basis of her disability; refusal by a seniors centre to welcome and support individuals to participate in the program and facility. The majority of reported negative encounters in the community was with professionals, primarily in the health care system, as opposed to neighbours or other community members met in social situations. This is consistent with the community attitude survey, where professionals in the health care system who were interviewed indicated generally more negative attitudes about people with intellectual disabilities, than other community members.

Concerns were also raised about how individual participants related to community members. In many of the case studies, support staff and family members recounted that after individuals first moved to the community there were often angry, sometimes violent outbursts, extreme mistrust of others, self-injurious actions on the part of individuals, and an unwillingness or inability to express their emotions in other ways. The Spring 1997 survey indicates that staff provided emotional support to 90% of individuals at least once or twice daily, and they were involved in "re-directing behaviour" at least once daily for almost 70% of individuals. In approximately one-quarter of case studies and individual situations reviewed, concerns were expressed about inappropriate sexual behaviour by an individual, and in a few situations concerns were expressed about the potential for repeat sexual offending by an individual against children or adults.

Relationships with paid staff

People also developed significant personal relationships with support staff and the "alternate families" with whom they live. Friends and families of paid staff often became an extended social network for individuals. In one instance, a woman has become very much a part of the family with whom she lives—headed by a woman who is a nurse and a man who is principal of the local school, and with three children. The family has taken her on a holiday, celebrated her birthday in a local restaurant, and taken her to church with them on Sundays. She has become attached to the family, and is especially excited when one of the children is present. While her brothers and sisters live some distance away, contact and visits are made when they can.

"Associate families" were contracted in the Alberta project as a means to provide paid respite support to families of children with disabilities and complex medical needs. Different than "foster" families, associate families do not replace the primary care-giving role of a child's primary family. Interviews with associate families and a review of individual cases in Alberta with project staff, indicate that close and nurturing attachments by associate families to children with multiple disabilities and complex needs have been developed. This happens most consistently where there are appropriate back-up supports to establish the relationship between the two families, and where there are clear agreements about roles and responsibilities with the child's own family. In situations where a child's parent(s) did not feel they had the control they wanted over the arrangement with the associate family or other respite caregivers, the relationships tended to breakdown and concerns about the quality of care for their child increased.

There were a few reported instances where paid support staff violated an individual: through sexual or physical assault, through stealing of funds, or through social and emotional neglect, resulting in an individual's isolation in the community.

There were more instances where staff experienced physical and verbal attacks by individuals, and in a few instances sexual harassment. In most situations, back-up assistance of social workers and/or behaviour management professionals were available to staff to deal with situations and develop a plan for dealing with the behaviour. There were reports in a few situations that the back-up response to staff concerns was not there, leaving staff physically hurt and emotionally distraught. In most instances, staff learned to interpret individual's behaviour, find ways of re-directing it, and respond to underlying concerns. Some individuals disclosed previous sexual abuse as they began to trust staff. As individuals became more trusting, and experienced longer-term personal relationships with staff and others, the violence and behaviours found difficult by others usually declined.

Relationships through self-advocacy and family networks

All of the projects invested in building self-advocacy and/or family networks to provide participants with access to a broader network of supportive personal relationships in their communities.[22] The project in Alberta created a network of families who were available to meet with families using Rosecrest, to share experiences, concerns, and ideas about how to develop community rather than institutional respite supports. However, some parents who were using Rosecrest for respite were concerned that the network was part of a plan to close the facility. Consequently, the network pulled back from playing a proactive role, and simply let people know they were available.

The organizations and networks created through the projects were used to a greater or lesser extent—depending on the resources available to develop and maintain them, and the links built between project participants and the organizations and networks. In PEI, for instance, no direct links were made between individuals moving out of the Hillsborough Hospital and the People First organizations developed. But the organization did take root in a number of communities in the province as a result of the project, and the self-advocates who participated indicated they were committed to making their organizations last, but needed the advisors and support to do so. In Ontario, the self-advocacy group established in the Kitchener-Waterloo site regularly held "Welcome Home" parties for individuals moving to their community from institutions. The organization became a source for building friendships for many of the individuals moving from facilities.

In Alberta, a couple of parents did call members of the parent network created for information about what was available in the community. Another parent who was considering placing a child met with a family who had kept their child at home—and then made a decision not to place their child in the facility. In reference to how long it takes to develop supportive relationships between families, one parent on the network said,

> *Relief and staffing models are such a small part of what people need. They need to explore relationships with others and what it means to have their child part of a community. Building links with other families needs to be seen as long term. It cannot be a three-year project. Gentle persuasion takes more time.*

For the most part, the networks and organizations created played a larger role in community development than they did in providing a source of personal relationships for individuals and families participating in the initiatives. They raised issues affecting individuals and families, held informational meetings, provided representatives to participate at meetings and committees of the project partners, and built networks with other community organizations.

Analysis of the demographic survey indicates that the extent of supportive personal relationships in individuals' lives still has enormous scope to grow.

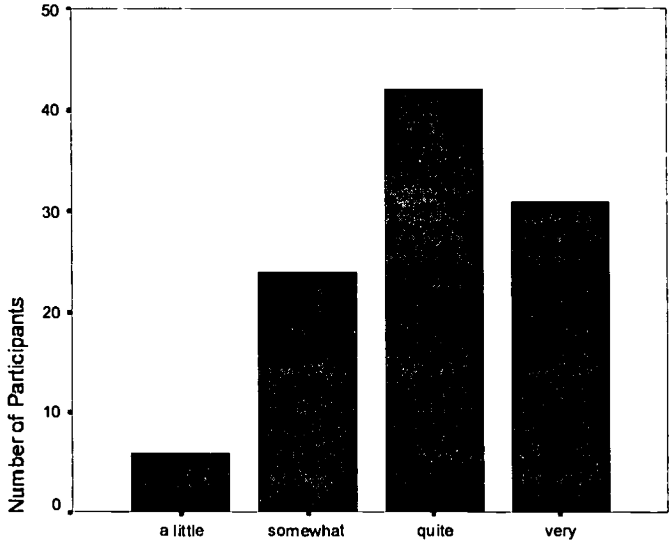
Twenty-five percent of individuals have "hardly any" supportive personal relationships in their lives, and 40% have "none" or only "a few" relationships that reflect his or her interests.

The Place of Supportive Personal Relationships in Community Inclusion

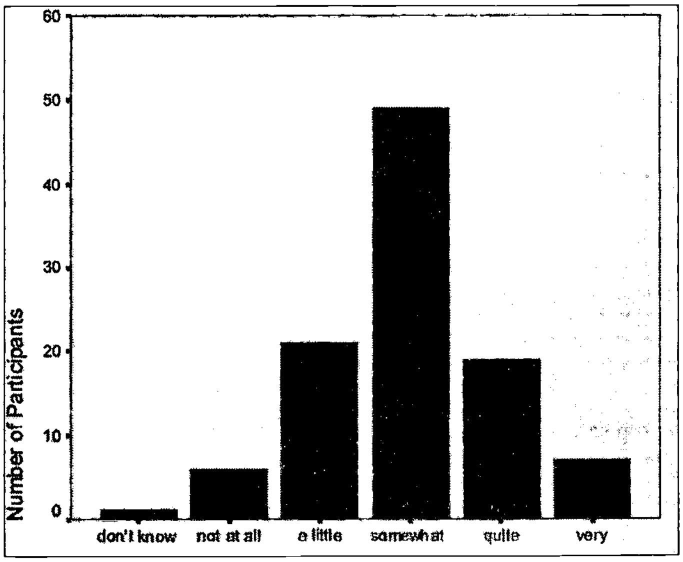
The building of personal relationships contributed to community inclusion in a number of ways. They helped to create a community of value and respect for individuals; created an enabling social environment; enhanced communication capacities; provided linkages to the community; and were a new source of knowledge of individuals.

First, supportive personal relationships played a key role in inclusion because they helped to create a community where ***individuals were valued and respected.*** The survey indicates that 71% of individuals are "quite" or "very" valued and respected by those who know them; whereas there is a perception that only 25% of individuals are "quite" or "very" valued and respected by general community members who do not know them, but whom they encounter. (**See Graphs 6 & 7.**)

Graph 6—Value and Respect Afforded by Those Who Know Participant



Graph 7—Value and Respect Afforded Participant by Larger Community



Statements by family members, community members, and paid staff pointed to how *they* changed as a result of getting to know individuals who became participants in the initiatives:

I'm more open and accepting of people with disabilities now. Before I felt uncomfortable with people like this.

I've never really been around people like this. Now I'm more comfortable and relaxed... Most times you don't know how to react. George has helped me with this.

I have never had much experience with disability and have discovered that these are people too, and they know how they are being treated.

I know that he loves kids... I was wary about having kids *around him, but after the first day I met him I knew he could be trusted with my son. They took to each other, he's good in caring for himself as well. I'm pleased that people are finally starting to take a look at what's going on with people with disabilities... and that they are being cared for in loving homes rather than looked upon as monsters.*

He is happy and loves to be involved in things going on. His being in the community has taught a lot of people... He has taken the fear out of people. It's been a big advantage for children to know someone like Mark.

Developing supportive personal relationships changed the lives of participants in the projects; the relationships also changed the community members who came to know them. Over 90% of those surveyed in the Newfoundland community attitude survey indicate that those individuals are valued and respected by those who know them. The survey also indicates that having positive attitudes about an individual's personal relationships with others tends to be associated with having positive attitudes about individuals' broader inclusion in their community and society.[23]

One of the key factors that appears to engender positive attitudes towards individuals with intellectual disabilities is coming to know an individual in a personal way. Of those surveyed in the Newfoundland community attitude survey, almost 40% indicated their views changed as a result of getting to know a person who moved from the Waterford Hospital. All but one of those respondents indicated that the change in their views was a positive one, with the majority indicating their views had changed "a great deal" as a result.

Supportive personal relationships also ***provided a social environment for building self-esteem and personal capacities***. Skills and capacities of individuals changed over the period of moving from a facility and/or obtaining community supports through the projects. Rather than a pre-test, post-test measurement of behaviours or skill development,[24] an ethnographic approach was taken in this evaluation to examine the changes in people's lives.

In almost all of the case studies, the accounts point to impressive change. Individuals stopped "institutional behaviours" like grabbing for food; in many instances individuals' previously violent outbursts declined over time, physical capacities grew to the extent that some individuals who were in wheelchairs at the outset were beginning to try walking. According to a staff person who worked at an institution, " [one man] *wouldn't sit down during the day, he would stand near the wall, he would dump his head in the toilet, he would spit.*" Since he's moved none of this has happened. An alternate family provider indicated, "*now we can get a smile out of him, he giggles, he's more content.*"

Personal relationships provided ***a context for enhancing communication***. When individuals were in relationships where they were valued and respected, their confidence and desire to communicate with others often grew. Family members, support staff, and community members pointed to a number of changes: using new words, talking much more than when a person first moved, initiating conversation, expressing wishes and making demands where at first the only verbal expression used was "no"; and increased hearing capacity on the part of one individual. In one situation, a man who had communicated only with a few signs at first, had at the time of the final interview a vocabulary of eighty words. In some instances, others also began to adapt their communication skills in response to individuals' particular needs. For example, members of one support network took it as their responsibility to begin to learn sign language because an individual they were supporting did not speak verbally.

A few individuals expressed in interviews their enthusiasm to learn to read and write, something they thought they could never accomplish. In one interview, a person pulled out a workbook he was using in his literacy class, another talked of how proud she was of her growing ability to read and write. The Spring 1997 demographic survey indicates there is some participation in formal literacy and adult education programs by those who have moved: six individuals were in mainstream adult education classes and eight were involved in home-based tutoring.

In the context of improved communication, it was reported that individuals could also begin to deal with their anger in more appropriate ways. One alternate family provider said of a man who had moved from a facility,

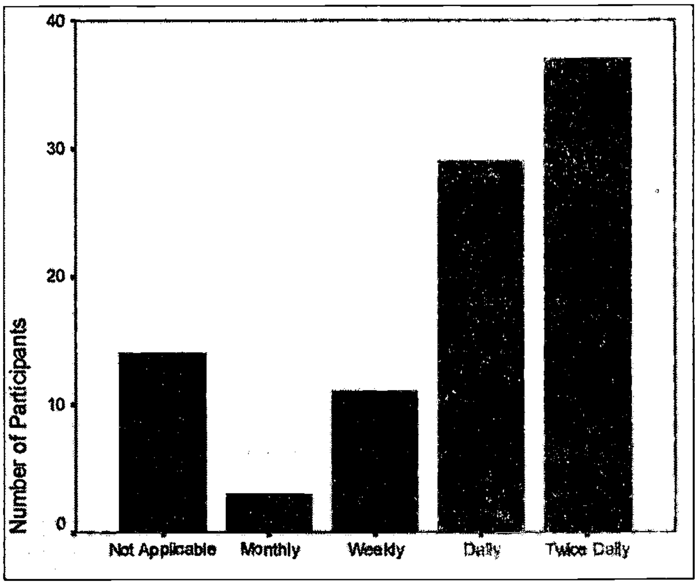
He feels more comfortable talking about what he wants and decisions he wants to make. He's much more in control, doesn't get angry as much. He has much more freedom and control now.

One individual reflecting on what a difference it made to him to have personal relationships in which he was understood, said,

When people didn't listen to me, that hurt me most.
People would say, 'you don't know how to talk.'...
When I came here I was afraid people wouldn't listen.

The need for staff support to assist individuals in communicating with others appears substantial. The second demographic survey indicated that 70% of individuals need daily communication assistance from support staff in the form of initiating contact by telephone or in interpreting individuals' gestures, or through some other form of assistance. Staff support another 12% of individuals on a weekly basis in this regard. (See **Graph 8.**)

Graph 8—Requires Assistance with Communication with Others



Individuals who had supportive personal relationships, tended to have ***more linkages with their broader community***. They were included in family events, in the social lives of paid staff, and their homes also became a place where others visited. As individuals experienced respect from others they met, their confidence to widen their activity in the community grew. They came to be known by others in the community—whether at the recreation centre, bingo-night, or the grocery store, for example. Incidents where individuals encountered negative attitudes from others often had the effect of diminishing, if only for a time, their circle of activity.

Finally, supportive personal relationships provided ***a new source of knowledge about individuals***. Institutionalization requires the construction of bio-medical and functional knowledge of individuals. Institutional case files of many individuals in the initiatives were voluminous. While this knowledge facilitated the provision of supports within the institution, new knowledge had to be created in order to facilitate a transition to community supports. All the projects put in place a "person-centred" planning approach, which drew on the personal knowledge of individuals, family members, and others who knew individuals. The personal knowledge required included a person's interests, activities and goals they wanted to pursue, communities they might want to live in, family and other relationships they had and wanted to have. At first, this more personal knowledge was scant for many individuals. They were known mostly by staff in institutions. Families were either no longer in contact, or not used to thinking about an individual's life in the community, and how he or she could be supported in different ways.

As the transition planning process proceeded for many of the individuals, more and more personal knowledge could be tapped: from the individual him– or herself, from family members' knowledge of an individual's past, from the staff at an institution who had come to know an individual personally. After individuals began using new community supports, and new relationships were formed, the repository of others' personal knowledge of an individual grew. The formal and informal sharing of this knowledge was found to be an important resource in building a community's awareness about the possibilities for including people.

C. EDUCATIONAL AND ECONOMIC INTEGRATION

Opportunities for greater self-determination, combined with the support of personal relationships—both paid and unpaid—provided a foundation for many individuals to become involved in the social and economic life of their communities. Many of the approximately 40% of individuals who did become educationally and/ or economically integrated in some way, found a direct path to recognition by others of their potential and their contribution. This form of integration gave people a place in their communities where they were engaged with others in learning and in contributing to their communities. Educational and economic integration thus became an important lever in the dynamics of community inclusion.

Educational and economic activities were identified by many individuals early in their planning process as a desirable pursuit. Their paid staff and support networks were to facilitate the development of these opportunities. Some individuals met with enormous success at a personal level: people found jobs; they learned to read and write; a number did find volunteer and part-time jobs; and some began and some finished educational programs. Others found that they first needed to deal with the enormous consequences of moving to the community from an institution, settling their housing and support arrangements, and beginning to build personal relationships.

Evaluation Findings: Educational and Economic Participation

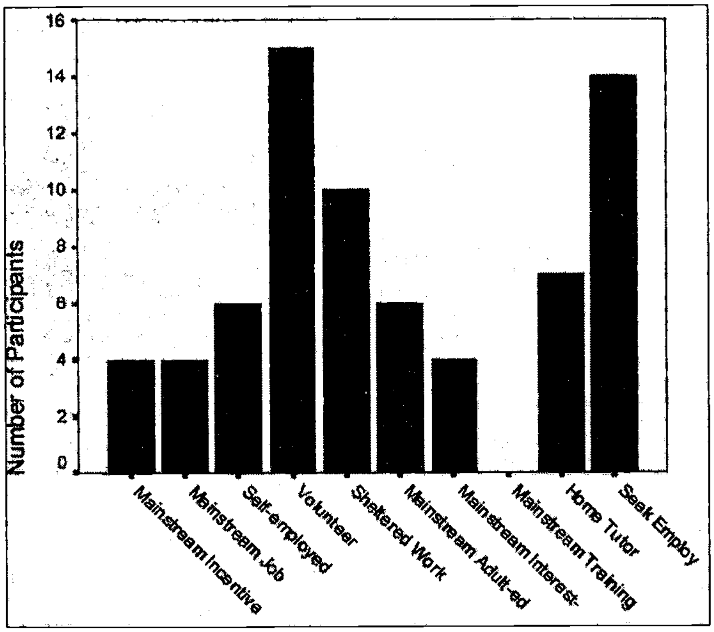
The evaluation found three predominant patterns in educational and economic participation of individuals involved in the projects:

- increased opportunities and participation
- diversity in forms of participation
- gender difference in participation rates

Increased opportunities and participation

Just over 40% of the adult participants in the projects obtained a paid or volunteer job, or participated in some form of education or training. The majority of this group are involved in education and employment-related activities in integrated settings in their communities (excluding sheltered workshops). **Graph 9** shows the kinds of economic and educational opportunities individuals were involved in as of Spring 1997. Individuals were mostly involved in volunteer work, sheltered work, some form of paid employment (an incentive program, a regular job, or self-employment) and various forms of education.[25]

Graph 9—Current Education/Employment Activities



Participation in these economic and educational opportunities represent a significant change for most of the individuals involved (a few of the individuals were involved in sheltered work in community settings prior to their participation in the projects).

Diversity in forms of participation

Expanded opportunities and participation rates were achieved through individuals' involvement in a wide diversity of settings. No clear patterns of involvement appear from the case study data, however the majority appear to be in private for-profit and non-profit, retail and service sectors. Individuals were not involved in the manufacturing sector, or in the public services sector. A listing of places where individuals were either employed or involved in volunteer work indicate the wide range of opportunity created. These include: working at a garage, a day care (washing dishes), hardware store, out of own home (making baskets), book shop, at church, library, pet store, auto parts junk yard, delivering flyers, hospital (deliveries to patients' rooms), women's shelter, recycling centre, beauty salon, record store, flower shop, own business selling dolls, bar, fundraising with boys and girls club.

Gender difference in participation rates

There is a marked difference in participation rates of men and women in integrated educational and employment-related activities. Almost 50% of men, and just over 20% of women, have some form of involvement in education/training, volunteer work, or paid employment. One factor that appears, statistically, to have some impact on the gender difference in participation is that men are much more likely to be involved in managing some or all of their funds, with or without support from others, than are women.[26] Those involved in managing their own funds are also much more likely to be involved in educational and/or employment-related activities.

The Place of Increased Educational and Economic Integration in Community Inclusion

Involvement in jobs, volunteer activities, or in education or training programs gave individuals ***opportunities to learn*** that they had not had in the past. That the participation rate in education and training is higher than other kinds of economic/educational involvement (paid or non-paid employment and sheltered workshop) is consistent with case study data from this research. Many indicated they wanted to learn to read and write, and wanted to enroll in adult education, literacy, and home-tutoring classes.

Educational and employment-related involvement also ***provided a path for individuals to a wider set of respectful and valued relationships*** in the community. Diverse educational and employment opportunities provided a place for individuals in many more areas in their communities than they had previously been involved in. According to the individuals themselves, or to their support staff, most of those who were involved in either paid or volunteer work settings had positive experiences. Their employers or educators spoke to staff of the contributions that individuals made, and the fact that their own expectations had been exceeded.

However, where individuals had not been adequately supported, or employers or education/training providers did not have the supports to fully include an individual, these encounters often proved to have negative consequences for the individual. Individuals tended to lose self-confidence and sometimes the motivation to continue looking for this kind of involvement. In other words, just getting into an education class, or into a job was not enough to spark a process of inclusion, nor for individuals to obtain the benefits of those involvements.

For example, two individuals in the case studies were asked to stop participating in adult education classes because it was felt they needed more "one-on-one" attention than could be provided. There was also a perception by some that individuals were "not ready" to participate. In one situation, staff wanted to support an individual to begin a vocational program, but reported that the man's sister felt he was not ready. In another, it was felt that an individual's personal behaviour was not yet suitable for an education class; and in another a person's poor grooming was cited as the reason he could not get a job.

Participation in employment also played a role in community inclusion simply because it gave people a chance to ***earn income***. This brought both self-esteem for individuals and additional income. Twenty percent earned income through employment. Earnings were small by Canadian averages, but were significant for these individuals, and they increased their earnings over the period 1995 to 1996.[27] Average annual earnings of those who were in paid work in 1996 was $850 (up from $600 in 1995), with an annual maximum in 1996 reported of $3,600 (up from a maximum of $3,000 reported in 1995). The average annual earnings of those in the Newfoundland project were twice as high as the national average for all those with earnings. Of those reporting earnings, only one-fifth were earning minimum wage or above in a "mainstream" setting.

Analysis of the Newfoundland community attitude survey indicates that those who have come to know individuals personally, through their social, educational or economic involvements, demonstrate widespread ***community support for educational and economic integration***. Over 85% "disagree" or "strongly disagree" with the statement that it is *not* good use of government dollars to invest in the education and training of people with intellectual disabilities, and believe that individuals can be productive in the labour force with support.[28] [29] In surveying the community concerns of this group, "employment and education opportunities for persons with disabilities" ranks fifth overall. (See **Table 2**.)

D. COMMUNITY ACCESS AND PARTICIPATION

Research findings showed that when individuals were able to gain access to the diverse social and physical environments of their communities, their opportunities expanded, and communities were better able to support individuals. Thus, community access and participation emerged as another defining aspect of community inclusion. Participants in the NSIPD projects now have access to and use a vastly wider range of community places and resources than before their involvement in the project.

