

# Independent Service Brokerage

Achieving consumer control through direct payment



## A Dinsdale Publication

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Empowerment of Canadians with Disabilities  
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# **INDEPENDENT SERVICE BROKERAGE**

## **Achieving Consumer Control through Direct Payment**

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In Association with

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**This Report of an informal Qualitative Research Project is the first in a series of publications on Empowerment produced by the Walter Dinsdale Centre.**

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**REHABILITATION STUDIES**



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## Shirley's Story

I was just an ordinary woman....a mother, a wife, a hockey fan. Then I gradually lost control

- of my legs, my arms, and my physical strength
- of my rights as a woman apart from my husband.

He and I would have had to separate in order for me to financially qualify for the help I needed to stay at home. We wouldn't get a divorce, so I had to go to an institution..where I lost control of all the little things that make life human - when and what to eat, shopping, someone to talk to in the early morning light.

Behind the walls that shut out my world I found others who shared my quiet anger and together we put our hopes into beliefs of independent living □ of taking charge □ of supporting each other and anyone else who shared our dreams.

Each one of us brings our strength. My outward stubbornness comes from an inner quiet and trust--that there is someone up there. He is a sculptor--when he takes away a little bit here he adds a little bit there, moulding and trying to make a better person. I just have to keep looking for the chances that his changes bring.

Now I'm taking charge and living on my own, in spite of:

□ your ideas that "people like me" should be in institutions because it is efficient even though I can hire my own staff to live on my own for much less

□ your need to protect me, to see me as sick, to look after me when I want to look after myself.

□ my own feelings of guilt that I am causing those who love me pain and anxiety because of my need to risk, to be on my own, to be in control of my life.

I know of your fear that no one will be there to rescue me if something goes wrong. I know you want me to be safe and secure--to accept my disability.

I may need someone to do the things I can't, I may need to use machines more nowadays, but I've got it together. I've taken the charge, done what I had to do. I'm still just an ordinary woman, living each day as it comes. I just wish I could physically reach out and touch someone.

Shirley Garth, 1987

# FOREWORD

This report has been prepared to document the beginning stages of an important shift toward consumer empowerment. It is a good example of what can be done with no money but a great deal of interest and volunteer effort.

The Independent Living Center in Calgary introduced an independent service brokerage model in 1984 which enabled persons to design, develop and monitor their own personal and community supports.

This document focuses on the first two years experience in supported independence of people who required a new funding pattern to meet their complex needs.

The new alternative applies the principles of consumer choice, environmental modification and self-help in a customized alternative for a group of persons, considered by many, to be too high a risk because of their complex conditions or because they were seen as unable to make decisions.

The **monograph starts by describing the context** within which independent service brokerage emerged --the Calgary Community, CAIL and the key players in the change process.

The **second section establishes the principles and current practice** for this particular direct payment alternative from the perspective of consumers, staff and government.

The **research section** begins with a file review of the 27 situations, followed by a consumer and staff satisfaction survey, government review and input from "brokerage related" services.

**Section four presents recommendations** by the focus committee.

**Section five** lists a series of articles relating to the early social change process, other brokerage alternatives, the independent living movement, the staffing model of Supported Independence, Joshua Committees, and the dignity of risk. These cover important aspects not included in this report.

Our hope is that this report will be used by those persons committed to improving the quality of life for persons with disabilities who want to be active partners managing their own lifestyles.

Nancy Marlett  
Dinsdale Centre for Empowerment of  
Persons with Disabilities

*Post script: The people described in this document continue to live in supported independent situations with the support of their natural support networks and CAIL volunteers, even though funding for independent service brokerage has still not been found.*



# FROM THE BROKER

Brokerage and supported independence are just reflections of the values of my family and neighbours in Cape Breton, who were experts in making do and helping each other .

This report represents the accomplishments of the persons who risked and lived on the edge of social change for four years. The Calgary Association for Independent Living responded to a serious service gap in 1984 that placed them and the persons with disabilities they supported on an emotional roller coaster. CAIL supported 27 individuals through this specialized funding route. Some, with dual diagnosis and behavior problems, had nowhere else to go but an institution; others left institutions with serious medical and physical conditions.

The transition from system control to a situation in which persons with disabilities controlled their own services was traumatic. We had no natural history to fall back on apart from the pioneering work of the Community Living Society in Vancouver.

Trusting that persons could make their own decisions and supporting them as they took control, meant certain professional vulnerability. There were those who were nervous of this new approach that challenged established beliefs and traditions.

Independent living supports persons with disabilities as they struggle to reach their dreams. The aligned professionals must listen and respond to people's hopes and needs even when this is neither comfortable or safe. There were times in the past three years when we were attacked because of our insistence on allowing persons to grow through risk, and our willingness to support those that others had rejected. There were those who feared that potential failure might reflect badly on disabled persons. This has been balanced by the support of persons with disabilities, parents and families, and many professionals and government officials who worked directly with us.