Accounts given by individuals, families, and their support staff indicate the diverse opportunities for involvement in their communities that the projects made possible: a child moving back to a family home full time, or receiving respite supports from another family in the community; an individual being recognized at the grocery store and having people stop to chat; the freedom of not being physically restrained at the institution and being mobile in the community; having a birthday dinner at a local restaurant; moving into an apartment on one's own; becoming "a regular" at the fitness club; having a traditional "feast" to honour an individual's return to his aboriginal community; starting a business; earning wages. The wide

TABLE 2—CONCERNS AS A CITIZEN OR COMMUNITY RESIDENT

N=114	Frequency	% Responses	% Respondents	Rank
opportunities for young people to stay in Newfoundland/Labrador	10	67%	93%	1
lack of employment opportunities	10	57%	92%	2
future of your community	99	7%	87%	3
health care system	99	7%	87%	4
employment & education opportunities for people with disabilities	97	7%	85%	5
public input into government decision-making	93	6%	82%	6
alcohol and drug abuse	90	6%	79%	7
education system	89	6%	78%	8
abuse of women and children	80	6%	70%	9
availability of facilities and services	77	5%	68%	10
stress on women from taking care of family members	78	5%	68%	11
poverty	74	5%	65%	12
abuse of people with disabilities	72	5%	63%	13
social isolation of people with disabilities	71	5%	62%	14
level of community involvement	68	5%	60%	15
justice system	68	5%	60%	16
level of volunteerism	65	5%	57%	17

 # Concerns: Low=9; High =17 (max) Mean: 12.55 Median: 13.39 N: 114

range of places that people identify in their accounts is telling of the extent to which communities opened up to people with intellectual disabilities: working at a women's shelter, ski-dooing in the woods, going to the bingo hall, attending hockey games at the arena, church, fitness clubs, hiking, camping, and fishing in the wilderness, going to the grocery store, People First group, social events at the sheltered workshop, the shopping mall, restaurants, running at the track, going to a pool hall, a home in the community.

In summary, there are low rates of participation in employment and education, relatively little attention given by support networks to employment, and a significant gender difference in participation rates. These trends suggest that a systematic investment in planning for and supporting this type of participation has not been made in most cases. Consequently, the potential for building inclusive communities that comes with economic and educational integration is not being realized to the extent it might.

Evaluation Findings: Changing the Physical and Social Boundaries of Communities

The physical and social boundaries of communities were re-drawn through the projects to include many individuals who were once excluded. Three aspects of the physical and social environments of communities were particularly affected:

- housing
- social life of communities
- services and facilities

Housing

The NSIPD deinstitutionalization projects mark a significant shift from previous deinstitutionalization and community support projects for people with intellectual disabilities. One significant departure from most other initiatives is that, for the most part, no new housing stock, designated as "group homes" or "supported living units" were produced as the means of meeting the residential requirements of individuals. Rather, the existing, private and unlicensed housing stock of communities was utilized for most individuals. Eight-five percent of adult individuals who obtained community supports, and all of the children in the Alberta project who ended the use of respite services at the Rosecrest facility, moved to private, unlicensed housing in the community. Almost 40% moved to their own apartment or house, and just under 50% moved into another family home in the community, or into the home of a member of their immediate or extended family. The remaining 15% moved to group homes or licensed boarding/service homes in the community. Only in Saskatchewan were these latter options used for the majority of individuals included in the project. There, funds were used to purchase placement in conventional residential services operated by community-based agencies or private operators (group homes [14 individuals], care facilities—e.g., nursing homes [4 individuals], and private, approved service home [3 individuals]).

Those who moved into the private housing market represented a cross-section of individuals in terms of level of disability and extent of need, age, and gender. Along with greater use of the private housing stock in these projects came particular issues, regardless of the level of disability:

➡ ***Funds needed for renovations, aids and devices***—All of the projects provided funds, or facilitated access to funds for home renovations (to improve physical accessibility) or to purchase needed equipment, aids and devices. Some difficulties in gaining access to needed funding for these items was reported in all projects.

➡ ***Inflationary impact of public funding for purchase of private market housing***—Concern was expressed by some in smaller communities to which individuals moved that housing rents were inflated because of the assumption that government would pay higher than the market rate. However, inflationary tendency, if it existed, was addressed in some instances as individuals sought less expensive housing after an initial move.

➡ ***Developing supportive relationships among those living together***—Those who live in private sector housing tended to live with others, not necessarily others who have a disability. Those with whom they live include members of an alternate or birth family, live-in support staff sharing the costs of the housing, a roommate who may or may not have a disability. Living with others, outside of a residential service arrangement brought with it the need to establish relationships of privacy and "ownership" of the housing environment. Where individuals lived with other families, they did have their private bedrooms, and were generally accepted in other parts of the home. However, it was clear that the home belonged to the providing family. Where individuals shared a home or apartment with others, either paid staff, or non-paid roommates, issues often surfaced about whose home it was, how decisions were to be made that respected all parties concerned. These issues are no different than those encountered when any two individuals live together. However, the relationships are distinct in that the majority of individuals have communicational, emotional, behavioural and other personal support needs that require additional supports. Back-up support was often needed, therefore, to establish effective decision-making and relationships for those living together.

➡ ***Housing options limited by extent of funding***— A determining factor in housing use was the extent of funds received for disability-related supports. While all individuals received some level of funding to meet disability-related needs, there was significant variation. Those who have more extensive needs received higher levels of funding for supports, enabling them to use their housing allowance to rent their own home or apartment. Those with less funding attached to them tended to live in "alternate family homes" or to live with their own families or relatives. While the family provider received a stipend for supporting the individual with room, board, and personal support, this tended to be much less than the funding allocated for those living on their own and purchasing up to 24-hour/day personal support at an hourly rate.

Social life of communities

The social environments of communities were also affected by the projects, and the efforts on the part of individuals with their support staff and support networks to gain membership in their communities. Change took place in two ways: 1) by individuals becoming members of community groups, and attending community events; and, 2) by initiating or strengthening community organizations such as provincial and local self-advocacy or People First groups.

After individuals made the transition to the community, dealt with the sometimes very difficult adjustments (anger, medications reduction, new surroundings), and began to develop personal relationships, their world often expanded geographically as well. The level of participation in the community appears to be increasing over time. **Graph 10** indicates that the majority of individuals do have opportunity to be involved in the community. Over 80% of individuals regularly attend community facilities, gatherings, or events. Moreover, about a quarter of individuals increased their contact with community groups between Spring 1996 and Spring 1997 (See **Graph 11** and **Graph 12**).

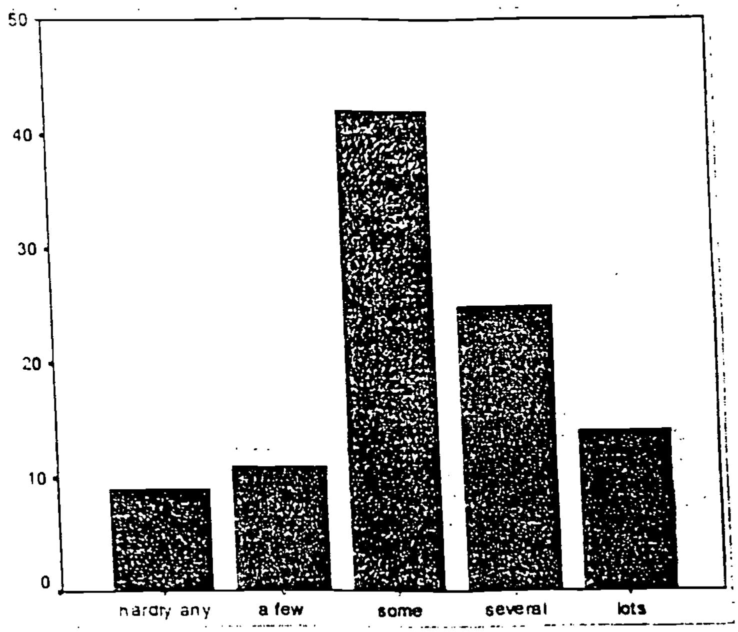
The projects in Newfoundland, PEI, and Ontario (in the Kitchener-Waterloo site) invested in the development of self-advocacy organizations as one source of social support and involvement for individuals. The self-advocacy groups that developed (4 in Newfoundland, 6 in PEI, and 1 in Kitchener-Waterloo), do provide a source of mutual support and personal relationships. Moreover, they are raising public awareness about issues of support and inclusion for people with intellectual disabilities, thus helping to re-shape the social, economic and political environments of their communities.

Services and facilities

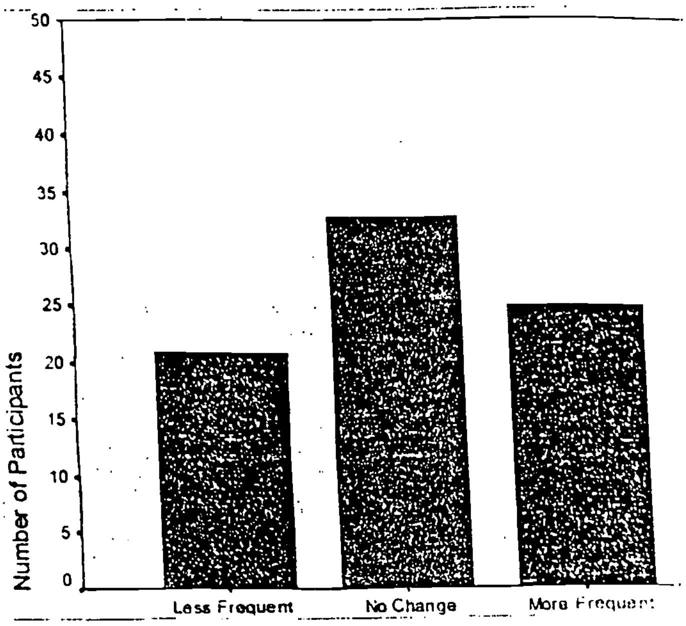
Through the case study data, it became clear that individuals were using a variety of educational, social, and recreation services and facilities in their communities to a much greater extent than they had in the past.

However, inconsistencies in strategies and commitment to inclusion appeared between communities, and between services within communities. For example, in one community, the local YMCA provided additional personal supports so that a man could be accommodated in the centre's fitness programme; in a YMCA in another community, staff refused to provide any assistance in lifting a woman from her

Graph 10—Opportunity to Contribute/ Be Involved in Community



Graph 11—Frequency of Contact with Members of a Community Group



wheelchair into the pool. The survey does suggest some common areas for needed investment in developing more accessible community services and facilities. (See **Graph 13.**) In Spring 1997, high costs of participation, the need for personal assistance, the lack of nearby facilities, and the need for supports due to physical disability, each accounted for the exclusion of 20% to 30% of individuals. Sixty-five percent of individuals faced at least one of these barriers; 35% of individuals faced no barriers at all.

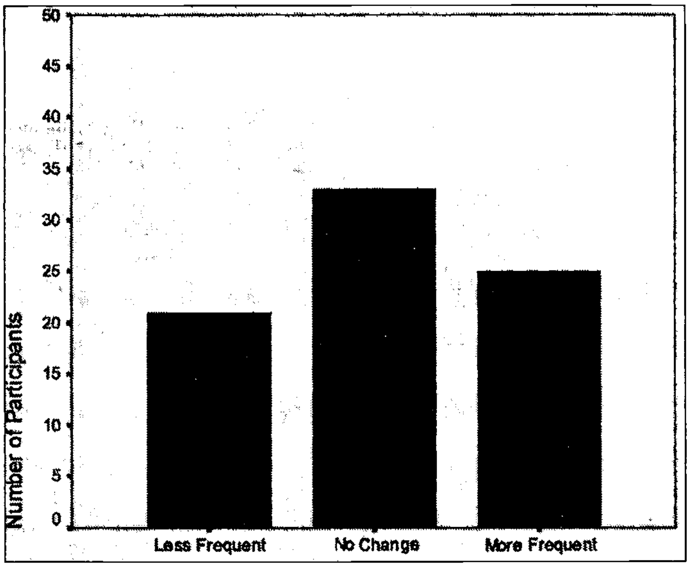
The case study data also point to the problem of negative attitudes in various community recreation services, education, and in health care services.

The Place of Increasing Accessibility in Community Inclusion

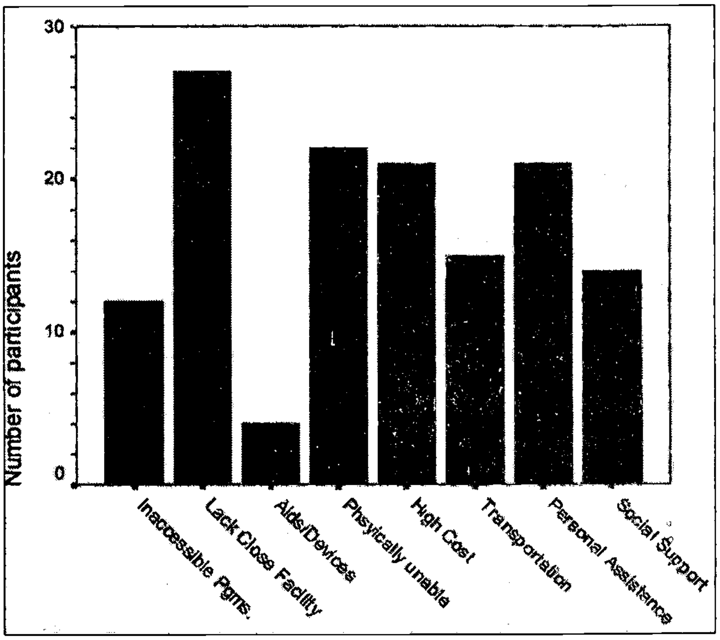
Re-drawing the physical, social, and service boundaries of communities was an ongoing process in the projects. Boundaries were re-drawn as staff supported an individual to participate in a senior's recreation centre, at first against the wishes of other members; or by working with an employer on how to include an individual; or by a community development group in the Newfoundland project working on developing accessible transportation services in St. John's; or as provincial funding mechanisms were created to enable provision of needed supports to individuals so they could participate more widely in their communities. Creating accessible communities was a daily effort in these projects, an effort mounted for both particular individuals, and for communities more generally.

Enabling access to the private housing market, to community recreation centres, to community groups and events ***increased personal mobility*** for individuals and ***created a wider context to form supportive personal relationships***. Through the projects the paths that defined people's daily lives expanded beyond the walls and grounds of an institution, or the social and physical isolation in their family or other home in the community. The increased mobility that came about for most participants offered them awareness of other possibilities in community life that many had not anticipated. The case studies point to attachments to places and to other persons that formed after individuals obtained community supports—a health club, Friday night

Graph 12—Change in Contact with Community Groups



Graph 13—Lack of Resources Limiting Community Access



at the bingo club, running errands for staff at the post office and the bank, a favourite coffee shop, the home of an "associate family." For one individual, the local People First group created through the project was one of the most important attachments she had, along with her job at a fast-food outlet. She said that the group provided her with a place, *to help each other through the hard times.*

The more accessible communities were, the more they ***broadened the arena for individuals to exercise self-determination***. Where the decision-making opportunity for some individuals was once confined to their limited personal space on the unit of an institution, the arena for making decisions grew, as the physical, social, and service boundaries of communities were changed in relation to them. Decisions about where to live, about leisure activities, about what events to attend, or groups to join, only became possible as community environments were reconstructed and barriers were lifted.

The process of increasing community accessibility, whether at an individual, community, or provincial level is itself a central element of community inclusion. It is this process that ***revealed the breadth and depth of social, economic, and political exclusion***. The experience of the projects suggest that there is no "blueprint" for an accessible community. The individual and community case studies indicate that the understanding of community barriers changed as individuals, their support networks and support staff, community development groups, and project partners made efforts to increase accessibility. Enabling access for one individual to a community event, service, or facility revealed new barriers to be addressed.

E. ACCESS TO NEEDED PERSONAL SUPPORTS

Access to accountable and sustainable personal supports emerged clearly in the research as an element of community inclusion that is integral to all of the other elements. The provision to individuals of needed disability-related, or more broadly "personal," supports set into motion the various threads of community inclusion that wove and re-wove the shape of people's lives. Underlying the personal relationships people formed, the self-determination they exercised, the economic contributions they made to their communities, and the access and participation they enjoyed, were individuals' particular supports. One need only look at those situations where the supports broke down to see how important personal supports were to meeting individuals' basic needs, and to enabling them to make and pursue their personal plans. When the supports were at serious risk in a few situations—whether formal, paid staff, or the more informal supports provided through the involvement of family or friends—the impact on an individual's life was immediate. Ability to meet their needs was put into question, as was their access to and participation in their community.

The supports people needed and used were visible in all of the stories told, whether about making friends or reconnecting with family members, about deciding how to spend their funds, in moving a child from institutional supports for medical care to an associate family in the community, and in all of the stories they told about many different activities in the community. Individuals used a wide range of supports to meet their needs—paid support staff and professional services of social workers or behaviour management specialists, the needed renovations to a home, assistive aids and devices, the personal assistance people need to overcome the physical barriers in their community and the communication barriers they faced, the communications board required, and others. The presence or absence of needed supports have played a decisive role in shaping individuals' lives.

Evaluation Findings: Changing Access to Personal Supports

Through their involvement in the projects, individuals and families experienced a number of changes in the personal supports they received:

- changing the "what," "where," and "who" of personal supports provided
- changing intensity of supports
- vulnerability of support arrangements

Changing the "what," "where," and "who" of supports provided

The most significant changes in ***what*** supports were provided was the provision of planning support to individuals, and assistance in the development of personal networks. Individuals had received personal assistance in a variety of tasks and activities prior to their involvement in the projects—whether from nursing and social work staff at an institution, from staff with community agencies, or from unpaid family members. Undoubtedly their tasks and activities changed to a large extent and the nature of the personal assistance received thus changed as well—but the need for personal assistance remained constant for all individuals. What individuals had not received prior to their involvement to any great extent was assistance in planning, decision-making, and support network development. Through the provision of this type of assistance individuals were able to develop plans, search out support options for living in the community, and for work, education, and other involvements. Planning support also helped individuals to develop a network around them to assist in planning and decision-making in an ongoing way.[30]

Where supports were provided also changed. Flexibility in funding of personal supports enabled some individuals to obtain supports not only at their home, but at work, in their education or training setting, and at the community events, services, and facilities they attended. Issues did arise in each project, about which government department should fund what supports.[31] Such issues are the "growing pains" in shifting from a public policy framework based on an assumption that supports will be delivered to places that house or provide service to people—i.e., institutions, special classes and programs, specialized housing units—to a framework that recognizes that individuals can be supported to participate in *any* of the places, services, facilities, and events that a community creates.

Who provided personal supports also changed. Only the 15% of participants who moved to licensed boarding, group, or nursing homes, used for their support the direct staff employed by community agencies. The majority of individuals hired staff to provide support to them in their own house or apartment (38% of individuals), or to provide respite and additional support to them at the home of the family with whom they lived (47% of individuals). These individuals also had the paid and unpaid support of the individuals in these families.

In addition to this direct, often daily personal support, over 60% of individuals had the personal support in planning and decision-making provided by members of a support network. They also had the intermittent support of planning support agents, social workers or other government officials who arranged funding, and behavioural and rehabilitation specialists. This group was to provide back-up in making needed arrangements and responding to issues as they arose.

This labour force looks very different than the nursing, behavioural, social work, and medical professionals who provided support to individuals when living in institutions.

For the most part, personal support staff were not organized through large employers, whether instititutional or community agency. This has provided the advantage of increased accountability of direct support staff to individuals and their plans. It has also minimized the multiple and sometimes conflicting accountabilities that result for support staff who are employed by agencies or institutions (accountabilities to the employer, the collective agreement, the family, and the individual). However, it has posed an additional challenge of training, managing, and monitoring the performance of this highly decenetralized group of staff supports, with as many employers as there are individuals they are supporting. Moreover, it has made it difficult for support staff to raise common concerns and to work with project partners in addressing them.

Changing intensity of supports

The highly individualized approach to provision of personal supports has enabled the intensity of supports to vary to some extent. Over the period of Spring 1996 to Spring 1997, the intensity of personal supports was reduced for about 30% of individuals (e.g., two-to-one support being reduced to one-to-one; or intensive behavioural supports being reduced to respite supports; or paid supports being reduced as individuals obtain the unpaid supports of others—for example, on-the-job co-workers, or friends, family, or other community members who include individuals in activities). Another source of reduction in intensity of support is the shift of individuals from living in their own apartment or house to living in an alternate family arrangement. This shift was encouraged in some situations to save costs. For about 10% of individuals, the intensity of support was increased over the same period. These findings are an indicator of flexibility and responsiveness in the funding and provision of supports. Had there been only *reductions* in intensity of support, and no increases, the change could have been attributed to some of the cost-cutting measures introduced. However, case study data, and the fact that intensity was increased for some individuals, suggests that the individualized funding systems were responsive to changing individual needs and to development of other resources.[32]

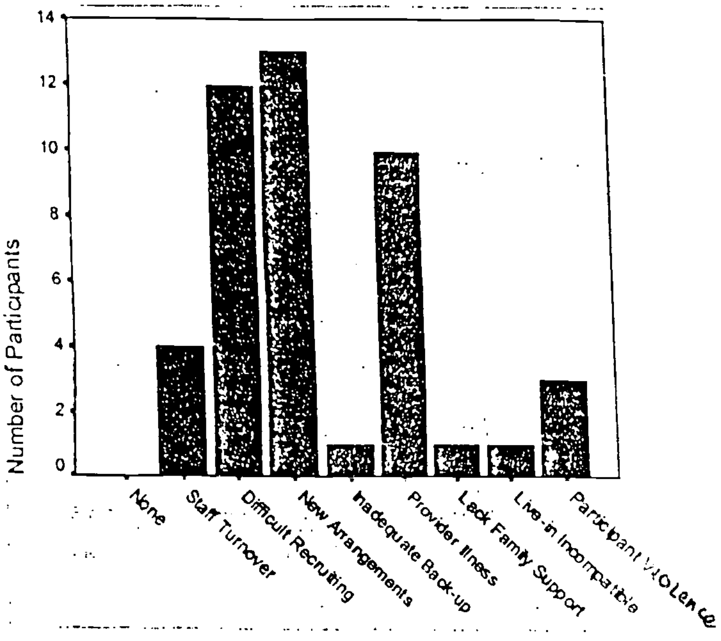
Vulnerability of support arrangements introduced

Support arrangements did breakdown for about a quarter of individuals, and over 70% of individuals had turnover in their support staff. The reasons most often reported in the survey for breakdown in support arrangements were related to support support staff—short notice given for changing the support arrangement and the need to find new staff, difficulty in recruiting staff, staff illness and lack of available back-up staff, and staff turnover. (See **Graph 14.**)[33] Particular vulnerabilities were found to have been introduced as a result of the nature of the decentralized support system developed through these projects.