The struggle to survive prompted this study. We offered our work openly to the community, to be scrutinized by all stakeholders. The process has not only documented the effective lifestyle changes for persons with disabilities, but has done much to stimulate dialogue in Calgary and beyond. Perhaps, most importantly, it validates what persons with disabilities have been saying for years; "trust us to make our own decisions."

I am very excited by the outcomes of the study and am proud of how CAIL and their supporters survived innovation. Whereas, once we were alone, brokerage is now an accepted alternative for persons in Calgary and Alberta.

Certainly, the struggles and the pain of this growing process will be with us for a long time. There needs to be a healing period when change occurs as rapidly and to the extent it has. Through the process of studying together we have been able to put the early struggles in perspective.

It is hoped that this study will bring hope to persons with disabilities, their families, friends and the professionals who are willing to support and risk with them. When you "hang in" and trust each other we all become empowered.

Heather MacLean

## DEFINITIONS

**ASSURED INCOME FOR THE SEVERELY HANDICAPPED (AISH):** AISH is a benefit program designed to enhance the living conditions of severely handicapped Albertans. The program guarantees a level of income currently equivalent to the benefits available to Alberta's senior citizens. If handicapped persons cannot meet their total financial needs from AISH benefits, they can apply for social allowance and may receive additional benefits. (Program document, 1987). The benefits of AISH are the highest in Canada and have made it possible for the majority of disabled persons to live in the community. The existence of this program within the overall Social Development Act has made it possible to interchange funding alternatives .

While the advantages of a benefit such as AISH are many, the advantages have been achieved at a great social cost -- in order to be considered eligible, the person must be considered unemployable. This means that persons who wish to take part-time or short-term work risk losing not only their income, but also their medical benefits.

Within the Act, there exists a program type that was the keystone to direct payment, Program Type I, (Social Allowance with a Handicap Benefit - AISH PLUS). Along with this, there exists program Type I, directly administered through social allowance, income security, (welfare), at each local District Office. This program had been utilized by people before the term direct payment through AISH was established.

**BROKER:** Is an instrumental link between the disabled person, funding sources and resources and services in the community. The broker assists, to the extent requested, the person and his/her network to identify the supports needed, secure the funding resources and negotiate customized services. (1988, CAILC policy document)

**BROKERAGE CONTRACT:** Identifies the responsibilities of the service broker to the person with a disability (Guardian/Trustee). All parties and person with a disability (Guardian/Trustee) sign the contract.

**BROKERAGE FUNDING PROPOSAL:** This is the proposal that is submitted to the department of Social Services for direct payment . (other generic funding routes may include insurance agencies, Worker's compensation board etc.) The proposal includes:

- *Support Needs*- areas that require support
- *Experience in the service system* --( need for funding ie.no other alternatives )
- *Goals Determined by the Individual* - in cooperation with friends, Joshua Committee members, parents etc.
- *Alternative Model*- described in detail
- *Audited Statement*- required for eligibility
- *Financial Proposal* for services needed
- *Monitoring Methods* - description of the methods for determining progress, financial accountability and reviews



**CONSUMER:** Refers to a person with a disability, his parent or guardian (in the case of a child or dependent adult) or other designated representative of the person with disabilities who uses the services of the Independent Living Center.

**CUSTOMIZED / PERSONALIZED FUNDING:** Service dollars from whatever source (social allowance, program dollars, workers compensation etc.) are based on individual needs and allocated to people, not programs or places. It therefore introduces the elements of flexibility and portability. It presupposes a negotiation process which recognized the rights, responsibilities and citizenship value of all people with disabilities. There are basically two alternatives, although there are many variations within the two routes.

- **INDIVIDUALIZED OR PERSONALIZED FUNDING**

This type of funding is "attached" to the person but dispersed, managed and monitored by a third party through a community autonomous board.

- **DIRECT FUNDING** Once the funding is negotiated, it is given directly to the person, family or guardian/trustee and the supports they choose. The person in need of service (and support network) are responsible for dispersal, management and monitoring. They are directly accountable to the funding source for the use of the allocated funds.

**DEPENDENT ADULTS ACT (Alberta., 1981):** The Act was created to provide a substitute decision maker for those Albertans 18 years of age or older who are unable to care for themselves and are unable to make personal decisions. This unique Canadian human rights legislation has given a voice to those persons who, because of disabilities such as mental retardation, chronic mental illness, brain damage or a disease associated with aging, have not been able to speak for themselves. The guardian is able to sign on behalf of the person and assume accountability - often with the support of a Joshua Committee - for the supports provided. The guardian is not able to handle funds, as this is the legal responsibility of the trustee, public or private, who is appointed by the court to manage the finances for persons unable to do so. Because the guardian is instructed to act in the best interests of the person and in the least restrictive manner, the public guardian's office has become the natural ally of search for individualized solutions.

**DIBS (Disability Information Brokerage System) :** A computerized data bank, staffed by disabled volunteers. It contains an extensive listing of services available for the disabled. There are three components: attendants, services and jobs.

**GENERAL SERVICE PLANS (GSP):** Technique for describing the services needed (similar to the proposal for funding). GSPs tend not to include methods of funding.

**INDEPENDENT LIVING CENTERS:** Situations which promote and enable the process of disabled citizens taking responsibility for the development and management of personal and community resources: (in Lord, 1986)

**Centers, while reflecting each community's unique character, incorporate the following characteristics:**

- *Consumer controlled.*
- *Cross-disability.*
- *Community-based.*
- *Promoters of integration and full participation.*
- *Non-profit.*

**Centers are required to develop and maintain four essential program components:**

- *Information and Referral.*
- *Peer Counselling and Support.*
- *Advocacy (Individual), in Calgary this is combined with brokerage*
- *Service Development Capacity.*

*Service development* capacity is to be accomplished by research and planning, demonstration programs, service delivery and coordination, service networking, and consumer monitoring of services.

*Direct services* may include housing assistance, attendant care, transportation, relief services, or technical aid loans.

**INDEPENDENT LIVING MOVEMENT :** Society is being challenged to view people with disabilities, not as needing to be "fixed", but as individuals who are able to determine their own needs with help from their supports (friends, etc.). The underlying principles of IL are:

- *Disabled people, through their experience of living with a disability best know their needs for support.*
- *A focus on changing the environment to support the person, not changing the person to fit society.*
- *Access to Information, Self-help and Natural Support Networks are the keys to community integration.*

**JOSHUA COMMITTEES:** Small committees - identified, developed and maintained by and for people with disabilities. Each committee of supportive family, friends and professionals is committed to one individual, helping them to identify their options and to assist them in making informed choices. Support networks allow the individual to take control of their own life without feeling alone.

**PROGRAM BASED FUNDING:** Agencies and services receive funding for their programs based on a number of targeted clients. The agency is then responsible for the dispersal and management of funds to meet the individual needs of the clientele within their program structure.



# PART 1 : THE CONTEXT

## 1.1

## The Past

---

by Pam Ranelli, graduate student and Margaret Willott, parent:

Services for persons with disabilities have been driven by two conflicting pressures:  
*professionalization and specialization & cuts to social service spending*

The two pressures come together in categorical rehabilitation i.e., group services offered "by disability" (services for the mentally retarded, services for the physically disabled etc.) and by "type of services" (vocational services, leisure services). In this the service sector concentrates on providing services to groups, rather than to individuals, on the grounds that group service brings standardization and therefore, efficiency. (eg. sheltered workshops for the mentally handicapped, institutions for residential care of mentally ill). Rather than viewing the person as a whole, the person is divided into parts:

- housing problems in the housing sector,
- an employment challenge to a placement agency or
- an educational dilemma to the school system

The end result is that decision-makers lose sight of the whole person in the process and the ultimate goal of serving the individual's needs is fragmented.

This is especially true when dealing with people who have mental and emotional handicaps. All too often, the service providers view these individuals as being in need of protection and rehabilitation and feel that they must control those who cannot provide for themselves. Decisions are made for them so they are "assessed" here or "placed" there to prevent them from making a poor choice. There are no simple solutions to these complex problems.

Group approaches seriously jeopardize control over personal quality of life. Day to day living decisions are made by service providers and the individual loses an essential human right • the opportunity to plan his own life.

The growth in case loads and expenditures over the past ten years has lead governments to consider privatization as an alternative. Privatization has considerable potential to provide a responsive alternative. However, if we move toward privatization without redressing the current lack of power of disabled persons, we just transfer ownership of disabled persons from large agencies to small, often hidden

alternatives. Stories of neglect, abuse and frustration are all too common when people are sold to the lowest bidder for servicing (Marlett, 1986)

Independent Service brokerage can provide the key to a responsive small business option that remains accountable to consumers. When the consumer is the purchaser of service she has a voice--a definite say in her own destiny. Services then must be accountable to the consumer for the consumer is the one who pays.

## 1.2

## The Calgary Region

---

by Yvonne Schmitz, supervisor of Client Services Coordination Unit, Calgary Region of Alberta Social Services

The institutionalization of persons with severe disabilities is no longer accepted as an adequate response to their needs. In spite of the push toward deinstitutionalization in the past decade, individuals from our Calgary community have been sent to the Mitchner Center, the provincial institution for the mentally handicapped as recently as 1986.

Provision existed in Income Security for extra funding to cover special circumstances but was not implemented except for a few physically disabled persons requiring attendant care. As recently as 1984, a request to obtain money through that route to hire specially trained support staff to keep an individual in her community was denied. The individual went to Mitchener Center where she remains today.

By 1985, changes were happening in the Calgary community that opened a route for disabled persons who could not access funded programs to avoid unnecessary institutionalization. A strong consumer movement of disabled persons was successfully arguing the benefits of community-based services for the disabled. Alberta Social Services supported this movement through a commitment to the prevention of institutionalization.