➡ ***Support staff concerns***—The vast majority of support staff who were interviewed expressed concerns about: low wages (many staff were paid at minimum wage), lack of benefits, lack of Workers' Compensation coverage, lack of clarity about who their employer was (the individual or the provincial social services department), and lack of training opportunities.[34] These concerns were most often expressed by staff who were not covered by collective agreements, and who were paid at a lower rate than those who were. It was these types of concerns that led to high turnover, low staff morale, and recruitment difficulties, rendering individuals' support arrangements vulnerable to breakdown.

➡ ***Monitoring and emergency response in a decentralized system***—Second, support arrangements were made vulnerable because the highly decentralized support system created new challenges for monitoring the quality of supports, and providing of emergency and back-up response. Rather than a centralized monitoring system, and the emergency response being delivered to designated facilities or group homes, a system was needed to respond to private homes with a wide geographic distribution. Most projects addressed this challenge by considering what monitoring needs each individual arrangement required. Support network members, planning support agents, or social workers played a monitoring role through regular visits. A decentralized support system, with a central role for support networks has clear advantages because of the immediate and personal response it can provide.[35] Nonetheless, there were reported incidents of a complete breakdown in monitoring and supports where an active network, with back-up support was not in place.[36]

Graph 14—Breakdown of Paid Support Arrangements and Reasons if any



➡ ***Lack of consistent back-up to support staff and networks***—Third, individuals' arrangements are made vulnerable in such a decentralized system because of the need for back-up paid staff and for networks to: 1) manage the often complex support arrangements, 2) deal with conflicts between staff, networks, and individuals, 3) ensure ongoing planning and adjustment of arrangements is taking place, and 4) make progress in realizing the often ambitious personal plans generated through the individual planning process. The reliance on volunteers in networks for assistance in planning, administration of funds, and management of sometimes numerous staff was found in many situations to be too onerous for them. The fact that the "vision" for individuals is "quite" or "very" clear in less than half of the situtations is one indicator of this fact. Networks and paid staff tended to lose sight of the vision for the individual as the difficulties of managing and delivering personal supports came to dominate their attention. Where networks were most effective, they had regular contact and back-up from a planning agent.

- ***Lack of clear roles and relationships***—Having effective networks was a valued source of decision-making assistance to individuals, of linkages to their communities, and of new personal relationships. However, the role of networks has been unclear in some situations, especially where they are without the needed personal resources to provide the administrative and management support needed to the situation. While they play an important role, the role in facilitating and providing back-up to networks in order to strengthen their capacities has not been clearly identified.

Government social services workers have played many roles throughout the project. However, as financial pressures intensified in all the projects, and as support networks found their capacities taxed beyond what they considered a reasonable limit, conflicts over funding for supports increased. A number of family members spoke of the need for planning support that is independent of government social workers, because of their other mandates for funding approvals and for restricting expenditures. Many respondents questioned whether government social services workers are in a position to play all of the planning, back-up and developmental roles for support networks that now appear needed.

- ***Concerns that unionization will contribute to vulnerability of individuals and families***—Decentralization of supports, and change in the structure of employer-employee relationships has changed the work environment for support staff. Many more are now working in situations where individuals, families, or support networks are their employers. The home in which they are supporting a person belongs to the individual being supported or a family member, or alternate family, rather than belonging to a service agency which acts as the employer of the support staff. Combined with support staff concerns about low wages, lack of benefits and Workers' compensation coverage, these changes have led to a drive by some unions and support staff to unionize support workers in these situations. With respect to the NSIPD projects, this was particularly the case in Newfoundland. However, similar trends are being found in other jurisdictions where the service and funding systems are undergoing change.

NLACL and many families and self-advocates see unionization as a threat to maintaining choice and control in their own homes. They are concerned that demands of unionized staff may lead to seniority provisions determining who will support individuals and families, rather than individuals and families themselves. Concerns have also been raised about the imposition of other conditions against the will of individuals and families, such as the establishment of smoking areas and staff areas in peoples' homes.

The Newfoundland and Labrador Federation of Labour has suggested that suitability and compatibility clauses can be negotiated into contracts.[37] However, NLACL, family members and self-advocates are concerned that seniority provisions would likely prevail. Even if they could deal adequately with seniority provisions, they are concerned that negotiating contracts with unions places an unfair burden on individuals and families. The vast majority do not have expertise in union negotiations or the resources to purchase such expertise. Few individuals and families are likely to be *un*affected as any two workers can apply for certification as a bargaining unit.

> Ensuring that individuals and families can continue to make decisions about who will support them, and how their own homes will be managed seems essential if deinstitutionalization is to lead to greater self-determination for individuals, and not simply the replacement of one regulated environment for another. At the same time, the legitimate concerns of support staff require recognition, as do existing commitments to international conventions on the rights of workers to association and collective agreements. Some compromises have been achieved in other jurisdictions through collective agreements and practice: such as removal of seniority provisions; the right of individuals and families to select staff with reasonable hiring and termination practices; and, clear control by individuals and families over the home environment, providing that health and safety concerns are addressed.

What remains unresolved is a process by which collective agreements can be negotiated across such a diversity of individual and family employers. Options to address this concern have been proposed. They include establishing community staffing agencies which employ the support staff, and which have a contract with individuals or families for provision of support. Such agreements provide individuals and families with control over who will provide support, and how their home will be managed. They place responsibility on the employing agency for training, some supervision, and re-allocating support staff to other positions if they are not compatible with an individual or family member.

It is clear that additional work and options are required to more fully and adequately address this set of issues, including alternative processes for negotiating collective agreements. Otherwise, the decentralized support systems being created will be less able to secure potential benefits for individuals and families, and address the legitimate concerns of support staff.

The Place of Personal Supports in Community Inclusion

The individuals with disabilities included in these projects all used some form of paid personal supports, in addition to the unpaid supports provided by family, friends, and community members. The evaluation found that, depending on how personal supports are funded and delivered, they can either contribute to a community becoming inclusive of the individual, or can entrench their exclusion from opportunities.

There are substantial challenges in putting a decentralized system of community-based personal supports into place, one that is accountable to individuals and families. However, in the case of the NSIPD projects, the system did prove ***responsive to the diversity of individuals' personal visions and plans***. The wide range of personal visions and goals constructed through the individual planning processes, and the strategies put into place to realize them, could only have been accomplished with the decentralized and accountable approach for delivery of personal supports. Only with this kind of flexibility were individuals able to participate in diverse social, educational, and economic settings.

The structural accountability of support staff to individuals through the individual's funding, decision-making and contractual status provided for ***an enabling rather than custodial approach to provision of support***. Custodial models of support tend to be associated with facility-based and congregate approaches to care, where provision of support is managed only by restricting the personal options individuals are afforded (about where to live, who they will live with, the activities they will be involved in). The goal of such services is to ensure delivery of basic personal care, rather than to *enable* individual self-determination and participation in the community. By decentralizing provision of personal supports, and attaching support providers to individuals rather than to institutions or agencies, support staff were "freed up" to assist individuals in pursuing personal visions and goals in their communities. This appears to have happened for between 40% and 50% of individuals supported—those who were supported to make decisions about their own money, those for whom their personal vision was clearly understood by others, and those who, consequently, gained social, educational, and economic participation in their communities.[38]

An important measure of the enabling community environments, created through restructuring personal supports, was the perception of community members about how disability-related supports should be provided, and whether they believed these supports should be focussed on community integration or segregation. For example, over 80 percent of those surveyed in the Newfoundland community attitude survey believed that "most community members are pleased that individuals moved from the Waterford Hospital." Seventy-six percent believed that even if institutional supports are "cheaper," that individuals should still live in the community. Just over 50% believed that individuals do better in integrated rather than segregated settings.

The extension of people's lives into the social, economic, and political spaces of their communities would not have been possible without the fundamental restructuring of personal supports that many examples from the evaluation illuminate. The consequence was a deepening of the process of community inclusion to the point that, in some communities, the majority of community members were willing to support individuals to stay in the community even it was more costly than keeping them in institutions.

III. COST-EFFECTIVENESS

One of the objectives for this evaluation was to develop a framework for assessing the cost-effectiveness of community supports. The aim of such analysis is to facilitate the most efficient use of resources. The evaluation did not include comparative analysis of the cost-effectiveness of institutional and community supports, because the National Strategy, and each of the six projects, were based on an assumption that community supports by definition are valuable, and should be made available. The question for a cost-effectiveness analysis for this evaluation was, therefore, how cost-effective were the community supports provided, not in comparison to insitutional supports, but in relation to the public investment made? In other words, was the public investment managed in a way to maximize effectiveness for individuals?

Broadly defined, cost-effectiveness analysis measures the relationship between investments (costs) and outcomes (effectiveness). Conceptually, effectiveness describes the extent to which the program meets its stated goals. Cost incorporates direct expenditure outlays and may also include indirect costs and cost savings.[39] Cost-effectiveness is often presented as a ratio of effectiveness scores to cost. For example, a support option that produces an effectiveness score for individuals that is equal to another support option, but that is higher in cost would have a lower cost-effectiveness ratio.

The framework for cost-effectiveness developed through the evaluation has four elements, including:

- indicators of effectiveness
- range of individual needs
- indicators of direct costs
- relationship between needs, costs, and effectiveness

A. INDICATORS OF EFFECTIVENESS

The indicators for effectiveness were selected to measure outcomes in relation to the objectives of the National Strategy for the Integration of Persons with a Disability: effective participation, equal access and economic integration. An index was created to measure effectiveness in relation to each of these objectives. Indices were designed for individuals to obtain a score ranging from 0 to 10.[40]

Effective Participation

The index measuring effective participation was derived from the responses to 15 questions in the demographic survey, organized into six categories:

- ➡ frequency of contact with any family members (5 variables—mother/step-mother, father/step-father, sister(s), brother(s), other relative(s))
- ➡ frequency of contact with community members (5 variables—community advocate(s), neighbour(s), friend(s), members of a non-religious group, members of a religious group)
- ➡ supported decision-making mechanism in place (1 variable—two or more family or community members provide planning and decision-making support to the participant)
- ➡ supported in planning activities
- ➡ supported in strengthening personal relationships
- ➡ frequency of participation in social activities (goes shopping, attends religious services and related activities, goes to community facilities and events)

Equal Access

The index measuring equal access contains five variables, that define barriers to access[41]:

- ➡ lack of accessible facilities

- ➡ cost barrier
- ➡ transportation barrier
- ➡ lack of personal assistance
- ➡ lack of familial support

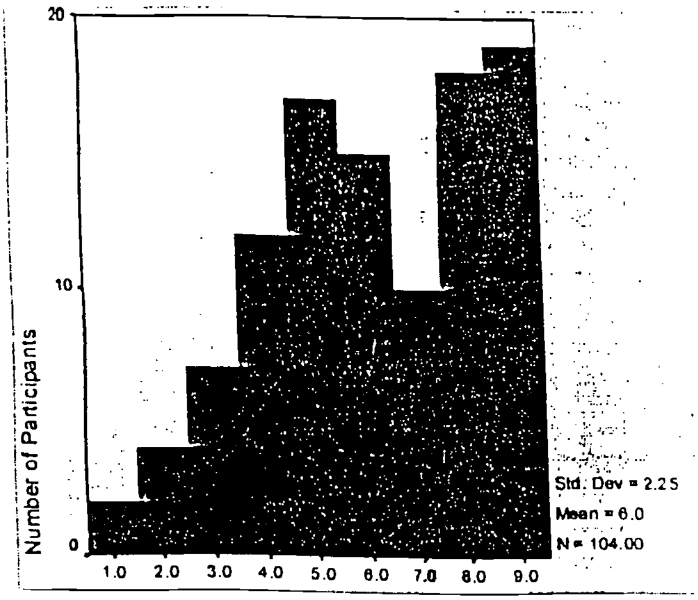
Economic Integration Index

The index included three variables:

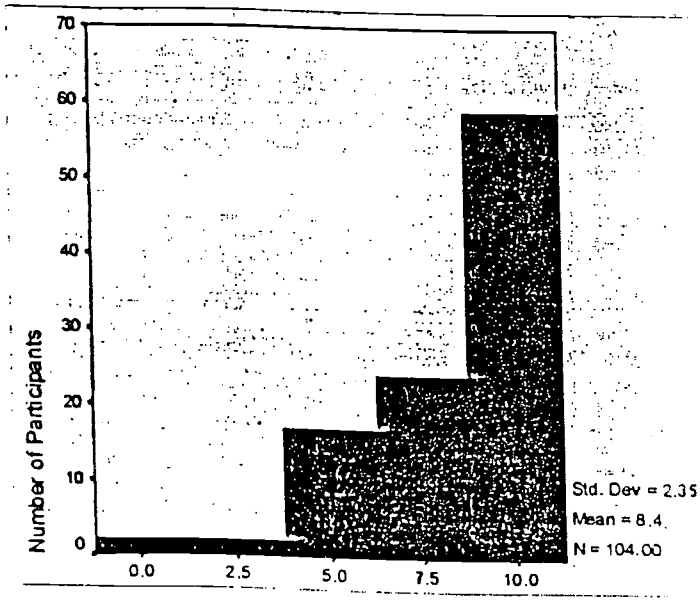
- ➡ any work-related activity
- ➡ volunteer involvement
- ➡ an involvement in management of funds

The scores on each of these indices for individuals included in the national survey are presented in **Graph 15, Graph 16**, and **Graph 17**. Out of a maximum score of 10 on the participation index, the average score for individuals was 6.0; the median score was 5.8 (50% of individuals at or above this score, 50% below this score). On the access index, the average score was 8.4, the median score was 10.0; and on the economic index, the average score was much lower at 2.8; the median score was 0.0. These scores are consistent with the discussion presented in the section on outcomes. Participation in employment-related activities was low, and planning support tended not to be focussed in this area. While access scores are higher than participation scores, this is also consistent with the finding that real barriers to participation are only encountered as people become involved in their communities. Thus, those filling out the survey did not perceive barriers for individuals, where individuals had not yet become involved.

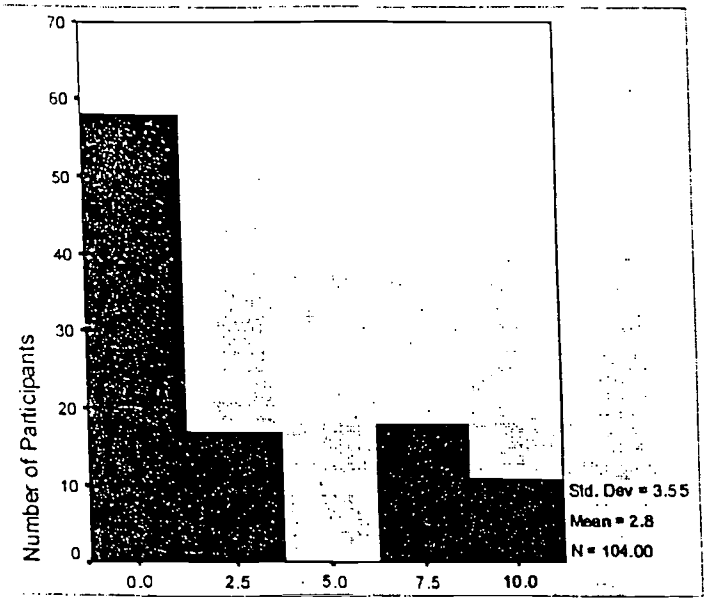
Graph 15—Frequency Distribution of Participation Index



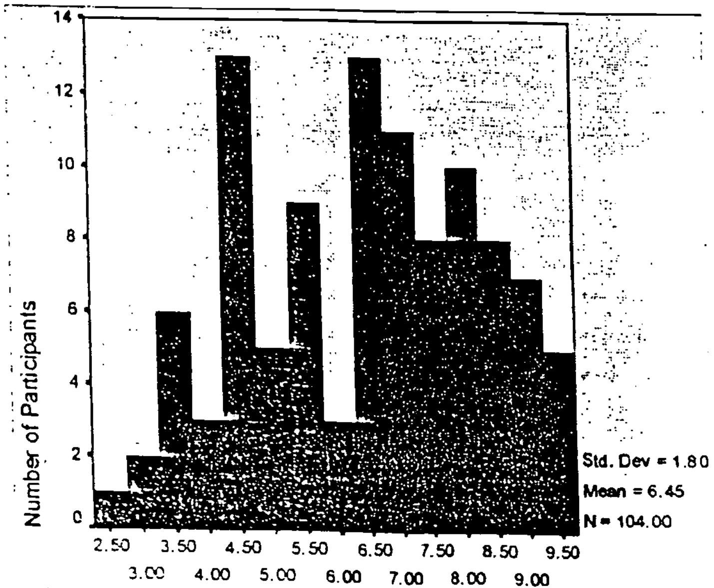
Graph 16—Frequency Distribution of Access Index



Graph 17—Frequency Distribution of Economic Integration Index



Graph 18—Frequency Distribution of Needs Index



B. RANGE OF INDIVIDUAL NEEDS

Cost-effectiveness of support arrangements for individuals with disabilities cannot be adequately assessed without taking into account the range and extent of needs for support. Those with higher needs are likely to face more extensive social and physical barriers to inclusion and tend to require more costly supports (e.g., persons with certain levels of need require 24-hour support). Without taking the level of need into account, lower-cost options may be erroneously associated with higher cost-effectiveness.

A needs index was created drawing on a number of variables from the survey,[42] including:

- ➡ frequency assistance was needed, if at all, with bathing, dressing, toileting, health/hygiene, transfers, eating, preparing meals, cleaning, laundry, communication, emotional support, and behavioural challenges
- ➡ whether the disability affects an individual's learning
- ➡ whether the disability affects an individual's physical mobility[43]

Graph 18 presents the scores on the needs index, based on those individuals surveyed. The graph indicates a wide range of extent of need, with an average on a scale of 10 of 6.45. Responding to such a diversity of need in ways that promoted community inclusion was one of the major challenges of the projects.

C. INDICATORS OF DIRECT COSTS

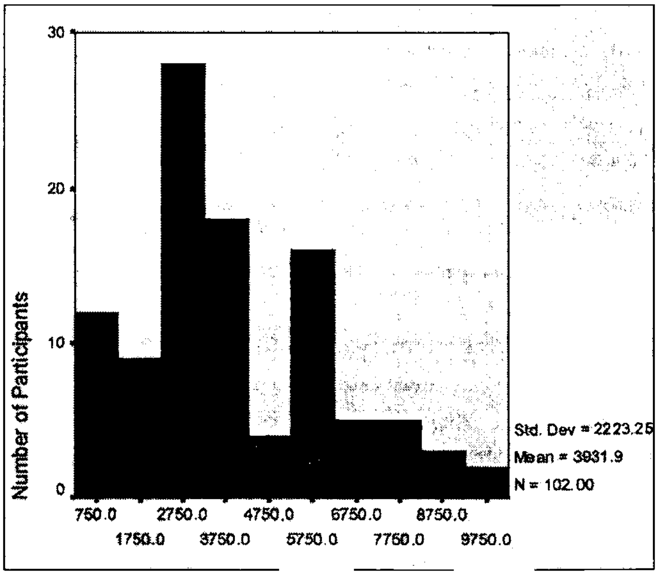
The direct costs for supporting people to live in the community was calculated from the monthly budget recorded for each individual surveyed. Respondents were asked to provide the average monthly budget, from all public sources, to pay the individual's direct paid support plus the amount for accommodation and living expenses. If the budget for any of the items had recently been changed, respondents were asked to provide the most current figure. If the individual shared paid direct support or accommodation with others, respondents were asked to provide only the amount pertaining to the individual. **Graph 19** shows the range of the monthly budgets of individuals—from $750/month to $9,750/month, with an average monthly budget of $3,900.

D. RELATIONSHIP BETWEEN NEEDS, COSTS AND EFFECTIVENESS

In examining the relationship between extent of needs, costs, and effectiveness, a number of analyses were undertaken.

First, the ***relationship between needs and costs*** was analysed. The analysis shows a highly statistically signficant relationship. This means that as the extent of needs rose, so too did the costs. This is an important finding from a set of projects based on individualized funding. In all of the projects, processes were put in place to cost and negotiate funding on an individual basis, and according to an individual plan. One of the common concerns about individualized funding is that it may prove inflationary, leading to provision of funding for individuals who may not actually need the extent of resources provided. The findings from this evaluation suggest that such a concern is unfounded, at least for this group. There is almost a one-to-one relationship between individual needs and funds allocated, even with the implementation of individualized funding processes across such a diverse set of projects.

Graph 19—Frequency Distribution of Monthy Total Budget



Second, the ***relationship between effectiveness scores and extent of costs or investment*** was analyzed. The evaluation found that participation increased with greater investment in individual supports—the higher the expenditures for individuals, the higher their participation score. Indicators of participation relate to having a support network in place, having ongoing support in planning activities, and being supported to become involved in community activities. Developing these support resources requires substantial investment. All of the projects focussed on enabling community participation—and that investment clearly paid off. The way in which the supports were provided did not lead to high levels of economic participation, and consequently no significant relationship was found between increasing investments and economic integration.

Importantly, the cost-effective analysis found that investment in participation was cost-effective over the long term. In those situations where intensity of paid supports were reduced after the individual's transition period in the community, participation scores did not decline. Following the initial investments in a person's paid supports, and in the development of their support network, those paid supports could be reduced without affecting the extent of the individual's participation.

Third, an analysis was conducted of ***cost-effectiveness ratios based on the housing/support type individuals used***: individual's own apartment or house; living with family or alternate family; group home; and boarding home. The analyses, as anticipated, showed that those living in boarding homes or with families or alternate families tended to have higher cost-effectiveness ratios on both participation and access scores. This is due to the fact that those living in these arrangements had much lower costs than those in group homes or living in their own apartments or houses. Interestingly, even with the higher costs, those living in their own apartment or house had higher cost-effectiveness ratios for economic participation than those living in other housing/support options. Those few who did obtain economic integration tended to be living in more independent living arrangements, with more extensive paid and unpaid supports.

Fourth, the ***relationship between the three dimensions of effectiveness*** were analyzed. There is a significant relationship between the three: that is, those that score higher on one index tend also to score higher on the other indexes. This finding is not suprising. Those who are participating in the community more and are having the barriers they face more effectively addressed, and tend to have more opportunities and support for economic integration.