Through a combination of CAIL staff, consumers, advocates within Alberta Social services, and support of the AISH administration, the barrier was overcome. In May of 1985, the first disabled person received special funding to enable him to hire support staff to stay in the community. Since then, over 60 people have attained a better quality of life through the judicious use of special funds.



## 1.3 The Calgary Association for Independent Living

---

by Karen Hope, independent editor

The Calgary Association for Independent Living grew out of an international consumer movement in the 1980's that aimed at increasing consumer control over personal and community supports that lead to full integration and participation of disabled people in the mainstream of society.

**"Independent Living"** began in Canada in 1980 with a resolution supporting the concept of Independent Living by the Coalition of Provincial Organizations of the Handicapped. After several Calgary Independent living study groups and short-term projects, a core of disabled persons, many residing at the Fanning Center (a large rehabilitation, extended care setting), formed a self-help group devoted to developing the supports they needed to leave institutions or to live in the community with dignity.

While their focus was the need for personal, flexible attendant care and transportation, they soon recognized that their needs for personal support were shared by others who wanted to be part of the community - persons with diverse problems ranging from the frail elderly and the multiply handicapped to street people with psychiatric problems.

Five major projects were funded:

The first, **Community Education and Advocacy** project was sponsored by the Calgary Actions Group and funded by Health and Welfare Canada. This project acted as the foundation of the Independent Living movement in Calgary. The project mandate was to run workshops throughout the province to identify the information on service and resources available to disabled persons and to identify the needs for further information. This project worked with a University of Calgary project, sponsored by Canada Employment and Immigration (CEIC), that developed a computerized service registry related to disabilities. These two projects, along with the Vacation relief project formed the basis of the first DIBS line -- Disability Information Brokerage Service.

The **Vacation Relief/Brokerage** project was sponsored by the Central Mennonite Committee and funded by CEIC. The mandate of the project was to match personal care attendants with disabled consumers wishing to take short holidays. Fourteen staff were hired through this project and the other supporting grants through the government. The project was extremely successful and has served as a

model for a number of other such projects in Canada and abroad. This project was the foundation of the independent service brokerage model.

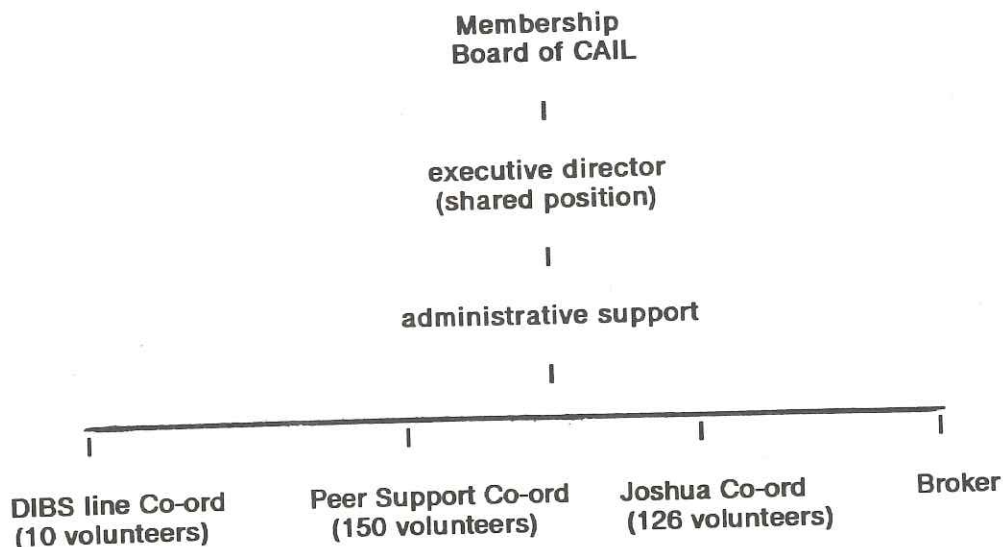
The third project, "**Joshua Committees**", undertook to demonstrate the role of social networking for disabled persons wishing to assume control over their own lives. This project was funded by a grant from Health and Welfare Canada. The mandate of the project was to develop committees and disseminate information on social networking throughout Canada.

The fourth project, **Peer Support**, was sponsored by the Entrance Society of Calgary and funded by the United Way. It established a peer support/volunteer base that has become the grass roots of the organization. Through the peer support program, people can locate others to share ideas and activities with, find volunteer and paid positions and be involved in the self help component of CAIL.

The fifth project, **Disability Information Brokerage Service**, saw the establishment of a computerized information referral service for disabled consumers: The DIBS line. It was funded as a pilot project through DISC (Disability Information Services of Canada). DIBS has over two thousand records in three (3) sections. Attendants: providing names of people willing to work directly with disabled persons. Jobs: a listing of volunteer and paid positions recruited for severely disabled persons. Services: a listing of informal and formal services, identified as needed by disabled persons. This project is used as the model for other computerized information services run by disabled persons. It is currently being used as the base for an Alberta Network of Independent Living Information Services.

In addition, two development grants have been received from Secretary of State to assist in the formation of the Center and to identify funding alternatives.

The organizational chart displays how CAIL operates with its combination of paid staff and volunteers.





**Calgary Association for Independent Living:** Membership pays a nominal membership fee. This committee meets once a year to elect the Board of Directors.

**Board of Directors:** A governing body of disabled persons ensures that policy and practice are in line with IL principles. They approve funding strategies, program proposals and general coordination of projects.

**Core Staff of CAIL:** There are four key positions offering program support.

- **DIBS Coordinator** who supports the volunteers and provides technical and program direction for the information and referral component.
- **Peer Support Coordinator** who facilitates matches between peers, volunteer opportunities and oversees the grass roots involvement of CAIL
- **Joshua Committee Coordinator** who facilitates the formation of committees and assists in maintaining committees as requested.
- **Broker** who assists those who require customized and personalized options to live and work in the community.

The **director's** position was shared with that of the broker during the time of the study. A large number of people help out by answering phones, and doing clerical work.

The current status of CAIL is similar to most, if not all of the Independent Living Centers in Canada -- program and service rich but without a core funding base. IL Centers need to find a funding route that will permit stability as a focus in the community, ensuring the continuity of necessary services.

In the meantime CAIL continues to offer the four main programs -- ***Information and Referral (DIBS), Peer Support, Joshua Committees and Brokerage*** through heavy volunteer commitment, community donations and short term funding. The effort to secure core funding will continue. After almost one year without formal funding, the commitment of board and volunteers still remains strong.

## 1.4 Community Change Agents

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by Heather MacLean, past Director of CAIL

### Alberta Government

The Alberta Government has been a leader in the field of human services. The provincial government for the past 5 years has proposed initiatives related to community and independent living - individualized and direct payment, small business alternatives in human services and supported employment. Just recently the Minister of Social Services made positive changes within the direct payment route( AISH plus)

### AISH Unit

The mandate of this unit is to provide persons, who are unemployable due to disability, a financial benefit of \$720.00 per month- the highest disability benefit in Canada. The Unit is part of Social Services, governed by the AISH ACT.

In May of 1985, the AISH unit authorized (approved by Regional Management) the direct payment of service dollars to Larry Bain. In responding to a community request (CAIL, Larry's Joshua committee, and the client services unit) they created a solution to an obvious gap in the service system. In doing so the AISH Unit created problems for itself.

The Unit has had to weather the storm which comes with setting precedent--especially when the precedent includes challenges to established practice of disabled persons being served through agencies. It has meant establishing new relationships with disabled persons.

While all of the issues have not been resolved a great deal of progress has been made because the Unit has been open to dialogue with consumers and the stakeholders.



## The Public Guardians

Alberta is the only mandated province in Canada with legal guardianship. This legislation has prevented , to a great extent , persons from becoming lost in the system.

Guardians have provided an allied voice with consumers in promoting direct payment. Four of the first five supported independent situations involved public guardians; in fact over 80% of the direct payment situations at CAIL involved the Public Guardian.

Guardians have commented on the dramatic changes of their wards in supported situations and their ability to develop natural supports. Those once considered dependent are more able to express their own opinions and participate in their lives.

CAIL would have been forced into a service delivery/brokerage model if the Public Guardian had not been supportive in hiring staff, providing monitoring with the Joshua committees, and providing support to the emerging situations.

The Guardians office struggles still with the conflicts of being a substitute decision-maker and advocate for services through direct funding while being accountable to the same government department that supplies the funding. While these conflicts are not new, direct payment adds new urgency to the eventual resolution.

## Client Services Coordination Unit

This unit advocated and supported the first, precedent proposal in the Calgary Region along with the Independent Living Centre. The unit has maintained their mandate as case managers (providing information and referral and ongoing support for those with no programs) and have not elected to become government brokers. The commitment of the service coordinators has prevented the conflict that could arise when one government program advocates within another program in the same government department.

## Regional Management

The regional management of Calgary was an integral component in the establishment of direct payment for no actions could have been approved without their understanding and support.

Regional management and the board of CAIL worked together in the early stages to resolve the policy and practice issues related to direct payment and to respond to situations as they arose in the development of the situations.

## **University of Calgary, Rehabilitation Studies Program**

Universities have played a key role in supporting Independent Living Centres, especially in the United States. CAIL as a young self-help group, depended on the University for training programs, practicums, back-up clinical support and as a partner in participant research. The editor of this volume acted as a participant observer, providing support and encouragement, providing feedback, writing about what was happening, reconceptualizing the directions that the process was taking.

The University's receptiveness to partnership between persons with disabilities and professionals provided a model for others who wanted to participate in this new approach to human service delivery.

In return, University students were involved in many of the situations, and learned first hand what partnership entails.