Fifth, the ***relationship between effectiveness and extent of need*** was analyzed. The evaluation found that there was no relationship between whether a person had high levels of participation or access, and the extent of their needs. This suggests a positive outcome. People are able to participate, and barriers to community access are overcome, regardless of need. However, a signficant negative relationship was found between the extent of a person's need and their economic integration. This finding suggests an inadequacy of support for economic integration for those with more extensive needs, rather than a simple fact that those with more extensive needs cannot be economically integrated. Studies, using the sample of the Health and Activity Limitation Survey of thousands of people with disabilities, have shown that economic integration depends more on extent of support provided, than it does on level of disability.[44]

In summary, the framework for cost-effectiveness developed through this evaluation provides ways of measuring public investment, assessing extent of individual need, and of measuring effectiveness according to the established National Strategy goals: participation, equal access, and economic integration. Rather than provide scores of cost-effectiveness for one support option over another, the framework suggests various lines of inquiry that should be examined in an ongoing way, to assess the dynamic relationship between investment, extent of need, and outcome.

Using this framework in relation to individuals in the NSIPD projects is telling: it points to the long-term cost-effectiveness of investment in participation, and the consequences of under-investment in specific employment-related supports. Without the latter, the dynamic of "skimming" appears to take over—those with the least needs get the most access. The framework for analysis also reveals the cost-effectiveness of individualized funding approaches to allocating public resources—investment increases only as the extent of need increases.

IV. MECHANISMS ENABLING COMMUNITY INCLUSION

What makes deinstitutionalization and community inclusion possible? The evaluation found that an enabling environment for the process of community inclusion was created where seven key mechanisms, or building blocks were established. These were put into place in different ways and to different degrees in each of the projects. The extent to which they were put into place determined whether an environment was created to spark the dynamic of community inclusion and to sustain it. These mechanisms are the conditions that made community inclusion possible. They also underlay the cost-effectiveness of the projects in that it was through these mechanisms that funding was managed, and decisions were made about investments in participation and economic/educational integration. Where these mechanisms were not fully in place, limitations in cost-effectiveness and continued barriers to community inclusion resulted. **Table 3** identifies these mechanisms, each of which is discussed in more detail below.

No one mechanism on its own was able to secure community inclusion. Commitment of government and institutional facilities to deinstitutionalization was ineffective in creating community supports without the accountability structures, partnerships, and funding mechanisms that put that commitment into practice. Even with these changes at a systemic level, positive outcomes would have been elusive without the intensive provision of planning support to individuals and families that most projects provided. Some of the barriers that persist for individuals are accounted for by a lack of planning, decision-making and management support. Where these mechanisms were put into place, significant barriers to community inclusion were confronted. Barriers also persist because of ineffective community development processes.

Mechanisms to Foster Ongoing Committment to Goals

The process of community inclusion was generated through changes in policies, programs, services systems, and community attitudes. Making these changes happen required the shared commitment to project goals by a number of players. Mechanisms that proved successful in establishing and sustaining the commitments to the institutional and community change, include:

- ***Formal federal-provincial agreements*** established a funding framework for the projects, and expressed a commitment by both levels of government to the goals of the project, and to their sustained involvement in the projects.
- ***Partnership declarations*** were signed, in most projects, by the four project partners—federal and provincial governments, and national and provincial Associations for Community Living. These declarations are clear statements of the principles and values of human rights and community inclusion, and project objectives in light of these commitments.
- ***Strategic planning processes***, of a formal or informal nature, were established within each of the projects for detailed design and monitoring of project implementation. Strategic planning took place at the level of provincial partnerships, as well as in some com-

munity settings where local steering committees were established. Commitment to strategic planning varied from project to project, and among project partners. Where there was an established process for planning at the project level, and agreement to follow-up, issues were anticipated, and concerted action was taken. Where the planning process was lacking, or where all partners were not "at the table" when decisions were made, conflicts and misunderstandings tended to grow.

A focus on ongoing project planning, also helped to re-shape the articulation of project goals in response to emerging issues. In Alberta, for instance, it became clear to project partners through their initial planning stages that "deinstitutionalization" should not be articulated as the goal. Rather, the goal should be providing families with the opportunities to choose community supports for their children. Re-articulating the goal in this manner helped to affirm commitment by all partners to the principle that families should make decisions about how children should be supported, including when and if their child should leave an institutional environment.

- ***Leadership within institutional facilities*** also proved critical in maintaining a commitment to the projects, although the extent to which this was realized varied substantially between institutions involved. Establishment by the most senior administration of an organizational commitment to the goals and to a deinstituitonalization process was found to be an important factor in maintaining momentum.
- ***Leadership within government*** was also a critical factor in success. Project implementation depended to a significant extent on the capacity of the responsible provincial officials to work with their provincial ministers, deputy ministers, and other senior officials in building a sustained commitment. As projects were implemented, it also became clear that commitment was needed from provincial ministries or departments other than the department designated to provide leadership (usually the provincial department/ministry for social services). Building this commitment was not entirely successful, as continued issues about what departments should fund what supports constrained the provision of timely supports to individuals and families.
- ***Mechansisms to build public support*** for the project goals proved an important factor. Partners worked with the media to disseminate information about the projects, personal success stories, and information about supports being made available. Where media relationships and strategies were not proactively built from the outset, what some felt were "misinformed" media reports about the negative consequences of deinstitutionalization were circulated. In the case of Alberta, this did hamper the working relationships of those involved at the provincial level. The level of public commitment that was eventually generated is also due to community members' positive relationships with individuals who were supported. The extent of public support found in Newfoundland for community living, even if it is more expensive than institutions, is some measure of the extent of the public commitment generated.

Formal Accountability Mechanisms

Structures to ensure accountability to project commitments were found to be important motors of change at a number of levels:

Project management was organized in a variety of ways, usually with some form of management commitee responsible for detailed design, implementation and operations of the project, and in most cases with a designated project manager. The management committee was to be responsible to provincial partners, either through the same management committee (as in Manitoba), or through another project advisory committee (as in Newfoundland). Where no clear structures for accountability were established between project management and project partners, there tended to be less focussed attention to achieving the project goals. In PEI, for example, management structures for the project became less focussed on project goals, as the four partners initiated another, larger-scale, project, the "Choice and Opportunity" project. The partners were then less able to address the significant policy and operational issues immediate to the deinstitutionalization project.

The research found that ***management structures within government*** were necessary to mobilize government commitment and to sustain and manage the significant fiscal resources provincial governments allocated to the projects. However, inter-departmental structures were lacking to coordinate efforts across government departments. As well, provincial government officials faced particular pressures in managing commitment to the NSIPD projects while meeting other provincial government mandates—especially the mandate to restrain expenditures.

Structures for ***ensuring accountability within institutional facilities*** were important in sustaining the deinstitutionalization process. Some affected institutions did not establish any apparent accountability structure for meeting project goals. Those that did, designated responsibilities by senior institutional staff to manage the process, to provide training and development of front-line institutional staff in order to build commitment at that level, and to track the planning and discharge of individuals. As well, where transition planning was most effective, both institutional staff, and community representatives collaborated in facilitating the process. In those facilities where this collaborative approach was not put into place, a number of project partners, including some facility administrators felt the planning process was not as effective as it could be. It did not take into account the relationships and knowledge of institutional staff, or the knowledge of the community and support options that community representatives could provide.

In order to ensure accountability at the institution to the goals and process and, at the same time, to address the very real consequences for institution staff, there was also a need to re-organize staffing and human resources. This was most effectively managed where the administration committed itself to minimizing the impact on staff by redeploying displaced staff, and shifting to back-up and casual staff where possible as full-time staff vacated their positions.

Ensuring adherence to the principle of self-determination required ***accountability structures at the individual level*** as well. Those that proved effective in enabling community inclusion, include:

- ➡ contractual, and decision-making status for individuals
- ➡ development of support networks to assist individuals in planning, decision-making, and development and managment of supports
- ➡ a process for costing plans, approving budgets, and arranging individualized funding for purchase and delivery of individualized supports
- ➡ awareness and commitment on the part of paid staff and support networks to individuals' personal goals, plans, and to securing community inclusion.

Mechanisms for Individual Planning, Decision-Making, Support Network Development

Another key factor in securing successful community inclusion for individuals was the establishment of a process and mechanisms for individual planning, decision-making, and development of support networks. The planning/decision-making process contributed to the process of community inclusion for a particular individual when it incorporated the following features:

- ➡ ensuring that the individual had status in decisions about the supports he/she would receive
- ➡ building a support network of people with a per-

sonal commitment to provide assistance in planning and decision-making (e.g., interpreting, communication assistance, critically evaluating options)

- ➡ developing a direction for the future (about where they would live, the kinds of things they would like to do)
- ➡ creating a plan to move in that direction
- ➡ providing funding on an individual basis for supports to realize individuals' plans
- ➡ putting in place mechanisms to appeal and re-negotiate funding and support decisions
- ➡ providing planning support directly accountable to individuals and support networks, for the purpose of:
  - developing an individual plan
  - strengthening the capacities of the family and support network to include, support, and assist individuals
  - assisting in the development of needed personal supports
  - resolving conflicts over decisions to be made.

While all of these features were not in place for many individuals, and inadquately developed in other cases, the research did suggest a number of directions to pursue in ensuring these features are put into place to a greater extent.

The research found that effective planning requires a ***clear understanding of self-determination and how to achieve it***. One of the difficulties in realizing the goal of greater choice and self-determination for individuals was the lack of a clear model of what it meant for individuals to exercise legal, contractual, and decision-making status. This was the case where individuals and/or their families resisted the move from an institution. It was also the case where staff or support networks questioned individuals' decisions after they moved, and were concerned that decisions put individuals or others at risk. As one person said of an individual who had sold most of her furniture, and was spending money on what staff considered were unnecessary expenditures, *"These are awful decisions, we don't agree."* In one case a support network, in the words of one of the members, *"blew apart"* because an individual was making decisions about his personal income that were disapproved of by the support network.

The evaluation suggests that a framework is needed to assist institutional and community, staff, planning agents, and support networks in creating an environment for individuals to exercise self-determination—an environment where the focus is less on choices an individual can or cannot make, and more on a process for making decisions. The research findings clearly indicate that where an active support network is in place, assistance is available to develop a plan and explore opportunities in the community, a personal vision has been developed and is clearly understood, and supports are in place to realize it, then self-determination is maximized. In carrying out such a process, conflicts are bound to emerge. These conflicts can be managed within a well-supported decision-making process where there is a consideration of different views in light of a person's vision and plan, and there is back-up assistance.

Planning support directly accountable to individuals and families was found to be critical in developing viable arrangements for community life that respected individuals' and families' choices. Accountable planning support was available to most individuals and families at the outset, for the purposes of transition planning. In all cases, except Manitoba and Alberta, it appears that long-term planning supports will be delivered through provincial government social workers or case managers, thus putting at risk the initial independence and autonomy of planning supports.[45] A means of ensuring more independent planning support, by restructuring the roles and accountabilities of government social services workers, or by testing community-based models for delivery of planning support could be considered.

The experience of the projects suggest that ***fostering and sustaining the capacities of families and support networks*** was one of the foundations for enabling community inclusion. Families and support networks have experienced two critical challenges: the burden of responsibility of managing support arrangements, and conflicts between members of the support network—often paid and unpaid members. These conflicts arose because of a lack of clarity about the roles of paid and unpaid individuals on the support network, and the extent to which paid professionals were accountable to family and other non-paid members of the support network. Planning support providers played a key role in the formation of networks, but no clear role has been formulated to provide them with ongoing assistance.

Mechanisms for Development and Management of Individual Supports

A management model for individual support arrangements was not designed at the outset of most of the projects, but the need for one emerged over the course of their implementation. With the creation of a highly decentralized system of individualized supports, not managed by service agencies except in Saskatchewan, a responsive and sustainable management approach was found to be lacking in a number of situations.

A wide range of management needs emerged as support staff and support networks sought to put individual plans into place: staffing (recruitment, management, scheduling); staff training and development; coordination of supports; developing ongoing strategies to create a vision for an individual and to realize the goals of the individual plan; identifying community development needs and ensuring these are addressed; monitoring; ensuring accountability to the individual and support network; financial tracking and invoicing procedures; negotiating and renegotiating funding; emergency/crisis response; conflict resolution between support network members and staff, or among staff; restructuring supports as individuals' needs changed; developing guidelines as needed for planning, decision-making, and communication.

Elements of a management model that were found to be effective in carrying out these various functions in a way that enhanced community inclusion, involved:

- ➡ an active support network of people committed to an individual and his or her plan
- ➡ a supervisor or lead support worker as part of the paid staff team with clear accountability to the individual and support network
- ➡ back-up support, other than front-line staff or other professionals encumbered by a direct service or funding approvals role, to assist in the various functions of management, to help resolve conflicts among support staff, networks, families, and the funding agency, and to fill in where support networks are not in place or not able to
- ➡ information resources and a support role to assist the network to:
  - become aware of the management needs of the individual arrangement
  - strengthen and sustain its capacities to meet the management needs
  - to create an environment that fosters individual self-determination
- ➡ a protocol for dealing with crisis situations (whom to call, roles and responsibilities)
- ➡ a protocol for supporting individuals to address challenging behaviours, including:
  - coordinated information and communication about the nature of individuals' behaviour, some of which can be anticipated, and any history of sexual assault, either as survivor or as perpetrator
  - orientation and training about such behaviour
  - back-up and emergency response plans
  - clear responsibility for providing staff with ongoing direction and management to deal with the behaviour

  - supports to staff to deal with the harm that comes to them from physical attacks and sexual harassment

➡ a strategy and resources for ongoing staff training and development

➡ attentiveness to the concerns of support staff.

The need to create new management approaches for a highly decentralized and individualized support system is consistent with analysis of trends in other jurisdictions. Except in that minority of situations where support arrangements were managed by community agencies, there has been a signficant "thinning" of intermediate management. Management responsibilities have shifted from the managers within community agencies, to front-line staff and individual support networks, with back-up support as needed. Analysis of cost-effectiveness of community care suggest that it is the appropriate use and management of human resources that is the "key to economic efficiency." Those systems for managing human resources, that are most likely to "generate value for money," are those characterized by: committed, informed staff operating with considerable freedom; based on consumer direction and choice; devolved financial power with clear budgetary constraints; coherent incentive structures to encourage responsiveness to individuals; explicit criteria to encourage participation of individuals, and to measure performance of staff.[46]

Structure and Process for Community Development

The evaluation found a number of aspects of a community development strategy that are effective in strengthening a community's capacity to enable inclusion.

It was found that a ***provincial-level mandate*** is needed to put in place an overall strategy for community development that emphasizes the aims and elements of community inclusion, the kinds of local structures that can be established, and that provides resources for an ongoing community development role. The evaluation makes clear that the issues of accessibility to communities are widespread and deeply entrenched—affecting community institutions, organizations, physical infrastructure, and social environments. Moreover, issues of accessibility cannot be identified at one point in time. They are continually revealed as the community development process fosters participation and inclusion.

Coordination between the provincial partnership and community-level structures was found to be important to assist those community-level efforts that faltered for lack of sustaining resources and direction. Community participants were not looking for provincial direction about what should be done in their particular communities. Many were looking for a framework for community development to guide their efforts at building inclusive communities—guiding principles, who should be involved, structures to use, how to support self-advocate and family networks, steps in strategic planning, and resources to manage the effort.

Those communities that ***established and sustained local structures***, which brought together a range of community interests, were most effective over the long term in raising and addressing issues of community inclusion.[47]

Those community groups that were most successful in sustaining the effort to build inclusive communities ***define the community development "process" as the mandate and outcome***, rather than the achievement of specific goals. Where the process itself was seen as the mandate, an emphasis was placed on:

➡ hiring staff that was accountable to the local community structure

➡ ongoing strategic planning, action planning, and monitoring of achievements by the group

➡ involving self-advocates and families through adapting how meetings were run, providing plain language materials, providing personal support at meetings and events, supporting self-advocates and families to meet separately and bring their concerns to the community steering committee

- ongoing dialogue with individuals and families to identify common issues
- identifying key sectors in the community where particular barriers needed to be addressed
- searching for resources to sustain the process

Finally, the community development process proved successful where it resulted in ***redesigning the community support system*** in ways that better enabled community inclusion for individuals. There are many examples of re-designing the support system through the community development process. In Regina, the co-management group of local service providers, while a restricted group of community interests, developed ways of coordinating provision of information to individuals and families, access to services, and funding and "vacancies" within the service system to encourage greater responsiveness by providers to individuals and families. The development of self-advocacy and People First groups in Newfoundland, PEI, and Ontario created an organizational capacity in communities that strengthened the political voices of self-advocates and offered them a place of peer support and social involvement in their communities. In Kitchener-Waterloo, self-advocates were hired with resources obtained by the local steering committe to act as community development workers and hold workshops for individuals still living in institutions—thus introducing the knowledge and experience of self-advocates into the community in a more systematic way. In Alberta, the provincial partnership established a number of new sustaining structures that provided the foundation for children with complex medical needs to live with support in their family homes, and for their families to receive respite services in the community. Such structures included the Community Support Team, the Medical Advisory Committee, the Relief Resources Committee of local service providers, and the Associate Family model for delivering respite resources.

Flexible Funding Mechanisms

The experience of the projects points to four key funding mechanisms which introduced far greater flexibility into institutional and community supports than conventional funding mechanisms have allowed. It was this flexibility that helped to build a foundation for community inclusion.

The evaluation found that the ***transition fund*** established through the NSIPD federal funding contribution enabled more individuals to move to the community where the fund was in place, than where it was not. Individuals were assisted to move from institutions in those projects where the fund was not in place, but not on the scale of Newfoundland and Saskatchewan where the fund was in place.

Clear agreements concerning the ***transfer of institutional dollars to funding community supports*** was found to be critical to expanding the funding base for community inclusion. The evaluation did find that the lack of formal agreements between institutions, provincial governments, and project partnerships about the conditions, timing, and extent of funding did lead to misunderstandings in some instances. The consequence was a more restricted funding base than was anticipated.[48]

The evaluation clearly points to how integral ***individualized funding mechanisms*** are to the exercise of self-determination and building of inclusive communities.[49] It was found that individualized funding best secured self-determination where individuals had contractual status and the accountabilities that come with that status. As well, it was more effective in providing individuals' decision-making status where they were supported to make decisions on a daily basis about how their income would be spent, and had clear agreements with support staff about terms and conditions of work.

The evaluation found that a ***sustained investment in community development*** was needed in order to strengthen the capacities of communties to become more inclusive. The NSIPD projects did not provide sustaining resources, although in a couple of communities, other resources were found to keep the process going. The evaluation suggests that *ongoing* investment in community development is necessary for building more inclusive communities for three reasons: 1) creating community awareness as a basis for community inclusion is long term; 2) maintaining structures, with paid staff, is needed to manage ongoing community-level strategic planning that addresses barriers to inclusion in key sectors; and, 3) strengthening the capacities of community services and programs to include and support people with intellectual disabilities, can minimize the demand for direct funding to purchase supp orts for individual disability-related supports.

Forum for Partnership

The partnerships established by the projects were found to be necessary in bringing about the changes that were needed in policies, programs, and practices so that deinstitutionalization and community inclusion could be accomplished for individuals. The evaluation found that national, provincial, and local partnerships played a number of key roles in bringing about the changes.

Partnerships at the provincial level ***created a forum for bringing various interests together*** beyond the four project partners. Representatives of families, self-advocates, the institutions involved, provincial funding programs, the business community, and community service providers all had an interest in how policies, programs, and practices were designed. Partnerships created a forum where different perspectives could be acknowledged and addressed, thereby limiting the organizational and institutional blockages to change.

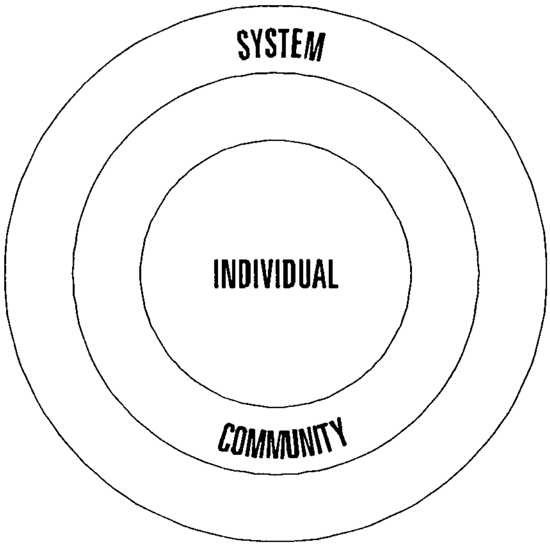
The partnerships provided a forum for ***articulating and clarifying shared commitments*** to deinstitutionalization and community supports. Having a framework of shared commitments assisted the government-community partnerships in keeping projects "on track" while dealing with a shifting policy environment.

With a forum in which partners could regularly meet, ***mechanisms and strategies were designed for project implementation*** that responded to the various perspectives and concerns of partners. Planning and funding procedures, delivery of planning supports, the establishment of standing committees like the Medical Advisory Committee in Alberta, all came about through joint and collaborative planning among partners.

Partner meetings, structures, and planning processes were found to provide ***a basis to build trust and communication among various interests***. This proved difficult in some situations given the sometimes conflicting mandates of partners at the provincial level. As one partner representative said,

> *A lot of time was spent trying to understand each other's perspective, to build working relationships with staff of different partners, and to stop 'pigeon-holing' people, because of who they work for.*

LEVELS OF CHANGE IN CREATING INCLUSIVE COMMUNITIES



Where trust and open communication was most difficult to achieve, there was a perception by some partners that others did not share the broad commitments of the project, and were thus not proactively working for change.

The evaluation found that leadership at a number of levels is necessary in creating and acting on the commitments to community inclusion. The forums for partnerships ***encouraged partners to foster leadership in their own sectors***—within government, within institutional facilities, within the community. Not all partners provided the needed leadership within their own sectors, in particular in the case of some government programs, and some institutions. In those cases, the partners tended to express commitments to overall goals, but did not exercise their mandates in ways that ensured accountability to achieving the goals. Partnership and commitment without accountability structures within the various sectors that partners represented, were inadequate in bringing about the scale of change anticipated by the projects.