## **Calgary Consumer Movement:**

The Calgary community had a head start in the development of Independent Living because of the presence of active consumers such as Leroy Thompson and Berta Fisher. These people along with others supported all persons with disabilities no matter how diverse or complex. The experience of working together on projects and issues to increase the voice of persons with disabilities, has served the IL movement well. In fact, CAIL began as a subcommittee of the Calgary Action Group of the Disabled. Currently CAIL is working with the Alberta Committee of Disabled Citizens and their members—each supporting the other in their separate mandates.



society. This means that disabled people are considered to best understand their own disability and needs, they are also the ones to best manage their ongoing services with support.

- **Cross disability:** IL proposes that the choice of lifestyle must not be based on diagnostic categories, but on interest and personal commitment. Because IL centers offer a number of alternatives for all persons who require support to live on their own, they are cost effective in providing common support services. A cross disability orientation also means that persons can find a wide range of peers who share common concerns.

- **Innovation :** IL works with existing services in the community to avoid duplication. Because IL tries not to offer direct services, it is in an ideal position to be a community response centre with a focus on information and referral, peer support and coordination of existing services.

## 2.2

## Direct payment concerns

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Direct payment is the most concrete and empowering way to ensure that persons with disabilities have the opportunity to take responsibility for their own lives. Although Direct Payment evokes enthusiasm among consumers, it also creates concern among agencies, governments and sometimes even parents. Here are some typical concerns and responses given by Independent Living advocates:

**CONCERN #1: Disabled people require specialized training experiences in specialized facilities to prepare for integration** This comes from "special education" and "parallel community options" approaches which make people ready to be part of the community by separating them from it.

**Response:** There is increasing documentation on the negative impact of long-term training programs that keep people away from their community. It is important to provide support in natural environments where people learn first hand how to make decisions and seek assistance.

**CONCERN #2: Disabled people are not capable of speaking for themselves or able to make their own decisions:** They need to be guided by a professional who is skilled in knowing what is best for specific groups of people. Those who are severely mentally handicapped or emotionally disturbed, need an intermediary to make decisions on their behalf.

**Response:** While this is a concern, the Independent Living approach would assert that even the most disabled child or adult can make basic choices, expressing likes and dislikes-- particularly when it comes to

choosing a primary caregiver. There is a contradiction when brokerage is founded on choice but the choice is totally in the hands of the guardian or professional.

**CONCERN #3: Service quality must be monitored by professionals:** This implies that disabled people may misuse funds and purchase poor quality service, or, they may be exploited by unscrupulous service providers.

**Response:** This is a direct result of societal pressures to control people receiving public money. In a direct payment model, there is direct accountability for the expenditure of funds- from the service recipient to the funder. Few agencies can match this level of accountability.

**CONCERN #4: Brokers must be monitored.** This implies that some brokers may act in unprofessional, unscrupulous ways to take advantage of vulnerable people in need of support. This is grounded in experience with private service providers who have accepted funds to serve persons who were vulnerable because they could not speak for themselves. There is always a concern that the service provider may control the person unduly in these situations if an outside monitoring system is not in place. **There are serious implications when the independent broker is also the sole service provider.**

**Response:** Either the broker needs to be part of an agency with checks and balances (such as is the case with community living) or the service broker must remain free of conflict by not offering service.

If there are a number of brokerage choices, the controlling factor is the consumer--the person seeking help from a broker. The "client" is free to select whom they wish to represent them. The funding is not attached to the broker but to the person.

The association offering support and guidance must ensure that the responsibility of the the broker is to the client. A board consisting of consumers who understand the struggle to become and stay independent, can be an important safeguard in this process.

**CONCERN #5: Direct funding undermines professional practice:** There has been a concern that, as disabled people take more responsibility for their own services, the role of the professional will be lessened.

**Response:** Many professionals feel trapped by systems which prevent them from forming creative partnerships. While there will always be agency-based alternatives, direct payment opens new options for those professionals who are interested in private practice. Programs such as the Rehabilitation studies program at the University of Calgary prepare professionals for these new opportunities.



## 2.3

# The Six Step Process

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There are actually three types of processes involved in the CAIL brokerage model. There is a six step process set-up to secure and monitor funding for the consumer, a six step process to administer an application through the government's AISH program, and the process of establishing the supported independence situation.

The following is a description of each six step process:

*...from the consumer's perspective:*

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### **STEP 1 MAKING CONTACT**

The person and / or guardian (not a referring agency) initiates the process. The broker describes the implications of direct payment and outlines the alternatives. This is important because some people feel more comfortable with an agency model of individualized funding i.e. community living, outreach services etc.

- *one family spent a year visiting alternatives before deciding to make the decision to try SI. Another parent, after two years in this approach has changed to an agency based individualized situation*

The relationship between the broker and the consumer is a good place to start the process of consumer control, for the broker works for the consumer, providing information and ideas but taking direction from the person with the disability in association with his guardian. This can be a lengthy process if the person or family has come to expect professionals to be in control.

## STEP 2 DEVELOPING NATURAL SUPPORTS

The person or family is first assisted to identify a group of persons who could support them in their quest for independence. The development of natural supports can be a lengthy process (Hicks, 1986) for it must follow the process of community development and self help. Support groups are not program teams, they are in place to assist the person and family to reach their dreams. Joshua committees change over time as the person's needs change.