The evaluation found that the funding, policy, and program changes needed to put the projects into place required ***ongoing identification of issues, negotiations and reaching agreement between partners***. Dealing with issues such as levels of funding to be allocated, which supports would be funded and which would not, how to work with various government departments who had mandates to provide community supports, all absorbed enormous energy and time. It was by working collectively on such issues, that partners developed a capacity to steer the projects as unanticipated events confronted them.[50]

The research found that these seven mechanisms are necessary to making the shift from institutionalized to inclusive and supportive communities. Each mechanism contributes to an enabling environment for this shift to take place. Their effectiveness also lies in the fact that together they can address the different levels at which inclusive communities are built—the macro- or systemic level, the individual and personal level, and the level of community structures and services.

First, systemic support for the shift from deinstitutionalization to community inclusion is created through the mechanisms for shared commitments, accountability structures, and partnership forums. These "macro-level" mechanisms are necessary in shaping the policy, program, and organizational environment in which large-scale changes can take place. Second, mechanisms are needed at the individual and personal level, where community inclusion is won and lost on a daily basis. These are the planning support, decision-making support and management structures for developing individual support arrangements that make community inclusion possible. Third, while less developed in the NSIPD initiative, mechanisms for community development are required at the "community level." These mechanisms help to bring about needed changes in the social, economic, and political environments in which individuals live, work, and participate.

V. EXTERNAL POLICY FACTORS

The six NSIPD deinstitutionalization and community support projects were formulated and implemented in a policy environment that was neither static nor entirely under the direction and control of those responsible for the projects. Through the course of the projects, a number of external policy factors emerged that had an immediate impact on the projects, shaped their direction, or are anticipated now to have implications for building inclusive communities in the future. The evaluation found that these factors operate at the three levels at which the NSIPD projects attempted to bring about change: the status accorded to individuals; patterns of investment and service delivery at the community level; and federal-provincial policy and governance arrangements.

Legal Status of Individuals

The evaluation found that the diminished legal status of individuals posed a barrier to securing the self-determination for individuals that is central to community inclusion. All Canadians have the legal right to equality before and under the law, to liberty and to security of the person, and to be free from discrimination in access to employment and to community services, without regard to mental or physical disability. These rights are protected under the *Canadian Charter of Rights and Freedoms*, and federal, provincial, and territorial statutory human rights codes. Yet for people with intellectual disabilities these rights have been limited in various ways by provincial and territorial substitute decision-making and guardianship provisions. For the most part such provisions assume that people need to independently exercise capacities to make personal care and financial decisions, if they are to retain their legal rights.

Compromise of the legal status of individuals was felt in various ways in the projects—from those individuals in Newfoundland who remained legally under financial guardianship of the Supreme Court, to those whom Revenue Canada assumed could not be employers of individual staff, to those who had "orders of supervision" imposed when they were committed to institutions, some of whom did not have the orders removed when they left. Some jurisdictions—such as Manitoba and the Northwest Territories—have passed statutory provisions recognizing the concept of "supported" or "assisted" decision-making.[51] The aim of these provisions is to provide a legal foundation for providing individuals assistance in decision-making without removing their legal status in personal and financial decisions when their capacity is questioned. It is still too early to tell the full impact of these provisions on securing individual legal status, in practice.

The evaluation has pointed to the critical importance for enabling community inclusion of securing the legal, decision-making, and contractual status that provides a foundation for individual self-determination. The extent to which this status is secured for individuals with disabilities remains limited by the current legal environment that draws distinctions with such profound implications between those able to make decisions on their own, and those who are determined incapable of doing so.

Patterns of Investment in Community Support Systems and Labour Markets

The NSIPD projects were introduced in communities where systems of support for people were already in place. The evaluation suggests that the long-term impact of the projects for building inclusive communities will depend on how the relationship is managed between these existing community support systems and the new systems of support put into place through the projects. Three distinct systems of community support now operate in a number of communities, each created through different investment strategies: the existing block-funded community agency system; individually funded personal supports; and the existing generic community service system.

The predominant investment strategy encountered in those communities where the NSIPD projects operated was the conventional community support system for people with disabilities. It is funded primarily through provincial government contracts with block-funded community agencies providing specialized residential and vocational supports. Charitable donations are also a funding source for this system. However, this system was used by only 15% of individuals in these projects.

The NSIPD projects introduced another type of community support system based on individualized personal supports in the private housing sector, created through the investment strategy of individualized funding. The labour pool for these two systems sometimes crossed over—those working for agencies in group homes, for example, also worked under contracts with individuals living in their own homes. However, the labour contracts were based on very different arrangements. Those working under the individually funded personal supports system tended to have much lower pay, lack of comparable benefits, concerns about workers compensation, unclear employment status, and lack of mechanisms to address common concerns of labour.

A third system for community supports is the generic community supports system that individuals used as they became more a part of their communities. This includes the voluntary, unpaid supports of neighbours and community members, the community-based physicians and health care systems, the seniors' centres, recreation centres and health clubs, the supports provided by employers in the community, the public transportation systems, and so on. This system of community support is the result of a wide range of investment tools that cut across government departments and the private sector. Although this generic system of supports excluded some individuals, nonetheless it has the potential to provide enormous resources to individuals to meet their support needs.

These three systems of support are not necessarily at odds. For example, the conventional block-funded agency system may help to address some of the issues emerging in the individually funded system (e.g., lack of management support, training of providers, community development to adapt the generic system). However, the relationship between them has not been fully considered or coordinated.

The fact that these three systems of support, and their linkages, have not been addressed within a coherent policy framework for investment, is one of the reasons that disparities and inequities between the systems were seen. For example, individuals tended to get staff supports with much better pay and benefits packages if they received their supports at a group home or sheltered workshop than if they lived in their own home. They could get supported at their own home, but often without needed management support. Or they could obtain needed supports and an inclusive environment at home, but not at the local recreation centre or the seniors' club.

All of these systems of support have important contributions to make in building an inclusive community. Without a policy framework that recognizes their inter-dependence, and the need to strengthen the labour market for individually funded supports, the gaps between the systems are likely to encourage exclusion rather than address it.

Current Delivery System for Planning Support

All of the projects established new arrangements for delivery of planning support for individuals and families that emphasized a primary focus on person-centred approaches. As the projects ended, most converged in the direction of using the existing government-delivered planning support, case management, or social work system for the purpose of developing plans, budgets, and funding agreements. The evaluation found a number of families, support staff, and partner representatives were concerned about whether this system will be able to operate according to the same principles and guidelines developed through the projects. The dual accountabilities of planning support providers to individuals and families, and to the fiscal restraints of government, could potentially undermine their effectiveness.

This evaluation found that the range of planning supports needed for community inclusion are not fully accounted for within the current policy frameworks for funding and delivering planning supports. In particular, three roles in planning support are needed that are not currently addressed: the need for planning support that is accountable to individuals and families, assistance in developing and sustaining a support network, and assistance in developing the resources and capacities of communities, beyond specialized services, to meet individual and family support needs. Without a clear mandate to deliver these kinds of planning support, one of the main levers for community inclusion will not be in place.

Federal-Provincial Fiscal Arrangements

Federal-provincial fiscal arrangements for funding supports to persons with disabilities changed substantially mid-way through the NSIPD initiative. With the end of the cost-sharing arrangements under the Canada Assistance Plan, provinces and territories could no longer rely on a sharing by the federal government of 50% of provincial expenditures on approved categories of supports.[52] Under the new fiscal arrangement—the Canada Health and Social Transfer (CHST)—provinces received a block of funds from the federal government as its contribution to the costs of health care, social services, and post-secondary education.

This funding arrangement, introduced at a time of provincial fiscal restraint, imposed particular difficulties on both Newfoundland and Saskatchewan, the largest of the deinstitutionalization projects. The shift to the CHST meant fewer federal dollars for funding of community supports, as well as an end to dollars targetted specifically for funding these supports. With the shift to a block-funding mechanism, competition for social services funding at the provincial level was intensified. Provincial social services programs had to compete for their share of the block fund with the huge demands on the fund from provincial health care and post-secondary education budgets.

As well, the federal transition funds for deinstitutionalization in Newfoundland and in Saskatchewan were key in enabling the projects to proceed. These dollars did not flow through a standing federal-provincial funding mechanism to support the transition from deinstitutionalization to community support, but were one-time special contributions. Since the NSIPD initiative began, Ontario has mounted a large provincial deinstitutionalization initiative targetted at almost 1,000 individuals currently living in facilities in that province. However, the scale of its provincial revenues enables it to proceed without transition dollars from the federal government. Smaller provinces may have more difficulty in doing so.

The federal government provided a fiscal context—through both the cost-sharing arrangements of CAP and the transition fund contribution—that made the projects fiscally viable from a provincial perspective. The fact that this context is no longer in place puts the feasibility of future deinstitutionalization initiatives, at least in smaller jurisdictions, into question.

Regionalization of Health and Social Services

The long-term impact of the projects in building inclusive communities is likely to be affected by the growing trend in provincial jurisdictions to a regionalization of health and community services. The shift to regional authorities to fund and manage delivery places decision-making closer to communities, and thus encourages greater local participation and accountability in services. However, with greater regionalization, also comes an increase in the number of centres of decision-making. Implementing a proactive policy framework to establish the enabling mechanisms for community inclusion becomes that much more difficult when it needs to be developed through so many distinct authorities. Because of the significant exclusion from communities faced by people with intellectual disabilities, giving greater local control to communities to determine the nature and extent of their supports will not on its own ensure inclusion. In Alberta, for example, 18 regional authorities are now established. The provincial Association for Community Living has expressed significant concerns about the frameworks for community supports being advanced in different regions, and their potential to undermine the enabling supports that are currently in place.

Regionalization without clear provincial direction is not likely to enable the mechanisms this evaluation suggests are the requisites for community inclusion.

Government Mandates and Accountabilities

The primary government partners in these projects tended to represent divisions, within provincial ministries or departments of social services, responsible for services to persons with intellectual disabilities. These partners demonstrated strong leadership and commitment to the aims of the projects, and to building government accountability for realizing these aims. However, research findings show that community inclusion cannot be achieved if it is seen as the mandate of a single government department or program. Community inclusion, as a mandate, cannot be confused with a mandate to deliver services to persons with disabilities. This evaluation makes clear that building community inclusion is a much broader enterprise that affects virtually all aspects of community social, economic, and political life. Many times the partnerships for these projects encountered declining commitment within government. They also encountered funding programs in home care or education, for example, that had funding criteria which restricted, rather than expanded, opportunity for individuals and families.

A major challenge in putting into place the enabling mechanisms for community inclusion will be, therefore, creating a cross-government, inter-departmental mandate and system of accountabilities for investment in community inclusion. Without this, the current contradictions in programs and policies will not be reconciled, and the advances toward community inclusion these projects mark, will likely not be sustained.

How widely should such a mandate and system of accountabilities apply? The jurisdiction for delivery of social services and supports to persons with disablities lies primarily with the provinces. However, it is clear that the federal-provincial funding and policy framework shaped the environment in which these projects proceeded, and in which community support systems were developed. Thus, the mandates and accountabilities cannot be designed and applied only at the the provincial level, if the enabling mechanisms for community inclusion are to be national in scope.

VI. FUTURE DIRECTIONS

Rather than undertake a program evaluation of each of the six projects, this study has sought to identify cross-cutting themes and issues. Therefore, the key directions for change that emerge from the evaluation are not focussed on specific project management issues, or policy and program disincentives in a particular local or provincial site. Key directions focus on what has been learned from the evaluation about how to sustain the deinstitutionalization and community inclusion process. Five broad directions for future deinstitutionalization efforts emerge from this evaluation:

• Create Partnership Mechanisms to Sustain Active Commitment to Deinstitutionalization and Community Inclusion

Government-community partnerships provided the leadership for the complex process of deinstitutionalization and community inclusion. Partnerships should be built and strengthened across the provinces and territories in order to continue the momentum for deinstitutionalization created to date.

Government-community partnerships were one of the key mechanisms in creating an environment that made deinstitutionalization possible, and in generating the needed leadership in government, institutional facilities, and community organizations. A variety of mechanisms could be used to organize the partnerships. While the partnerships could make deinstitutionalization a priority, the experience of the NSIPD projects suggests they are also needed for strategic action on a range of related policy and program issues. The partnerships proved effective, to varying degrees, in identifying and addressing these issues—such as conflicting government mandates, and the role of departments responsible for health, education, labour market training, and income supports in provision of needed supports for individuals moving from institutions. This evaluation has identified a number of partnership mechanisms that could be strengthened and expanded particularly through inclusion of additional provincial government departments. This study found widespread agreement that the role of People First nationally, provincially, and locally, should be more firmly established in future partnerships.

• Promote Inclusive Models of Support

Projects created individualized models of support that effectively enabled community inclusion. These models should be more widely adopted and promoted.

Most individuals obtained community supports in private housing in the community—their own homes, rented apartments, or the homes of families they lived with. Central to the models of support created for individuals were: the focus on individualized planning and funding; status for individuals in the decision-making process; the creation of support networks to assist in decision-making and building wider connections to the community; and back-up support to be accountable to individuals and networks to plan for and manage supports, and to deal with crises. Future deinstitutionalization and community inclusion initiatives should ensure that the policy and program framework encourages these conditions to be put into place. The projects did not assure that all of these conditions were in place for all individuals.

The models of support will be more widely adopted only if persisting support staff concerns are adequately addressed. Collective agreement provisions and processes are required that deal with support staff concerns, while protecting the capacity of individuals and families to decide who will work for them, and how their homes will be managed. As well, collective bargaining processes are needed that do not place undue burden on individuals and families.

• Strengthen Measures to Secure Individual Self-Determination

Deinstitutionalization led to community inclusion for individuals when their legal, decision-making, and contractual status to make decisions about their lives and needed supports were strengthened. Additional provisions are needed to secure these forms of status.

Legal status of individuals to make their own decisions is not assured in all jurisdictions. Guardianship and substitute decision-making provisions continue to limit the capacity of individuals to assume the status to make decisions about their lives, and to receive individualized funding. Provincial and territorial statutes, as well as protocols at institutions that determine when and how existing supervision orders will be lifted need revision in order to better secure individuals' legal status to make decisions.

The planning and funding processes put into place through the deinstitutionalization projects resulted in individualized plans and funding for most individuals, but did not always result in individuals having ***decision-making status*** on a daily basis. This can only be assured through the support of an individual's staff and support network. Additional resources may be needed to assist them in providing individuals decision-making status.

Because of restrictions on individuals' legal status to make their own decisions, ***contractual status*** in funding and service agreements was not always provided, thus limiting the recognition of an individual's authority to make decisions and determine their supports. Once the legal status to exercise decision-making power is assured, models developed in these and other initiatives could be used as a basis for giving individuals contractual status in funding and service agreements.

• Foster Community Development Processes

The deinstitutionalizaton projects demonstrated that developing individual supports that lead to community inclusion requires both individualized planning and funding, and a community-level change process. A mandate and resources are needed to foster ongoing community development processes that strengthen capacity for inclusion.

Projects established a variety of community development processes to encourage community responsibility and accountability for inclusion—consortiums of local service agencies, community steering committees with representation from various sectors, and development of parent and self-advocacy organizations. These community structures resulted in the development and use of community resources to strengthen inclusive supports for individuals. They demonstrated that individualized planning and funding systems cannot, on their own, tap all of the needed community resources, or address the systemic barriers communities present to people with disabilities. While community development was originally conceived in the projects as a time-limited and demonstration exercise, the experience clearly indicates that it should be conceived as a long-term effort, that should be supported and sustained. Policy and program incentives are needed to encourage community structures to mobilize resources and address barriers. As well, communities require information on best practices in the structure, principles, and process of community development.

• Establish an Enabling Policy Framework

The NSIPD Projects were implemented in a period of change in federal-provincial fiscal arrangements and restructuring of health and social services that resulted in a devolution of policy and

program responsibilities to provincial, regional, and local levels. The projects themselves contributed to devolution and decentralization of service delivery through the highly individualized approaches to funding and provision of supports they used. These shifts point to the need for a policy framework for deinstitutionalization that promotes adherence to a common set of guiding principles while enabling diverse approaches to implementation.

All of the directions identified above require an enabling policy framework to more fully implement them. A set of guiding principles for a national policy framework can be articulated based on the experience of the projects. These principles include:

- ➡ self-determination, equality, and citizenship for persons with disabilities
- ➡ equity across regions and jurisdictions
- ➡ accountability to individuals and families with children
- ➡ flexibility and responsiveness of funding and support arrangements
- ➡ partnerships between government and community as a basis for change

Wider implementation of the mechanisms that enable deinstitutionalization and community inclusion will require a more comprehensive mandate and accountability by governments than has been in place in the past. This does not mean that governments must do more in order to achieve the goal of greater community inclusion. It does mean, however, that the policy and program barriers that are currently in place will only be addressed when the accountability for this goal is shared clearly by both levels of government and across departments at the provincial level.

CONCLUSION: TOWARD A NATIONAL FRAMEWORK FOR COMMUNITY INCLUSION

The deinstitutionalization initiative funded in part through the National Strategy for the Integration of Persons with Disabilities (NSIPD) marks something of a watershed in the history of social policy in Canada, and in the provision of supports to persons with disabilities. Social policy-making in Canada has most often been the outcome of negotiated compromises between different levels of government and competing public agendas, rather than the result of a coherent vision.

The partnerships for these projects worked differently. Policies and programs were designed in the course of these projects through a federal-provincial, government-community partnership, not only in name, but in structure and in practice as well. They were not driven by the economic constraints of the times and shifting priorities on the public agenda, though they may have been affected by them. Rather, the partnerships were guided by a national commitment to human rights and to "righting the wrongs" of the exclusion of people with disabilities from Canadian society. Through these partnerships, and the experiences of so many individuals, families, support providers, and community organizations, a way of thinking about deinstitutionalization and community inclusion evolved. It has enabled the lives of many individuals to become dramatically different.

The framework for deinstitutionalization and community inclusion that has emerged through these projects is one of the legacies of the National Strategy for the Integration of Persons with Disabilities. It is one that could serve to guide future social policy efforts on a national scale to improve the quality of life of persons with disabilities. Central to a national framework would be the goal of community inclusion. The evaluation found five defining elements of this goal. Community inclusion is a process that happens for people when they are given real status to make personal decisions and thereby exercise self-determination; when they have supportive relationships in their lives that accord them value and respect; when opportunities and support are in place for educational and economic integration; when community structures are made accessible; and when needed personal supports are provided.

These outcomes have not been realized for all participants, and indeed a few individuals remain isolated and without needed supports in their communities; and some family members are frustrated by the lack of support given the promises made. Moreover, some of the major distinctions that determines who gets what in our society, like the distinction of gender, operate for these participants as well—men are much more likely to have jobs or be involved in education or training than women, for example. Yet for the majority of participants, major strides have been made in achieving one of more of these elements of community inclusion in their lives. People's lives look much different than they did when they needed to rely on institutional supports, rather than on supports they controlled, in their own homes. As people became more included in their communities, and were given greater status in personal decisions, enormous personal growth and development took place, and their health status improved significantly. Based on the findings from this evaluation alone, the importance of the goal of community inclusion appears indisputable.

A national framework needs a clear goal to guide investment, development, and regulation. It also requires a set of guiding principles to bring about the enormous changes in policies, programs, and practices that are required if the goal of community inclusion is to come any closer to being achieved. The NSIPD projects formulated a number of principles on the basis of which key mechanisms were established for enabling community inclusion. The effectiveness of those mechanisms that worked are one test of the validity of the founding principles. They include: self-determination, citizenship, and equality for people with disabilites; equity across regions and jurisdictions; accountability to individuals and families with children; flexibility and responsiveness of funding and support arrangements; and partnerships between government and community as a basis for change.

This set of principles has proven both compelling and effective in advancing community inclusion. Compelling, because the principles of self-determination, citizenship, equality, and regional equity are reflected in the Constitution of Canada and in federal and provincial human rights provisions. They impose both a responsibility to act and, in the case of people with disabilities, a sense of urgency given the signficant exclusions they face. The report of the recent Federal Task Force on Disability Issues affirms the importance of both the vision of inclusion and of these principles in building a national framework. Accountability, flexibility, and responsiveness in funding and support arrangements have been identified as guiding principles before for the provision of funding and supports to people with disabilities. The 1992 "Mainstream" consultation with disability organizations across Canada affirmed their importance. Finally, the principle of partnership has been articulated in recent years as a way of restructuring the demands on government, and of strengthening civil society. The partnerships for the NSIPD deinstitutionalization initiative, despite their many growing pains, demonstrated that such a principle can be put into practice, and that it can make for more inclusive communities.

Is a national framework viable politically? This is an essential question to ask in a country where the tradition of national social policy making, with important exceptions like health care, has been more the politics of fiscal arrangements and the art of compromise than it has been the pursuit of a shared vision. The NSIPD deinstitutionalization initiative has made clearly visible the contours of a shared national vision for community inclusion. It is one that seems capable, by its very definition, of doing justice to the diversity of individuals and communities across the country. The experience of the initiative makes clear that what was "national" was the breadth and depth of the commitment to community inclusion that was found in so many different communities. It was not a "federal" vision that proved compelling in this initiative. But the federal-provincial funding and partnership arrangements, along with the other mechanisms on which a national vision could be pursued across different jurisdictions, did prove to be an essential condition of success.

The findings from this evaluation suggest that a national framework for community inclusion *would* be a viable enterprise. A shared goal of community inclusion does exist, rooted in communities across the country. Moreover, provincial partnerships, with federal involvement, have been leaders in designing the mechanisms to achieve the vision. Mounting a national framework would require that further steps be taken to address the policy factors identified in this evaluation. Central to its realization would be a cross-governmental, and inter-departmental policy commitment and set of accountabilities. Such commitment and accountabilities are not currently in place. The provincial partnerships established through the NSIPD, if expanded and strengthened, would provide a solid basis on which to take this next step to community inclusion.

ENDNOTES

[1] For example, House of Commons Special Committee, *Obstacles, Report of the Special Committee on the Disabled and Handicapped*, Ottawa, Ontario (1980); Standing Committee on Human Rights & the Status of Disabled Persons, *A Consensus for Action*, Ottawa, Ontario (1990); Standing Committee on Human Rights & the Status of Disabled Persons, *Unanswered Questions*, Ottawa, Ontario (1990); and Federal Task Force on Disability Issues, *Equal Citizenship for Canadians with Disability: The Will to Act*, Ottawa, Ontario (1996).

[2] According to the social model, disability is understood as having been socially and legally constructed, rather than as a negative characteristic residing in the individual. It recognizes that disability is a consequence of systemic barriers to participation that are inherent to social institutions. See M. Oliver, *The Politics of Disablement*, London, England: MacMillan Press (1990); M.H. Rioux, *Disability: The Place of Judgement in a World of Fact*, Journal of Intellectual Disability Research (April, 1997), Vol. 4 Part 2, p 102–111; S.A. Goudry & Y. Peters, *Litigating for Disability and Equality Rights: The Promises and the Pitfalls* (1994); M.H. Rioux and M. Bach (eds.), *Disability is not Measles: New Research Paradigm in Disability*. North York, Ontario: Roeher Institute (1994); C. Barnes & G. Mercer (eds.), *Exploring the Divide: Illness and Disability*. Leeds, England: The Disability Press (1996).

[3] The Appendix provides background on the deinstitutionalization initiative, and an overview of each of the projects.

[4] For a number of reasons, there is a difference between those surveyed and those whose survey data were included in the analysis for this report: **Newfoundland**: Only 65 of the 72 surveyed had moved to the community; the statistical analysis was to focus on outcomes as a result of obtaining community supports under the projects. **PEI**: Not all individuals surveyed had moved to the community. **Ontario**: The majority of individuals surveyed had been receiving residential community supports; the project focussed on closing a sheltered work setting. It was decided not to include this group because most of their community supports had not been arranged under the NSIPD initiative. The focus in the Ontario project was on community development, rather than on supporting particular individuals. The eight individuals who were surveyed in Spring 1996 were not surveyed again in Spring 1997, because the agency supporting them decided not to provide the information and assistance needed to complete the survey the second time. However, the agency did arrange for the individuals, their support workers, and family members to be interviewed in Spring 1997. The qualitative analysis of these interviews is incorporated in the discussion of findings. **Saskatchewan**: Some of the survey data were incomplete and could not be obtained in follow-up, rendering these "missing cases" in the analysis.

[5] Profiles of a few of the participants are provided in Appendix B. They provide a sketch of their situations, and how their lives changed as a result of the projects.

[6] In this section a number of individuals are referred to in the discussion and quotes by a first name. These names have been changed in order to protect confidentiality of individuals.

[7] See Appendix E for review of key literature on deinstitutionalization that was drawn upon in designing and conducting this evaluation.

[8] Classical definitions of self-determination often emphasize individual capacities to make their own decisions, a definition that excludes people who require support. This concept of self-determination has been rethought in more recent philosophical literature, emphasizing self-determination as an inter-relational concept, the exercise of which requires support from others and from an enabling culture and society. See, for example, W. Kymlicka (1989), *Liberalism, Community and Culture*, Oxford: Clarendon Press. This con-

cept of self-determination has been developed in relation to people with disabilities. See, for example, The Roeher Institute (1993), *Social Well Being*, Toronto: The Roeher Institute, Canadian Association for Community Living (1993), "Task Force Report on Alternatives to Guardianship," Toronto: The Canadian Association for Community Living.

[9] Sixty-two of the 126 individuals who were originally identified as participants in the "Right Future" project came under this jurisdiction of the Supreme Court. In effect, it removed their status to enter financial contracts and to control funding for purchase of disability-related supports. Through consultations with the Estates Office of the Registrar of the Supreme Court, arrangements were made for individuals to move from the Waterford Hospital and for decisions about funding and delivery of supports to be made without the approval of the Registrar.

[10] These were, in effect, guardianship orders which could be lifted only at the approval of designated officials with the facility acting on behalf of the public trustee or guardian. In Manitoba, agreement was reached that for those individuals included in the project, the orders would be lifted as individuals moved to the community. However, in both projects officials were able to, and did, exercise discretion about whose orders would be lifted and when. For a couple of individuals orders were not lifted until some time after they had moved to the community.

[11] Early in the project, Manitoba was the one province that passed legislation to attempt to deal with the fact that, because of existing substitute decision-making provisions and orders of supervision, individuals' legal status was often at odds with the model of individualized approaches to planning and funding being developed in the province. In 1993, the province passed Bill 30 *The Vulnerable Persons Living With A Mental Disability and Consequential Amendments Act*, which recognizes in s.6. "supported decision-making" as a means of "enhancing the self-determination, independence and dignity of a vulnerable person." The Act provides for an individual to take advantage of a "support network" in providing assistance to make personal care or property decisions, thus limiting the need to resort to substitute decision-making provisions.

[12] The survey data suggest that as of Spring 1997 the vision for a person's life, as it is understood by those closest to him or her, is "quite" clear for about one third of individuals who have moved, and "very" clear for only 14%. For most of the other individuals the vision is "somewhat" clear (42%) and for the remaining individuals it is "a little" clear or "not at all" clear (9%).

[13] The Newfoundland community attitude survey of professionals indicated that physicians sometimes consulted no one in making health care decisions, including the individual who was to receive the medical intervention. In 11 of the cases one other person was consulted, in 2 of the cases, two people were consulted, and in 1 case, three others were consulted. None of the individuals in question were consulted with respect to decisions about their health care. Two of 17 health care professionals surveyed consulted family members. All the rest of those consulted were paid support providers or other professionals. In the interviews, some families expressed concerns that individuals were being taken to physicians without their consultation.

The Alberta project was distinct with respect to health care decision-making. Health care planning was a critical part of the planning process, given the complexity of most children's health care needs. Particular attention was paid to creating a planning process that focussed on the individual child and the family's wishes and decisions, while at the same time providing support in health care decision-making. This was assured by having a health professional on the planning team, and by establishing a Medical Advisory Committee. The Committee reviewed the plans and provided additional expertise with regard to meeting health care needs within the context of the overall plan for the child and family.

[14] Decision-making status was secured without contractual status for a variety of reasons. In Newfoundland, the fact that many individuals were under orders of the provincial Supreme Court, meant that they did not have the legal status or right to enter contracts. As well, an interpretation obtained from Revenue Canada during the course of the project also restricted the contractual status of individuals. The position suggested that individuals with intellectual disabilities did not have the legal capacity to be employers of their support staff, one of the staffing options originally anticipated. In Saskatchewan, individual plans were developed, and individualized costing of support needs were undertaken. However, most individuals used the existing service system for provision of disability-related supports (eg. group homes or sheltered workshops), which meant that contracts for delivery of supports were between the Community Living Division of the Department of Family and Social Services and those agencies providing supports.

[15] Networks proceeded continually through these phases. As individuals' support arrangements required changing, or a new plan was needed, networks in many instances returned to a developmental phase, to plan for and establish new arrangements. The projects were designed in such a way that support networks received most assistance in the developmental stage, somewhat less assistance in the phase of managing community connections, and usually little or no assistance in the very difficult phase of managing succession and renewal of the network.

[16] In the Manitoba project, the role established to provide support in developing and sustaining networks has been maintained, but it is as yet unclear if the same amount of time will be available per network. In Newfoundland, government social workers were to take on this role, but with increasing caseloads, and the termination of the "individual and family support consultant" role played by the Newfoundland and Labrador Association for Community Living, the capacity to provide networks with needed back-up support was substantially diminished from the outset of the project.

[17] There was no statistically significant relationship between having this decision-making status and the value and respect received from those who knew the individual personally. This suggests that the personal relationship itself was likely a source of value and respect, independent of the individual's decision-making status. However, the evaluation did find a significant relationship between status in personal economic decisions, and having greater value and respect from community members generally, those who did not have a personal relationship with the individual.

[18] The measure of statistical significance used was the T test (T = 3.28)

[19] See Carol Herbert and John Milsum (1990), *Measuring health: The documentation and evaluation of measurement procedures currently used to measure well-being*, Vancouver: University of British Columbia, Institute of Health Promotion.

[20] Decline in frequency of contact did not mean that family members were no longer in contact with the individual at all. It usually meant that daily contact had shifted to weekly contact, or weekly contact had shifted to monthly contact. The decline in daily and weekly contact for some individuals appears from the case study interviews to be due to the nature of involvement in an individual's life. Family members, especially mothers and sisters, were often very involved in the planning stages and the initial transition to community supports. Involvement took many forms—attending planning meetings, arranging housing, purchasing furniture, recruiting and hiring staff, attending meetings of "support networks" during and after the individual's move. The demands of such involvement proved too burdensome for some, and daily and weekly contact shifted to monthly and semi-annual contact. The increase in contact for others was due, in part, to the longer period of time it takes in some instances to strengthen relationships with family members.

[21] The reasons for these shifts are also similar. Upon

the initial move to the community, friends, and sometimes potential neighbours were invited to participate in the planning, welcoming parties were organized for when an individual moved, and various efforts were often made by staff and others to encourage contact and possible relationships. Sustaining the investment in building relationships with friends, and the wider community appears most effective when back-up supports were available to staff and networks to encourage this reaching out. Such assistance was not available in all situations.

[22]The projects in Newfoundland, PEI, and Ontario supported the development of local People First of other self-advocacy organizations. In the Saskatchewan initiative, opportunities were created for family members to meet other families through informational and mutual support gatherings. Family-to-family support was a focus in the Alberta project, especially at the outset of the initiative. In Manitoba, no organizations other than individual support networks were established through the project. The project sought to strengthen the capacity of networks to assist individuals and families to take advantage of other organizations in their communities if they wished to do so.

[23] Those who have positive attitudes about individuals with intellectual disabilities marrying, having children, and a sexual life, also tend to believe that it is good use of government dollars to provide training and education, that people do not work best in a sheltered workshop, that people can make basic living decisions on their own, and that people can be productive members of society with proper supports. How community members understand and support the development of an individuals' personal relationships has an important bearing, therefore, on their commitment and support for broader community inclusion.

[24]See, for example, J. Conroy and V. Bradley (1985), *The Pennhurst Longitudinal Study: A combined report of five years of research and analysis*, Philadelphia: Temple University Developmental Disabilities Centre; and R. Cummins and D. Dunt (1990), The Deinstitutionalization of St. Nicholas Hospital: Lifestyle, community contact, and family attitudes, *Australia and New Zealand Journal of Developmental Disabilities*, 16 (1):19-32.

[25]Volunteer activity was looked to as an option for many individuals who were not able to get paid work, but who wanted regular involvements in their communities. Whether the volunteer involvements of individuals will serve as a springboard to paid work, or whether they will result in long-term "non-paid" participation, it is still too early to tell for this group. What is clear from the evaluation is that the volunteer involvements are proving positive in terms of developing work-related skills, and the development of a network of community contacts.

[26]This represents a statistically significant difference (*Chi-square=5.88, P=.01*).

[27]Where individuals were in receipt of social assistance or welfare, as one source of funding for basic income and/or purchase of disability-related supports, their maximum earnings were restricted by provincial eligibility rules for this form of assistance.

[28]The small percentage who believe otherwise also hold other attitudes that would commonly be understood as more negative with respect to persons with intellectual disabilities. Those who tend to believe that people with intellectual disabilities are better off in settings only with others who have intellectual disabilities, or believe that they should reside in nursing homes, also tend to believe that: it is not good use of government dollars to invest in training; that people should work in sheltered workshops; and that they cannot be productive members of society, even with support.

[29]Recent surveys in PEI and in New Brunswick, under the auspices of other studies, found similar levels of support.

[30]In Alberta, for example, the planning support provided through the Community Support Team established under the project, provided most of its plan-

ning support not to children and families using the Rosecrest facility but to parents who were at risk of having to use Rosecrest, or who lacked information about funding and supports to meet the health care and other needs for their child.

[31] For example, in Alberta there were questions about whether personal supports for children to attend school should be funded through public education budgets, or through the Department of Family and Social Services' Handicapped Children's Services budget.

[32] In Newfoundland, where the overall reductions in supports were most systematic, they have not come without frustrations for some individuals and concerns on the part of some paid staff, family members, and individuals' advocates, that support arrangements may not be viable. There have been a few breakdowns in support arrangements and a conflictual decision-making process in a number of situations as reductions have been implemented. However, the reductions in paid support have not jeopardized meeting the basic needs of individuals. As well, the case studies suggest that individuals continued to make personal advances between Spring 1996 and Spring 1997 when the final round of interviews were completed. Reductions for many individuals indicate an increasing presence of unpaid relationships in their lives, itself a positive outcome. Reductions also indicate, in part, a capacity for individuals to be at home and in the community without the extent of support required when they first moved from the institution.

[33] This is not to suggest that vulnerabilities were not present in either the institutionalized support system, the community service system, or the unpaid supports provided by families. There clearly were vulnerabilities and these were recounted by individuals and families: the burden on families with no in-home respite; individuals lacking needed personal supports to participate in the community; lack of opportunity to exercise personal choice and decision-making; and the physical and sexual abuse reported by individuals in institutions and community services, most often inflicted by other residents, but by staff as well in a few reported situations.

[34] In Newfoundland, concern was expressed by a number of staff (those who were working for 24% of individuals in that project) about being "reclassified" into lower-paying categories because the intensity of their need for support declined (for example, from behavioural aide to respite worker). In only one case were staff reclassified into a higher-paying category. Thus, the changes in intensity of support were achieved, to some extent, by wage cuts for a significant number of individuals. Lack of coverage under Workers' Compensation was addressed in most instances through the course of the projects.

[35] In the case of one woman who was being sexually abused by a care provider, she disclosed to a member of her support network, who was then able to witness the perpetrator's approach to the woman. With the assistance of the planning support agent for the project, police were contacted and charges layed. As well, the support network moved in quickly with the help of project staff to re-organize the support arrangement and to work with the provincial adult protective services who initially wanted to remove the woman from the community and place her in an institutional facility for her protection. The woman was able to stay in her home, and remain in close relationship to support network members and staff to whom she had trusted enough to make the initial disclosure.

[36] For example: a couple of individuals were asked to leave their alternate family arrangements, with no where to go but back to the facility; a woman was\sexually abused by a respite provider; a couple of individuals were physically assaulted by staff over a period of time; an individual who moved with a support provider to a new community away from the support network, was then isolated and neglected. A few staff also reported physical and sexual assault by individuals they were supporting, and a lack of back-up support to help them deal with the situation.

[37] See *Submission by the Newfoundland and Labrador Federation of Labour to the Social Policy Committee of Newfoundland and Labrador on Home Care Workers*, St. John's, NF, March 4, 1997.

[38] Not all individuals obtained enabling supports, and case study data suggests a custodial model of care was instituted for some individuals even in the context of an individualized approach. However, this was due less to the structure of the decentralized and accountable support system put into place, and more to the lack of management and back-up supports referred to above—the supports needed to assist staff and support networks in establishing support arrangements that enabled diverse personal visions and plans.

[39] The cost-effectiveness method is more suitable than either of the other two methods commonly used to examine efficiency, the cost-benefit and cost-utility approaches. The cost-benefit approach attempts to monetize outcomes as well as program costs. It was originally developed to assist the governments contemplating large-scale physical infrastructure projects. However, assigning a market value to the benefits desired in the social policy field is fraught with difficulty and therefore, the cost-benefit approach is of limited value in dealing with social investments. The cost-utility approach has mostly been used to examine physical health care outcomes by assigning them a value. One such measure is the quality-adjusted life year (QALY), which measures both reduced mortality and reduced morbidity.

[40] The general procedure that was followed was the same for each scale. The primary test of inclusion was the Cronbach Alpha measure of internal consistency which was calculated for each of the indices. This is a measure of the extent to which the variables under examination correlate with each other. All variables were scaled so that their high scores meant the same thing as each other (eg. all participation items were coded so that a higher number meant more participation). This eliminated most negative correlations. An alpha should range between zero and 1, with higher numbers representing greater internal consistency. Variables were included where they did not substantially lower the reliability as measured by alpha—an alpha coefficient of .70 or higher was considered acceptable for inclusion of a variable, for the purposes of this evaluation. All scales met this reliability test.

[41] The formula for constructing this index was designed to produce a score that was higher as fewer barriers were encountered.

[42] Whether individuals needed assistance, and the frequency of that assistance was based on the perception of those who provided either planning or direct supports to individuals, not by any independent assessment of the research team.

[43] Variables concerning the perceived impact of a person's disability on vision, speech, and emotional health were excluded from the needs index. The research found that these characteristics, in and of themselves, were not associated with needs for support, for this particular group.

[44] See, for example, The Roeher Institute (1992), *On-Target? Canada's Employment-Related Programs for Persons with Disabilities*, Toronto: The Roeher Institute.

[45] In Manitoba, delivery of long-term planning supports for individuals and back-up to their support networks has not been determined; however, this is a consideration as the project is now taking on an additional group of individuals for individualized funding and network development. In Alberta, the Community Support Team does include a health consultant, a role created for the Support Team, and directly accountable to the provincial Services to Persons With Disabilities program at the Edmonton Regional level. However, the role is designed to provide autonomous and accountable planning support to families through two means: 1) collaboration on the Support Team from the funding agency, Handicapped Childrens Services, and a family representative from the Alberta Associa-

tion for Community Living; and 2) a statement of principles and practices to guide the provision of planning supports by the Support Team, that was adopted by the provincial partnership for the project.

[46] Research has found that increased 'consumer sovereignty' in community supports is more economically efficient in the long-term, but creates management challenges in the short terms. The research suggests that with restructuring community supports, it is the management of social care provision that will come under increasing scrutiny. Moreover, they find that efficient and effective management structures for a community support system should foster initiative on the part of front-line staff and will likely involve the "thinning" of intermediate management structures. For a review of research on the economic aspects of community care and supports, see David Taylor and Jean Taylor (1991), *Economic Aspects of Care for Individuals with Learning Disabilities*, London, England: King's Fund Institute, pp. 22–23.

[47] Structures took the form of "community teams" in various communities in Newfoundland, "regional advisory committees" in PEI, a local "steering committee" in Kitchener-Waterloo, Ontario, a parents group and local advisory committee in Ottawa-Carleton, and in Regina, Saskatchewan a "co-management" group of service providers. In Alberta, the provincial partnership itself became the community-level structure as the project was focussed primarily on the Edmonton region.

[48] In Newfoundland, PEI, and Saskatchewan, understandings were reached that facilities could transfer $500,000 to $1,000,000 after enough individuals had moved to make it feasible to close a unit or ward, or "cottage" housing from 16 to 25 people. Transfers did take place in Newfoundland and Saskatchewan. As of August, 1997, not quite 20 individuals had moved from the Hillsborough Hospital in PEI to make feasible the closure of a unit and the transfer of institutional dollars to community supports.

[49] In all projects except Saskatchewan, funds were directly attached to individuals, with various arrangements for flowing dollars for the purchase of supports. In Saskatchewan, support needs were costed on an individual basis, and then community service agencies were contracted through the provincial government's "Community Living Division" to deliver supports. Commitments were made that individuals could move to other supports, in effect making their funding "portable". Nonetheless, their support staff were employees of the service agencies

[50] In Newfoundland, for example, the termination of the federal governments' cost-sharing agreement under the Canada Assistance Plan mid-way through the project, put into question whether the provincial condition would be achieved that the project be "cost-neutral" to the province when the transition fund was depleted. Consequently, the rate at which people moved from the Waterford Hospital slowed to a halt by Spring 1996. The fact that a forum for partnership existed meant that all four partners could negotiate a new agreement—reached by reprofiling the project budget and through an additional contribution by the federal government.

[51] For a discussion of the concept of supported decision-making, as it has been developed in Canada see, The Roeher Institute (1994), *Legal research: Supported decions-making and the restriction of guardianship*. (Unpublished paper) Toronto: The Roeher Institute.

[52] When the projects began, the federal government had already placed caps on its contributions under the *Canada Assistance Plan* to the provinces of British Columbia, Alberta, and Ontario.

APPENDIX: BACKGROUND AND OVERVIEW OF THE INITIATIVE

BACKGROUND

The deinstitutionalization initiatives in the six provinces that are the focus of this evaluation were funded in part through a 15 million dollar federal government contribution under the National Strategy for the Integration of Persons with Disabilities (NSIPD). This five-year, federal, inter-departmental initiative was implemented in the period 1991-92 through 1995-96 with a total budget of 157.8 million dollars. The initiative involved ten federal departments and agencies in an effort to build government-non-government partnerships to address the significant social and economic barriers faced by people with disabilities. Objectives established for the initiative include achieving equal access, economic integration, and effective participation of persons with disabilities. Through the various efforts of the ten departments and agencies involved, action was to be undertaken on a number of fronts including:

- employment and training opportunities
- access to transportation
- community integration (including deinstitutionalization)
- partnerships development
- information exchange and coordination

The NSIPD was launched at the end of the 1980's, the United Nations Decade of Disabled Persons. With the publication *Obstacles: Report of the Special Committee on the Disabled and the Handicapped* at the outset of the Decade a perspective on disability as a human rights issue began slowly to take hold, among the disability movement, within service systems, and within government. Against the backdrop of the constitutional entrenchment of equality rights in 1982, disability organizations began to articulate a stronger human rights focus in their platforms.

The inclusion of deinstitutionalization efforts under the NSIPD was due in a large part to the persistent efforts of the Canadian Association for Community Living (CACL), representing over 400 local, provincial, and territorial Associations for Community Living. In the mid 1980s, the organization articulated a new mission to guide its advocacy efforts with and on behalf of people with intellectual disabilities and their families. Published in 1987 and titled *Community Living 2000*, the mission highlighted the principles of citizenship, self-determination, and membership of all people. The Association also identified closing institutions for people with intellectual disabilities as one of seven key objectives to realize its mission. This objective was based on an understanding that people's rightful place was in the community; and that institutional environments fundamentally limited the opportunity for people to develop and exercise citizenship, self-determination, and membership in their communities.

The National Deinstitutionalization Initiative

In partnership with its provincial/territorial Associations, CACL made deinstitutionalization a 5-year priority, based on two key understandings: 1) a recognition that institutions were not appropriate forms of support for individuals, and that continued investment in them meant that resources were not as available for community supports as they would otherwise be; 2) that provincial governments were showing some real leadership in deinstitutionalization efforts, and that achieving the goal of deinstitutionalization would require fostering federal government commitment. In 1987 CACL sought, but did not receive, a commitment from the federal government to phase out, over the following five years, the spending of federal funding contributions to provinces for the purpose of institutionalizing people with an intellection disability. The Association wanted the federal government to commit substantial resources to enable provinces to make the transition within the five-year period. However, federal conditions of this nature in an area of provincial jurisdiction were not considered politically feasible.