- *one young woman came to CAIL for assistance because a group through her church had turned a Joshua committee to a "gang" trying to tell her what to do.*
- *L's Joshua committee of seven powerful people were needed during the initial crisis but they could not adapt to the changes when L no longer wanted to be in a structured "program". L fired his first committee and now has his own natural supports that help him when he needs advice but are basically his friends.*
- *Mr. and Mrs. Q. have been struggling with the mental health system for years and have become exhausted. Their support group gives them the strength to carry on advocating for their daughter.*

## STEP 3 DEFINING THE SUPPORTS REQUIRED

This usually means helping the consumer to assess his own needs. Independent living is not built on defining strengths and deficits but on securing the supports that a person needs to live where and how he wants to. Therefore the broker does not use traditional assessment procedures unless the consumer requests that they be done. Instead the broker may spend time with the person in a number of options, using naturalistic observation and self assessment processes. ie. Marlett's Web, ecological inventories, social action approaches.

The broker's responsibility is to translate these needs for natural support into terminology that meet the requirements of the granting body ie. terminology which will increase chances for funding.

- *P could not describe what type of support he needed, so he was encouraged to select his own staff. He interviewed 20 potential staff before he chose the person who accepted his rights to his delusions but could support him in changing the topic. The characteristics of the staff chosen were used in the description of the staff required. The staff situation lasted for three years, evolving from staff to friends.*
- *M. J. who had no speech, chose her eventual staff by showing excitement when Corrine cared for her.*

## STEP 4 SECURING DIRECT FUNDING

After the individual and the broker complete a customized support proposal (see appendix 1) it is submitted to the government as application within the AISH Program. The plan will go through a six step government process (see government process, in the following section).

There are a number of other alternatives where incomes can be supplemented without exceptional considerations funding through the AISH Unit.

- *Shared AISH* - eg. In Raymond Alberta, former residents of



an institution combined AISH allowances to purchase a home and hire staff. This group, called the Raymond Go Getters, now are helping others to leave institutions.

- **Private funding**-using a person's own earned income or inheritance.
- **Individual service contracts**-- with funding to cover unique service requirements. In this situation the broker act to set up a private service arrangement between the government agent (usually within a program branch) and the service provider. The role of the consumer is often in question in this arrangement.
- **Insurance settlement and worker's compensation** - in this situation the broker would be contracted to estimate ongoing costs for the settlement and could then be asked to assist in developing the package once the settlement is agreed to.
- **Income security** - For this type of funding to be used the person must be eligible for social allowance ie. must meet the means tests ( eg. assets under a set amount, no income over a set amount etc.) This section of the social allowance act is similar in all provincial statutes. It generally requires a doctor's confirmation of need and is most effective with persons with physical disabilities with clearly defined attendant care needs.

## STEP 5 SETTING UP THE SUPPORTED INDEPENDENCE (SI) SITUATION

There are basically two alternatives when setting up SI situations:

- An *agency* who manages a person's services and funds, or
- *The individual and/or his support network* manages their own services either alone or with the support of a resource Centre.

The consumer, no matter how disabled, should be involved in the hiring of the personal support staff (PSS). To date, the most effective PSS's have started with a strong commitment to the principles of Independent Living and most have had considerable clinical skill.

## STEP 6 MANAGING AND MONITORING

The monitoring of the situations, at the present time, is the responsibility of the natural support network with the assistance of the Center staff. Regular reports, changes in employment contracts, changes in funding are all part of the review process. This is probably the most accountable human service in existence today for the person and the direct staff are both accountable directly to the funding body.

## *...from the government perspective*

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by Dave Dewar, supervisor of the Calgary region AISH Unit

Direct funding for exceptional needs started as a precedent within an existing funding route (AISH plus) because funding sources and program alternatives were not able to respond to a particular individual's needs. Once started, however, the precedent quickly became an effective but uncomfortable solution to the problems of people who could not be supported by the existing services.

In order to ensure fairness and accountability, the director of the AISH Unit, in consultation with other departments, established the following 6 step process:

### **STEP 1 DOCUMENTATION AND SUBMISSION OF A WRITTEN PLAN FOR DIRECT FUNDING**

A plan is prepared by the person with the disability, or his guardian often with the assistance of a broker or by a broker acting on behalf of the person. The plan is submitted to the person's AISH worker.

While any format can be used, all written submissions must include:

- *Demonstration of the need for exceptional funding* - i.e. why other existing services have not worked
- *Clear description of the need for services support.*
- *Plan for administration / monitoring of funds*

If the plan is within guidelines for AISH approval (ie. a straightforward plan with limited extra funds) it can be approved directly. If not, it is sent to the REVIEW TEAM along with the recommendations of the AISH worker.