Nonetheless, as an initial expression of commitment to CACL's priorities, the federal government committed one million dollars to the Association in 1988. The funds were to be spent over a 5-year period to enable the organization to work with federal and provincial/territorial governments and with provincial and territorial Associations to pursue their deinstitutionalization objectives. This was a significant and unprecedented expression of support by the federal government for deinstitutionalization, and was the beginning of a growing commitment within the federal bureaucracy to CACL's goals. At the same time, the federal government indicated it would consider funding options to make deinstitutionalization more feasible for provincial governments. A number of funding issues had to be addressed. Provincial governments and CACL were concerned that under the primary federal-provincial funding mechanism for institutional care, *Established Programs Financing* (EPF) for block funding of health care and post-secondary education, there were few incentives to transition individuals from institutional to community support options. Nor were transition funds in place to enable provinces to keep institutional facilities in operation through the process of moving individuals to the community. There was also some concern that the funding arrangement for provincial cost-sharing with the federal government for community supports under the *Canada Assistance Plan* (CAP) did not enable the full individualization of the supports that were envisioned. Furthermore, there were concerns that the 50-50 federal-provincial cost-sharing arrangement under CAP and the *Vocational Rehabilitation for Disabled Persons Act* (VRDP) would end up requiring substantially more expenditure by the provincial government than was the case when individuals were living in institutions and costs were shared through the EPF.

By 1990, as a result of the work of CACL and its provincial/territorial affiliates together with the federal government at both the bureaucratic and political level, there was growing federal interest in establishing a national deinstitutionalization funding initiative. The federal government made a formal commitment of 15 million dollars to deinstitutionalization, and included it as part of its NSIPD initiatives. Deinstitutionalization became the largest initiative of the NSIPD in dollar terms, and was the only one where the leadership came from outside of government.

The 15 million dollar fund was initially secured for a national demonstration in New Brunswick, called "Exodus". Detailed proposals were developed and consultations between the federal and provincial governments were struck to establish a funding arrangement. While the proposal came very close to being approved by the province, ultimately it was not granted. The provincial government expressed concerns about the costs to the province, and the investment in individual and community planning infrastructure that was proposed. The withdrawal of the provincial government in December 1991 made clear the need to resolve the federal-provincial funding arrangement as a condition for achieving the goals for deinstitutionalization.

Despite the failure of the one project, CACL was able to secure from the federal government a commitment that because the investment in the New Brunswick initiative was part of a national deinstitutionalization strategy, the funds should be protected for a national project in another site. The condition would be that the designated province would mount a deinstitutionalization effort with the outcome that all individuals with intellectual disabilities in that province would live outside of institutions within a five-year period. Because its commitment was to a national initiative CACL had been working with provinces and territories on its priority in the period 1987 to 1991. After the collapse of the effort in New Brunswick, Newfoundland was looked to as the next site for the major initiative where full deinstitutionalization was considered feasible. The Newfoundland project, approved in 1992, called for a federal contribution of 10 million dollars, leaving 5 million of the original federal commitment. It was decided by CACL and the federal government that these funds would be used to initiate smaller projects in other provinces in order to generate best practices that could contribute to a national framework for deinstitutionalization. Proposals were accepted from five provinces as part of the initiative: Prince Edward Island, Ontario, Manitoba, Saskatchewan, and Alberta.

Each of the six initiatives was funded through a federal-provincial Agreement and guided by a Memorandum of Understanding outlining the goals of the project, and the federal funding contribution. As well, each project was directed by a four-way partnership including the federal and respective provincial government, and the Canadian Association for Community Living and the respective provincial Association for Community Living. While the largest federal contribution was to the Newfoundland project, all projects received a separate federal funding contribution, in addition to any contributions the federal government would make during the project and after through the cost sharing mechanisms of CAP and VRDP. The projects operated in the period January 1993 (some formally began April 1993), and most were formally completed March 31, 1996. Because of the scale of Newfoundland's Right Future Project it was to be completed March 31, 1997, and was extended to December 31, 1997.

Newfoundland: A Future with Rights — The Right Future Project

A significant amount of work had already been done in deinstitutionalization in Newfoundland prior to the Right Future Project. Children's Home in St. John's, which provided primarily institutional medical care to over 60 children and young adults with intellectual disabilities, physical disabilities, and various medical conditions, had closed in 1984. Exon House, also in St. John's, provided institutional care to 80 children and young adults with intellectual disabilities when plans to close it were adopted in the early 1980s. It was closed in 1989. With those two institutions closed, the only remaining institutional facility in Newfoundland where people with intellectual disabilities lived was the Waterford Hospital in St. John's, a psychiatric facility. In the early 1990s when the Right Future Project was approved, over 120 individuals with intellectual disabilities lived at the Hospital, primarily on five designated units.

When CACL turned to Newfoundland as a possible site for its national initiative after the New Brunswick Exodus proposal was rejected, there was already a "Working Group" in place to develop a proposal for moving those with intellectual disabilities from the Waterford Hospital to the community. With representation from the provincial government and the Newfoundland Association for Community Living, the Working Group was building on proposals that had first been developed after the 1983 release of the "Futures of Quality Report". The report had been commissioned by the Board of the Hospital, and recommended that all those with intellectual disabilities living at the Hospital receive supports in the community in order to better secure the exercise of their human rights. It took almost ten years to craft a proposal that was financially feasible. The federal contribution of a 10 million dollar transition fund, and the commitment that the costs to the provincial government would be no more after individuals moved to the community, were two of the conditions that made provincial government approval of the Right Future Project possible.

By August 1997, 85 individuals had moved to the community from the Waterford Hospital, 13 were in the planning stages, and another 13 had not yet begun planning either because they did not wish to move to the community and/or because their families did not wish them to move.

Prince Edward Island: A Time of Change

The Time of Change project was initiated through a joint proposal by the Prince Edward Island Association for Community Living and the provincial government. The proposal highlighted two aims: to assist individuals in planning to move from the Hillsborough Hospital, a psychiatric facility in Charlottetown, where over 50 individuals with intellectual disabilities lived; and to develop the capacity of communities to include people. While the provincial government did not have a formal deinstitutionalization policy at the time the project was announced, there was a discharge planning process in place at the Hospital. The project was to encourage a more focussed effort in discharge planning for moving people with intellectual disabilities to the community. By August 1997, 14 individuals had moved from the Hillsborough Hospital to the community, and another 3 were preparing to move.

Under the project, the federal government committed $600,000 to the initiative, $100,000 of which was to be used as a transition fund for deinstitutionalization. The final budget for the project did not include this transition fund.

Ontario: Opening New Doors

The Government of Ontario has a long-standing commitment to downsize and close institutions for people with intellectual disabilities. While there has been no firm policy framework for achieving full deinstitutionalization, *Challenge and Opportunity*, released by the government in 1989 articulated a number of policy objectives including downsizing of institutional facilities, development of community supports, and enhancing the opportunity of individuals to exercise greater self-determination through individualized approaches to funding and planning. In order to achieve the policy objectives the provincial government established a multi-year plan and planning process to assist in downsizing institutional facilities and developing community supports.

The Opening New Doors project was to support deinstitutionalization efforts already underway at four facilities in the province. It focused on community development efforts in four "demonstration" communities and regions to which individuals were to move: the Francophone community in Ottawa-Carleton; Northumberland-Peterborough-Victoria Counties; Kitchener-Waterloo; and the Southwest region of the province encompassing a number of communities and municipalities. Person-centred planning approaches and individualized funding were to be promoted through the project in order to assist individuals in making the transition. Many of the project's efforts were invested in establishing community development processes and structures in the four communities. In addition to various community development efforts, the project in Northumberland County provided person-centred planning support to 32 individuals leaving a sheltered workshop attached to D'Arcy place in Cobourg, and to 2 individuals leaving the residential facility of D'Arcy Place. As well, the project in Kitchener-Waterloo had assisted one individual move from Oxford Regional Centre, and provided planning support to three other individuals to begin preparing for their move from Midwestern Regional Centre.

Under the project both the federal and provincial government committed up to a maximum of $450,000 each, separate from their respective shares of eligible costs under CAP and VRDP.

Manitoba: in the Company of Friends

As in the case of the other NSIPD deinstitutionalization initiatives, the Manitoba project built on previous efforts in the province to support people to move from institutions and to develop community supports. The roots of the project can be found in the 1989 throne speech in which the Government of Manitoba committed to establishing a "Working Group on Community Living" to review disincentives to community living and to make recommendations for initiatives that would strengthen community capacity. This commitment followed shortly on the heels of a major deinstitutionalization effort, the 1985 to 1988 "Welcome Home" initiative to assist individuals to move from the Manitoba Developmental Centre. Concerns had been raised in the evaluation of that initiative that many of the former residents there had limited opportunities for freedom and choice in their new communities; social networks were minimal; and real inclusion in their communities had not been realized.

The Working Group was established in June 1990 to develop guiding principles and objectives and to recommend policies and programs to address such concerns. Based on the Group's recommendations, and various submissions from the community proposing demonstration initiatives, the provincial Department of Family Services, in conjunction with the Manitoba Association for Community Living and the Working Group established the "In the Company of Friends" project. The project was to develop individualized funding approaches for the project participants to enable greater self-determination, and to assist them in developing support networks comprised of people who would commit to providing decision-making support and connections to their communities.

Originally to include 25 individuals, the project ultimately included 15 people, 8 of whom were living in institutions at the outset, and 7 who were living in the community without adequate supports and at risk of having their support arrangement breakdown (5 lived with parents, and 2 lived at a foster or group home). At the end of the project, all 15 individuals were living in the community, with support networks, and individualized funding arrangements.

Under the federal-provincial project agreement, the federal government was to contribute up to $550,000 towards the project.

Saskatchewan: Coming Home—Staying Home

The Coming Home—Staying Home initiative was to build on previous deinstitutionalization efforts of the provincial government and the Saskatchewan Association for Community Living. At the time the proposal was developed for the NSIPD initiative, the 5-year provincial initiative know as the "Community Living Plan" had been completed. Under that initiative significant deinstitutionalization had taken place. North Park Centre at Prince Albert had closed in 1988 (120 people had moved to the community), and over 150 residents from the Valley View Centre at Moose Jaw had moved to the community, leaving approximately 500 people still living at the Centre. However, downsizing of the Valley View Centre stopped in the early 1990s. Community services were lacking, in particular capacity to support individuals with challenging behaviours. Funding for community services was lacking generally, and services were unevenly distributed across rural areas where much of the population of the province lives.

The Coming Home — Staying Home project aimed to reinvigorate the deinstitutionalization of Valley View by providing planning support to individuals, resources for community development, and by investing in the rural areas. This project was the second largest of the initiatives in fiscal terms with the federal contribution being 1.8 million dollars. Over the course of the project 27 individuals moved from the Valley View Centre. Movement of the individuals enabled closure of two of the "cottages" on the grounds of the facility, housing 16 individuals each. One million dollars in annual operating funds was transferred to the provincial government budget for community services for persons with intellectual disabilities as a result.

Alberta: Family, Friends and Community: Together

The initiative in Alberta was the only one to focus specifically on children. Launched a few years after the "Claiming my Future" (1989) report in Alberta and the "Action Plan" of the Premier's Council on the Status of Persons with Disabilities (1990), the project was to build on the groundwork those reports laid for deinstitutionalization and expansion of community supports. In order to limit the use of institutional care for persons with disabilities, in 1990 the Alberta Department of Family and Social Services adopted an admissions policy to cover six facilities, including Rosecrest Home in Edmonton, which provided short and long-term residential care for children with disabilities and complex medical needs. The aim of the policy was to ensure that facilities were used only as a "last resort", admission would be for short-term only, information would be made available prior to admission about community supports, and any admission would be accompanied with a planning process for the development of community supports.

The Alberta initiative began with a focus on developing community-based and home-based options for families who have children with complex medical needs, in particular those living at the Rosecrest Centre. As the project evolved, it developed mechanisms to provide planning and back-up supports to families with children in the community and in need of additional support. By Spring 1997 it had provided direct planning support to over 100 families, including assistance in helping them to arrange medical and other supports for their child. As well, it initiated planning with four families living at the Rosecrest Home, and assisted two families in developing community-based alternatives to Rosecrest for their children with complex medical needs.

The federal and provincial government each contributing $450,000 to the project, and the Alberta Association for Community Living contributed $150,000 of its own funding. Funding went both to project staff and management, and to purchase of specific disability-related supports (e.g. needed devices) which had a one-time cost.

OVERVIEW OF PROJECTS

Despite the common focus across all six initiatives on deinstitutionalization and community supports, the goals, structure, and process of the projects varied considerably. The projects are described in brief below according to seven common elements.

Project Goals

Review of each project's goals makes clear some common aims: enhancing the self-determination, empowerment, and decision-making opportunity of individuals; moving people from institutions; providing support to families in the transition process; providing both individualized funding and individualized planning supports; development of personal networks; and development of community services and the capacity of communities more generally to include people.

Struck in the early 1990s, these goals reflected the latest thinking about deinstitutionalization and community living. Most of the provinces involved had in the 1980s put into place either institutional closures or downsizing programmes. Many of the goals articulated for the NSIPD initiatives sought to address what had been learned about the limitations of previous initiatives: many had moved from institutions only to find life in the community characterized by a lack of opportunity and needed support; lack of personal relationships; less decision-making opportunity than anticipated. While many had found "placement" in the community, more real inclusion in the social, economic, and cultural life of their communities seemed a distant possibility. The NSIPD initiatives sought to overcome these barriers. They were to set firmly into place mechanisms to promote individual human rights and well-being, and to strengthen the capacities of families and communities.

The range of goals adopted for the NSIPD initiative made clear that what deinstitutionalization entailed was a complex process, to be measured not only by the movement of people out of institutions, but by the changed status and opportunity for individuals, and by the outcomes for families and communities as well.

Newfoundland: The Right Future Project

Goals for the project included:

1) To enable persons with developmental disabilities living in the Waterford Hospital to move to the community.

2) To terminate admissions and re-admissions to institutions of persons with intellectual disabilities.

3) To provide community support for all persons leaving the hospital which will maximize their potential for participation.

4) To develop a process for evaluation of the strengths and weaknesses of present and planned community based services and supports.

5) To conduct the project through the full partnership between Canada, Newfoundland and Labrador, the Canadian Association for Community Living and the Newfoundland Association for Community Living.

6) To share information on the project in an active endeavor to promote and encourage development of community based alternatives to institutional care throughout the country.

Prince Edward Island: A Time of Change

The project proposal identified two key goals to guide the project:

1) Develop communities that are prepared to accept and support people with mental handicaps.

2) Assist individuals presently receiving institutional care as they move to alternate living situations in communities across the province.

As the project began in 1994, the two general goals were further specified to include a mission statement for the project, a vision statement, purpose, and project goals, including:

1) To demonstrate responsible alternatives for people now living in Hillsborough Hospital and assure on-going access to alternatives and support in the community;

2) To empower people with mental handicaps to achieve personal autonomy;

3) To include people with mental handicaps in decision making regarding the changes that affect them;

4) To ensure the service system is improved and flexible enough to provide services designed to meet individual needs;

5) To provide public education to inform communities about people with mental handicaps and how responsible communities are including everyone in all their services.

Ontario: Opening New Doors

Goals identified for the Ontario project included:

1) To facilitate preparedness of communities to receive individuals with developmental disabilities from institutional settings;

2) To support the next phase of the provincial Multi-Year Plan in creating an expanded range of opportunities for individuals moving from institutional facilities to more competent and caring communities; and

3) To develop effective community strategies that will foster a person-centred approach to planning and individualization of funding.

Manitoba: In the Company of Friends

The mission statement for the Manitoba project included two general goals:

To enhance the self-determination and dignity of Participants residing in Manitoba through two unique methods of support:

1) funding the Participant directly as opposed to funding the service or service provider; and

2) the establishment of personal support networks to support, sustain, and enhance the autonomy of the Participant.

Saskatchewan: Coming Home — Staying Home

Goals for the Coming Home—Staying Home project included:

1) To empower individuals living in Valley View by giving the opportunity to choose life in the community;
2) To develop new approaches of supporting rural service providers so that people with challenging behaviours can stay at home in their community; and
3) To develop new strategies for supporting staff so that the needs of the most challenging individual can be met in the smallest, most home-like environment possible.

Alberta: Family, Friends and Community: Together

The mission statement for the Alberta project included four goals:

1) To improve the way in which services are delivered to children with mental handicaps in Alberta, and to return individuals to their communities and families;
2) To develop a range of community and home-based family support options to offset the current use of the institution for family relief;
3) To address the medical and physical needs that many of the children have, with careful and considered community supports; and
4) To enable parents to come to an understanding and level of comfort as to the benefits of a new range of personalized supports.

Partnership Process and Structures

All projects included a four way partnership: including both the federal and provincial governments, and the Canadian and respective provincial Associations for Community Living. In each case, the four partners designed a workable structure given the aims of the project. Much can be learned from the different approaches taken to partnership. Four key distinctions in the structure of the partnerships are noteworthy: representation, the operational mandate of the partnership, project management structure; and the relationship between the provincial partnership and local sites designated for community development.

While all projects were initiated and approved by the four respective partners in each case, the partnership structure designed included other representatives at the provincial and/or local level. Only in the case of Newfoundland was a separate structure — an Advisory Committee — designed with representation restricted to the four partners. In addition a Liaison Committee was struck and included representation from senior management of the Division of Family and Rehabilitative Services, Board and Executive members of Newfoundland Association for Community Living, the Department of Health, Waterford Hospital personnel, People First, and a self-advocate from the Hospital. Both the national partners also often attended Liaison Committee meetings. The role of the Committee was to monitor implementation of the project and to make strategic decisions as needed.

The partnership in Saskatchewan was constituted through the Governance Team which included the four partners as well as the representation from the Valley View Centre and the Valley View Centre Parents Advisory Group. The provincial partnership was more widely representative of community service agencies than the partnership structure in Newfoundland. It included the Saskatchewan Residential Services Council and the Saskatchewan Association of Rehabilitation Centres. In the case of Newfoundland, service provider representation was found at the local level on the "community teams" established to assist in community development. Similar to Saskatchewan, the Alberta project's Steering Committee included representation from the facility, from community service providers, as well as parents, in addition to the four partners. In PEI representation included the four partners, Hillsborough Hospital, and People First. The partnership in Manitoba was built upon the existing Working Group on Community Living, adopting many of those members into a Project Management Committee. The partnership included the four partners, as well as representatives from the broader community, including business, and the independent living movement for people with physical disabilities.

In all projects except Ontario and Manitoba, institutional facilities were represented on the provincial partnership. In Ontario, two of the regional partnerships — Southwest and Ottawa-Carleton — included representation from the institution involved. The diversity of experience with representation of institutional facilities suggests that simply having institutional facilities involved on the partnership is not enough to secure an effective working relationship. It appears to be one of the conditions; as well, structures are needed within institutions to exercise leadership in the deinstitutionalization initiative.

All projects except Manitoba adopted a partnership structure which was designed to govern the project as a whole, ensuring that strategies were in place to achieve the project goals. In the case of Manitoba, the Project Management Committee also had an operational mandate to approve the budgets and funding for each of the 15 individuals included in the project. In all of the other projects, the consideration and approval of individual proposals was handled by existing processes, usually within provincial government departments or ministries of social services. The management responsibilities in the Manitoba project were substantial, requiring extensive time of the senior-level officials and community members who sat on the Committee.

While the Manitoba structure combined project direction and project management within the same structure, most other projects established a separate management committee. In all projects a project manager or coordinator was appointed. In all cases except Ontario and Alberta, the project manager was a government official in the provincial department of social services (in PEI in the provincial Health and Community Services Agency). While project coordinators were accountable to the project governance structure, being situated in the government bureaucracy often meant they could encourage bureaucratic support for the initiative. In both Ontario and Alberta, project management was vested with the provincial Association for Community Living. While vesting project management within government appeared to have short-term benefits in some cases, in terms of securing needed approvals in the bureaucracy, it did not address the longer-term issue of effective leadership within government to create a sustained policy and program environment enabling of projects' goals: this concern was raised in all projects.

Project management in Prince Edward Island faced particular challenges with the establishment shortly after the "Time of Change" initiative began, of a $5,000,000 strategic initiative funded by the federal government, and to be directed by the same four partners. The "Choice and Opportunity" initiative was aimed at restructuring the funding of disability-related supports for persons with intellectual disabilities in the province, to enable a community support system based on principles of individualized funding. As this initiative would affect the Time of Change project in communities and at the Hillsborough Hospital, and could, in theory, support and build upon that project, it was decided that the Time of Change project would be enfolded by Choice and Opportunity. In effect, it became one of the sub-committees of the larger initiative, with project staff accountable to project management of the Choice and Opportunity project. Because of the much larger scale of Choice and Opportunity, the focus by the partnership on Time of Change diminished, leaving the project without the direction that many felt was needed.

In Ontario, Newfoundland, and Prince Edward Island, the provincial partnership established a local level structure in some regions and communities as part of the project and with some accountability to the provincial partnership. This was more so the case in Ontario where local partnerships were established in four communities; in three cases (except for Southwestern), project staff, accountable to the provincial project manager, were hired to support the local partnerships. Substantial resources were allocated to each of the local partnerships for staffing purposes and for local-level initiatives related to project goals (e.g., Development of person-centred planning tools and process, one of the goals of the Opening New Doors initiative). In Newfoundland, "community teams," were established in a number of communities, and received support from the four individual and family consultants funded through the project as part of the provincial Association for Community Living's staffing component. These staff were not able to commit full-time to the local partnership, because of the demands of supporting individuals and families in the transition to the community. In Prince Edward Island, regional advisory committees were set up under the project to guide local community development efforts and to consider how to support individuals who would be moving to the regions from the Hillsborough Hospital. However, the committees did not become effective mechanisms for local development under the project. Because of the onset of Choice and Opportunity, the committees were drawn into becoming advisory bodies for that initiative. As well, because of the limited funding for purchase of individual supports for those moving from the Hillsborough, community agencies involved in the regional advisory committees did not believe that it was fiscally feasible to agree to provide them support.

Eligibility, Selection, and Promotion to Individuals and Families

Eligibility for individual and family participation in the project varied depending on the project mandate, and the funding framework used. In Newfoundland, the full-scale deinstitutionalization effort meant that all individuals with a primary diagnosis of "developmental disability" living at the Waterford Hospital were originally eligible. However, because in the case of eight individuals still living at the Hospital their family members have rejected the move, they have not yet been selected for the transition planning process. Another five individuals still at the Hospital are also eligible, but because they have indicated that they do not wish to leave, neither have they been selected to begin the planning process.

In a couple of projects, the funding framework used affected eligibility, either formally or informally. In PEI, only welfare plus the Special Care allowance and the Personal Comforts Allowance were available. Thus, those with more complex and intense support needs were more likely not to be included in the project. No additional funding was available for purchase of disability-related supports. In Manitoba, it was decided not to make welfare, or social allowance-eligibility a criterion of the project, even though this meant that costs would not be shareable with the federal government under the Canada Assistance plan. The Project Management Committee wanted to ensure wider opportunity to participate in the project.

The criterion of individual desire to move was a guiding eligibility criterion in all projects; with family approval being used as a criterion in the case of some of the projects. Saskatchewan adopted much of the same approach as Newfoundland; however, from the outset was aware that some families were so opposed to the move from Valley View that legal challenges might be mounted including obtaining legal guardianship of an individual in order to prevent the move. The Coming Home-Staying Home project clearly asserted at the outset that individual rights to move should prevail over family wishes for them to stay. However, as in the Newfoundland project, an "individual rights" model for making decisions was not sufficient when it came into conflict with an understanding of a planning process inclusive of family members and others who, it was hoped, would provide ongoing planning and decision-making support to individuals once they left the institution. The concern was that a short-term achievement of individual rights to move could be won at the expense of long-term, sustainable supportive relationships between families and individuals. Moreover, the provincial governments themselves were reluctant to proceed against the direct wishes of families given the possible political repercussions.

Given the focus of the project in Saskatchewan, to support individuals for whom community supports had been difficult to secure, additional selection criterion favoured those who had not had recent opportunity to move, as well as those for whom community placements had broken down, resulting in a return to the facility. Referrals for participation in the project could come from individuals themselves, family members, Saskatchewan Social Services, Associations for Community Living, or the Valley View Centre. Final selection of up to 30 participants for the project was up to the "Individual Planning and Tracking Committee", a structure in place before the project began for approval of budgets under the Community Living Division (CLD) of Saskatchewan Social Services, and for individual placements in the community. The Committee had representatives from CLD district managers, senior managers of the Division, and field staff with the Saskatchewan Association for Community Living.

In the case of Alberta, family support for a child to move from the Rosecrest facility was a key criterion. However, building family support for community-based alternatives proved a considerable challenge because the project was originally understood by some as a "deinstitutionalization" project in a traditional sense: the movement of children from the facility. For most families, the lack of needed medical, respite and other supports in the community was the reason children had been placed at the Rosecrest for either short or long-term care. Many feared that such supports were still not available in the community. As efforts began under the project to meet with families whose children were at Rosecrest, some went to the media to ensure their concerns about the project placing children at risk were publicly understood. The result was a polarization of views about the true nature of the project, and pressure on the project to clarify its purpose. The effect was a solid commitment by the partners that family choice was paramount; that the project did not aim to close the Rosecrest facility; and that the project would focus on creating the community supports necessary to enable families to make informed choices. This direction was completely consistent with the original aims of the project; but the tensions that had erupted in the polarization of views and the subsequent media coverage had led to a very clear and shared understanding of what deinstitutionalization meant in the context of that particular project.

Because of out-of-date records, the project spent over the first year clarifying who used the facility, as a basis of determining the extent of those who might take advantage of planning support to move to the community. At the outset it was determined that over 90 children used the facility for short and long-term respite. By October 1995, a methodology for determining use of the facility had been established and it was determined that there were 11 long-term residents, and another 25–30 who received respite services of varying lengths.

The Manitoba project did not focus on a particular facility, but rather on individuals in a number of institutions and on individuals already living in the community. In the case of Manitoba, two facilities were asked to make referrals of individuals to participate in the project, as were provincial government local social services offices, and local Associations for Community Living. Individuals had to meet a number of criterion: having an intellectual disability and being 18 years of age and over, living in a developmental facility or living in the community with support arrangements that were at risk of breaking down, and having a desire to participate in the project. The Project Management Committee received 126 applications, of which 30 were short listed, based on achieving a diverse group of participants (gender, geographic location, in the community/living in a facility, range of needs, whether or not any supports were in place). Budget limitations meant that 15 individuals in 12 situations (one of the situations was 3 siblings living together) were ultimately selected instead of 25 as had originally been anticipated. Those who were selected based on these criteria were then interviewed by project staff, to ensure that the individual him or herself wanted to participate in the project, and to obtain community supports. The project management decided at the outset that individual rights would prevail over parental resistance to their sons or daughters leaving an institutional facility. Parents were to be informed of individual rights, and told of the individual's desire to participate in the project. In fact, this situation did arise in at least one of the situations, but the individual moved from the facility under the project. However, an official with one of the facilities involved did indicate that referrals were not made to the project unless there was family approval. As well, one set of parents had referred their son, but the facility rejected the referral. In this case, the referral could not proceed without the assent of the facility.

In the case of Ontario, the project built on deinstitutionalization initiatives already underway. Determining which individuals were a part of the project was not among the first tasks. Rather, the project focussed on developing the local structures and processes in the four demonstration sites with an understanding that support would be provided to individuals moving from five designated facilities (Rideau Regional Centre, Southwestern Regional Centre, Midwestern Regional Centre, Oxford Regional Centre and from D'Arcy Place). Connecting each of the four projects to specific individuals proved to be a substantial challenge, primarily because individuals were moving under other initiatives, or with resources that did not flow through the projects. Thus, the projects did not establish criteria for participants, but sought to support individuals where they could through other initiatives. Clarifying the role of local project staff in this regard proved difficult at first, as staff wanted to work directly with institutions to provide planning support to individuals and to assist them in the move. Yet this was not the project's mandate. As in Alberta, the difficulties in determining the role of the project proved clarifying: the local partnerships came to understand that the focus of the Ontario project was not on specific individuals but rather on developing the capacity of communities. As the project developed, community development proved to be significant, especially in some of the sites, laying the foundation for more intensive efforts in assisting individuals to move to the community.

In the PEI project, participants had to have a diagnosis of developmental disability, be referred by the planner at the Hillsborough Hospital to begin planning, express the desire to move and have support of the family as well.

As the criteria of individual desire to move, and family support to move, were so central to most of the projects, various means were used to support individuals and families in their decisions. At the Waterford Hospital, the Newfoundland Association for Community Living, People First, and Hospital Staff held "Wednesday Night Meetings" at the Hospital, to share with individuals living there a sense of what it was like to live in the community, and to give them a chance to express their concerns and wishes to move. ACL individual and family consultants as well as designated government social workers spent a good deal of time initially meeting with families to help foster commitment to the move and to address their concerns. Media coverage of some of the first individuals to move was sought; a video was made of one man's successful move and beginning of a new life. The emphasis was on getting coverage of success stories and promoting them widely through the media. Public information meetings were held in St. John's when the project was announced in order to provide information and to generate support among families and the community more broadly.

In PEI, People First also held a few meetings with individuals living at the Waterford, but they were much less frequent than in the case of the Newfoundland project. The provincial ACL developed a series of information resources for general public distribution on community living, including workshop presentations, print materials about support options and success stories of individuals living in the community, and videos. In Saskatchewan, the planning facilitators met with families and with individuals living at Valley View Centre in order to determine who was supportive of participating. The experience in Alberta, led partners to come to an understanding later in the project of the need for up-front and early media coverage that communicates success stories and the options for community living; while at the same time ensuring that families have good information and an opportunity to express their concerns and wishes. In Saskatchewan, a communications strategy was developed including information meetings in twenty-five communities, and a number of press articles. Parent support was fostered through the inclusion on the provincial partnership of a representative of the Valley View Parent Advisory Committee.

In Ontario, there was difficulty in establishing working relationships with the institutions involved because of the initiatives already underway, and the lack of clarity about the role of project staff in delivering information and planning support to individuals in institutions. The Southwestern region project was to have provided planning support to assist 20 individuals to move from the Southwest Regional Centre who had behavioural challenges. However, as that regional project got underway a court case was launched over the use of faradic shock at the Centre, and whether this form of intervention to regulate individuals' behaviour was a violation of their human rights and should therefore be prohibited. It was decided that outreach to families and individuals should not begin in the midst of such a case, as it was likely to polarize views about deinstitutionalization. In Kitchener-Waterloo, individuals associated with the project began visiting Midwestern Regional Centre in July 1997 to meet with individuals living there, four years after the project began. However, in the interim the capacity of self-advocates who were living in the community (some of whom had moved from institutions), to promote community living had been strengthened. Some had attended workshops on empowerment, and the "People Helping People" self-advocacy group started through the project had held a number of "keeping your dreams alive" workshops for self-advocates. Some of these formed what became known as "The Dream Team" and agreement was reached with Midwestern Centre for the team to hold workshops at the facility to promote community options for individuals.

Individual Planning Process

All of the projects put into place planning processes that focussed on emphasizing individual's strengths, fostering a vision for their life in the community, and developing a commitment by family members and others who were, or who were willing to be, in personal relationship to the individual to provide ongoing support (in planning, decision-making, and through sustained personal relationships). A range of planning tools were used to guide individual planning, but all were based on these principles.

Delivery of planning support both inside facilities when preparing for the transition, and ongoing planning once individuals left, varied significantly between the projects, for the purposes of the demonstration, but the sustaining structures for ongoing planning converge, with two exceptions, toward the same approach: delivery of planning support by provincial government social workers or case managers.

In Newfoundland the Hospital and the provincial ACL designed a pre-planning process for managing the first stage in planning inside the Hospital. A Clinical Coordinating Committee with representation of the provincial partners met regularly at the Hospital to identify individuals ready to begin preplanning, and to follow individuals through the process up to and including their move to the community. Once it was determined that individuals were ready to begin pre-planning, a planning session was arranged, including family members (travel costs were covered for family members regardless of where they lived in the province, some travelling from as far away as Labrador). The planning process was jointly facilitated by an ACL and a Hospital staff person and focussed on the individual, his or her strengths, what he or she hoped for in moving to the community, medical concerns, and other support needs. Once a pre-plan was established, social workers, hired specifically for the project (but to retained as generic government social workers once the project was completed), conducted a more detailed general service planning process and development of a budget. A behaviour management specialist with the Department of Social Services determined behavioural support needs for budgetary purposes. NACL individual and family consultants also assisted in the planning process at the community level where the individual was moving. Assistance was provided in setting up an individual support network of family members and/or other community members to assist in ongoing planning, decision making, and management of the individualized funding arrangements. Social workers with the Department of Social Services are to provide ongoing planning support and assistance in renegotiating budgets.

A similar process was used for the next largest project (in terms of numbers of individuals moving) — Coming Home-Staying Home. Planning facilitators were designated — three with the Saskatchewan Association for Community Living, and one with the provincial department, Saskatchewan Social Services, first to provide information to individuals and families about possible participation in the project. Once individuals were selected for participation, the planning facilitators worked with Valley View Centre staff to plan for the move to the community, to identify support options in the community, to assist individuals in making visits to possible community options, and to prepare a plan and budget for approval by the Individual Planning and Tracking Committee.

In the case of the Time of Change Project in PEI, the planning process was managed entirely inside the Hillsborough Hospital, by a planner designated under the project. Because of concerns by the Hospital about capacity of individuals to give consent to have non-family members involved in the planning, who were not specifically identified by the individual, no community members were identified to participate either as facilitators of the planning process, or as potential members of an individual's network. This particular interpretation of consent also meant that the PEI Association for Community Living did not know where individuals moved to in the community once they left, restricting their capacity to follow-up with supports to assist in building connections to the community.

In Ontario, planning support to the individuals at the sheltered workshop at D'Arcy Place, and those living at the facility was provided by an individual contracted by the partnership to work with the local project advisory committee. A person-centred planning approach was used to identify the volunteer and other day options individuals wanted to pursue. At the Kitchener-Waterloo site, the local project staff person also provided the planning support to five individuals. The Area Offices of the Ontario Ministry of Community and Social Services were given primary responsibility for individual planning for initiatives underway at the time the project began, and for the 4-year provincial deinstitutionalization initiative announced in July 1996 affecting approximately 980 individuals in six facilities in the province.

Planning support in Manitoba was provided through the two project staff seconded to provide planning support to individuals and to assist in developing support networks. The staff used a "PATH" planning tool to facilitate the planning process, involving the individual and his or her support network in a visioning process for the individual's life, and the development of strategies and specific actions to achieve it. The process also entailed support network members examining their own commitments and identifying contributions they could make. In those situations where individuals had very few who could participate in their network, project staff recruited potential network members from paid staff who knew the individual well, from the neighbourhood where the individual was living, from a church community known by project staff, or from the extended network of an individual's family. The identification of potential network members was one of the first tasks in the planning process; managed by brainstorming with the individual and those who agreed to be involved, about who else might be invited to join the network.

Project staff played a key role in developing the network through providing: an orientation to values and human rights; assistance in managing decision making focussed on the individual; and assistance in critically examining their practices in light of guiding values. Commonly, concerns by network members at first emphasized "protection" over encouraging choices and risk-taking. Once the individual and network developed a plan, the network was involved in looking for housing, recruiting staff, and making connections in the community to which the individual was moving. As in other projects, network members were busy with the individual in the transition process in setting up arrangements, painting apartments, arranging staff, buying furniture. After this phase, roles often began to shift. Network members became more involved in building relationships with the individual and assisting them in making relationships in their wider community.

In Alberta, the project established a "Community Support Team" and a "Medical Advisory Committee" to assist in the planning process. The Medical Advisory Committee included health professionals with expertise in designing community supports for individuals with complex medical needs, and was in place both to consult on community options and to help determine if feasible community supports could be put in place for particular individuals at the Rosecrest Facility. The Community Support Team included a health consultant attached to the Edmonton Regional Health Authority, a staff person with the provincial Handicapped Childrens' Services Program, which provides funding for community supports to families, and a parent and staff member with the Alberta Association for Community Living. The team responded to families as they expressed interest in moving their child from Rosecrest or in considering other options. As well, the team accepted referrals for families in the community who had children with disabilities and health care needs that were lacking needed supports, or facing a health crisis or breakdown in supports. With the different members on the team, there was capacity to respond to a variety of situations and needs; whether for establishing health care, dealing with funding issues, or a need for the perspective and support of a community advocate and another parent.

Funding Mechanisms and Arrangements

At the outset, all the projects sought to establish an individualized approach to funding the disability-related supports needed by individuals and families. In this approach to funding, individuals, or families where the person with a disability is a child, obtain funding based on their particular needs, and have status in the decisions about what will be funded and who will provide supports. Individualized funding provides contractual status to individuals or families in both the funding agreements and in agreements with those paid to provide supports.

In Newfoundland, individualized budgets prepared by social workers and behaviour management specialists were considered, revised in some cases, and ultimately approved by the Project Manager in conjunction with other officials in the Department of Social Services. Funding was flowed through banking arrangements set up to manage payroll for paid staff, and through individual bank accounts for basic income for purchase of housing, food, clothing, and other personal comforts.

In the case of Manitoba, a similar approach was used, with the Project Management Committee making funding approvals. The Management Committee in the Manitoba case was unique in that it included one of the most senior officials in the government, the Assistant Deputy Minister for the Department of Family Services, who also chaired the Committee. This meant that the ADM could ensure accountability of the project to the government sector, while at the same time being involved in the difficult decisions about how to allocate resources to individuals and families.

The Prince Edward Island project was unique in that individuals did not have access to any funding other than that available through the general welfare system and the special assistance provisions for those with disabilities. By nature, this is an individualized funding mechanism, although providing a substantially lower funding level than was the case with the other projects.

In Ontario, funding for purchase of individual supports for those moving from Tri-Con industries to other day support options in Coburg was not directed through the project, but rather as a transfer payment from the provincial government to community service providers. However, for one of the individuals, these dollars were later individualized by the agency and transferred to another provider in order to secure more appropriate supports.

In the case of Saskatchewan, project partners did hope to establish an individualized funding mechanism through the project. Individualized budgets were prepared, and dollars were attached to individuals. However, individuals did not obtain contractual status in funding and service agreements; for the most part the dollars were flowed directly to the community service providers delivering supports.

In Alberta, existing funding sources were used to fund the community supports required, although the project itself provided individualized funding for such items as home renovations, or purchase of needed devices, when no other funding sources were available. The major funding program used was the Handicapped Childrens' Service program, an individualized funding mechanism, although there are restrictions on the extent of supports that can be funded. Families also took advantage of the Health-funded Home Care program for those with medical needs who are recommended by physicians. Under this program, nursing care is arranged through a designated community agency. Eligibility restrictions, and restrictions on when and how supports can be provided limit the flexibility of the program for families with children who have both a disability and complex medical needs that do not meet the established criteria.

Individual and Family Support Options

A wide range of support options were used to support individuals in the community. Newfoundland emphasized at the outset individualized living arrangements, where individuals rented their own apartment or house, with live-in or live-out staff. As financial restrictions on community supports were introduced mid-way through the project, increasingly "alternate family arrangements" were selected, where an individual lives with a family in the community who acts as the primary source of support, with additional support staff for respite purposes and for dealing with particular behavioural challenges. A few individuals moved in with their natural families, and into boarding homes. One individual obtained family support to purchase his own home. Back-up management and planning support was available from social workers, and consultation to deal with challenging behaviours was provided by Departmental behavioural management specialists.

The range of options in Prince Edward Island was more restricted due to the lack of funding designated for purchase of disability-related supports. Consequently, most individuals have moved into alternate or foster family arrangements. One individual was preparing to move into his own apartment as of Spring 1997, and as in Newfoundland a few individuals had moved to boarding home arrangements.

All of the 15 individuals in the Manitoba project were living in rented homes or apartments, with a range of intensity of support staff from 24-hour, to back-up support staff available as needed.

The Saskatchewan project drew primarily on existing community service providers, and thus most individuals lived in group homes at the end of the project. Four were living in other facilities such as nursing homes, three were living in private service homes, two were living in their own rented house, and one was living with his family.

The Alberta project developed an "associate family" support model, distinct from alternate or foster family arrangements for adults. An associate family shares care with the natural family, under an agreement about the number of days of support to be provided, the kinds of support to be made available, with a clear role for the family in providing direction. The Community Support Team assisted families in setting up associate family arrangements, and in establishing training and agreements with the associate family. Other support models made available under the project included respite to the family and associate family, and foster care arrangements.

Community Development Process

All of the projects, except for Manitoba, established goals for community development in addition to the goals for providing funding and planning supports to individuals and families. In the case of Manitoba, the assumption was that by focussing on the development of personal support networks for individuals a community development process would take effect. Support networks would provide the link to community involvement for individuals, and would address barriers as they arose. This model of community development was, thus, individually-driven with the primary mechanism being a strong support network.

This mechanism was used as a community development tool in Newfoundland and in Saskatchewan to some extent as well. However, these and other projects also established community-level structures and processes to strengthen community capacity. The "community teams" established by Newfoundland included representation of community service providers, self-advocates, family members, sometimes municipal politicians and officials, and community members (for example, a local church pastor). The teams identified issues affecting persons with disabilities in their community and were to develop strategies to address them. A range of approaches were used in designing the teams. In St. John's the team was organized into various sub-committees (on transportation, housing, etc.) and developed specific initiatives. The team did not have a direct relationship with individuals moving from the Waterford, but their experiences were communicated to the team through different members. In Sheshatshiu, Labrador, on the other hand, the community team was built around an Innu man who returned his community. The community team represented both the family and the community more generally, linking the individually-focussed community efforts with the broader changes needed in the community to support the individual and others more generally. Because of a lack of designated staffing resources, and a lack of clarity in some instances about the role and process of the team, many of the community teams were not sustained after the end of the project.

In Prince Edward Island, community development efforts focussed on creating regional advisory committees, which represented community service providers and other community members, support to People First and the provincial ACL's public education strategy. The regional advisory committees were not able to play the development role anticipated as they were quickly absorbed by the larger Choice and Opportunity project with a mandate to provide input into the design of a model for restructuring the funding of disability-related supports. Through the work of People First of Charlottetown, People First Groups were established in six other communities in the province, and a provincial organization was established with a founding conference. The group in Charlottetown expanded from just a few members at the outset of the project to about 25 regular members at the end of the project. The group co-wrote a play with a local playwright about a man moving out of his parents' home and the discrimination he met and overcame in his community. The group has performed the play a number of times throughout the province in the year after the project was completed.

The local advisory committees of the Ontario partnership project were the primary community development mechanism. Each local committee established a different focus, although there were common elements to the process. All local committees arranged for a strategic visioning and planning process early in the project to define local goals, actions, and to build community commitment and resources for the initiatives. In Ottawa-Carleton the focus was on strengthening community services for Francophones returning from Rideau Regional and on the development of parent-to-parent support for families in Ottawa-Carleton. In Northumberland, the focus was at first on developing day supports for individuals moving from the sheltered workshop at D'Arcy Place, and later on various community training and planning events to address issues and barriers communities in the County were facing.

The local committee in Kitchener-Waterloo decided to make a priority the provision of support to self-advocates. The People Helping People self-advocacy group was formed, "welcoming parties" were organized for moving from facilities, workshops were organized for self-advocates. By the end of the project the local committee had secured additional three-year funding, part of which was used to hire three self-advocate community development workers; and to develop a "keeping your dreams alive" workshop for individuals living at institutions. The local committee also restructured its own process to make it more accessible to self-advocates: plain language minutes, fewer printed materials, ensuring that meetings proceeded at a pace in a format fully accessible to self-advocates, co-chairing of meetings by self-advocates, and the use of personal stories and experiences at the committee meetings.

In the Southwest region, the committee established working relationships and a set of guiding principles agreed to by the institution and the community service providers. A two-day conference was held to build relationships among agencies, the institution, unionized staff at the institution, family members, self-advocates, and government. The local committee was abandoned after the July 1996 provincial deinstitutionalization announcement, and the provincial decision that the Area Offices of the Ministry would take the lead in planning for individuals to move. Nonetheless, the local partners did establish working relationships that had been undermined in the past.

Saskatchewan initiated through the project service reviews in a number of regions of the province. Studies were commissioned in North Battleford, Regina, the Northeast Region of the province (Porcupine, Nipiwin, Kinnistino), and Saskatoon. These studies entailed reviewing the capacities, primarily of disability-related community service providers, and generic health and other services as well. The review process provided an opportunity for agencies and community members to raise issues and consider strategies for the future. Common issues identified included the lack of coordination between services, the lack of adequate training for staff given individuals's behavioural and other needs, the need for effective individual planning, funding restrictions, and the need to develop the generic services of communities to help address the unmet demand on disability-related community service providers. An ongoing "co-management" group was struck in the Regina region, made up of community service providers in order to co-manage existing and new funding so that individuals could be more effectively served.

The community development strategy in Alberta included a number of components: parent-to-parent support group, which had difficulty engaging many parents at Rosecrest because of the polarization among families early in the project with respect to the future of the Rosecrest Home; the establishment of the Community Support Team as a mechanism for developing community supports; the establishment of the Medical Advisory Committee; and the establishment of a Relief Resources committee. The latter was constituted by service providers in the Edmonton region to consider how to best develop and coordinate resources for provision of respite services to families. Lack of adequate community-based respite services was one of the primary reasons families were using the Rosecrest facility.