### **STEP 2 REVIEW OF THE APPLICATION**

The AISH supervisor along with the supervisors of Residential Resources and the Client Coordination units, meet once per month to review the applications for exceptional considerations funding. The team considers whether the plan is clinically sound, cost effective and if the plan could be covered within the existing service alternatives.

The team also considers the safety of the plan and the safeguards and the support available for carrying out the plan.

### **STEP 3 ADMINISTRATIVE PROCEDURES FOR DIRECT FUNDING**

Once the proposal for exceptional funding is approved/amended, the contract is given back to the AISH Case Worker to make arrangements for payment



- *A monthly cheque can be sent directly to the person and the person is accountable directly to the AISH worker for the allocation of funds and the effectiveness of the provided.*
- *If there is a private trustee (legally appointed to handle the funds of the person) the cheque is sent to him/her or his designate, who is then directly accountable to AISH*
- *When there is a Public Trustee appointed, the Trustee assumes responsibility for disbursement and accountability of the funds on behalf of the person.*

#### **STEP 4 VERIFICATION OF EXPENDITURES:**

In order to ensure that the direct funds meet the requirement of accountability, the recipient of the funds (disabled person or private trustee) submits regular reports and receipts to the AISH unit to verify that funds were used for the purposes intended. cf. appendix 1 for example of verification form.

At this time, alterations which are necessary because of changing circumstances, can be made. This is necessary because of the changes which occur in the situations- either staff, roommates, locations, day programs etc.

#### **STEP 5 REGULAR REVIEW OF CONTRACT:**

At the designated review date (3-6 months, 1 year etc.), the committee considers the plan to identify other funding routes, other services or possible ways of shifting to a less costly alternative. Recommendations are made for continuance, revision or cessation of funding.

The person may appeal the decision to the supervisor of the AISH unit or the AISH appeal committee.

#### **STEP 6 GENERAL AUDIT OF SITUATIONS:**

Once per year, all exceptional / direct funded situations are reviewed by the Auditor General and recommendations made about the accountability procedures and the cost effectiveness

## ... from a staff's perspective:

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by Sheldon Goldenberg, former personal support staff and graduate student,  
extracted from MacLean, Marlett and Goldenberg, Supported Independence:  
One more step in the evolution of individualized services

I was one of the original staff involved in a supported independence situation and have had the opportunity to meet others who also left comfortable, familiar agency positions to enter into a unique and often confusing relationship with a person with complex needs. These situations require major adjustments to the way that most professionals perceive their roles and responsibilities. The person with the disability is a true partner, and is, in reality considered to be in the driver's seat when it comes to making the decisions.

Now that we have been able to participate in a number of individualized situations we have noticed a consistent pattern in the chronology of the staff ; person relationship. Essentially staff must move beyond the role of service provider who follows a program plan, to being a support, a friend and advocate for the person while being in an intensive intervention process.

- *S left a job as a group home supervisor when he became frustrated with the lack of freedom and the growing bureaucracy. He used his clinical background to assist a severely brain injured young man to establish control over his own life. It was a serious commitment, at times draining, but looking back S feels it has changed his life and affirmed his belief in the abilities of persons with disabilities.*

### STEP 1 THE MATCH

Being hired by someone that one would ordinarily consider to be a client is a strange experience. The person I worked for had no functional speech so a number of applicants were encouraged to spend time with him and he made his preference known through non-verbal cues-- by his attitude and behavior. I also had to meet and be approved by the Joshua committee who were to become both my support and my monitor.

### STEP 2 THE CLINICAL CHALLENGE

For both staff and employer the first months involve an " early learning" process in that new expectations, routines and language are being learned for the first time. This can be an intensive and exhausting process for both the staff and the employer ( previously the "client" ). Both must assume new roles and responsibilities. Although the staff retains the responsibility of providing suitable interevention strategies, the selection and implementation of these approaches must be approved by the employer.

The person often looks for the traditions and conventions of "programs" ie. staff in power, able to intervene and solve problems and make decisions. In many situations negative behavior increases at this stage as it is essentially an extinction process--the extinguishing of learned behaviors from previous agencies and programs. The testing period usually marks the beginning of a new relationship -- if staff can survive the challenge to his / her commitment.



*When B first moved into his apartment, he struck out at the staff and the surroundings. Staff used gentle redirection techniques and continually asked "what do you want me to do". Staff responded to any request. Over the first three weeks, B was wary, looking for tricks. His behaviors resumed sporadically until he was convinced that he was in control. After three years, B is comfortable in his SI situation and now helps others to understand SI even though he is still very limited and continues to experience problems in his day program.*

### **STEP 3 ACQUISITION**

Once the person is in control, there is a re evaluation of the dynamics of the partnership and the abilities of both parties. There is an excitement during this time as the individual is encouraged to try new skills, motivation is high and progress is reinforcing to everyone. The changes in the first 3-6 months are so dramatic that peripheral stakeholders have trouble comprehending how the changes could have occurred. Suggestions that the person was misdiagnosed may be raised since the frequency of abnormal behavior rapidly decreases eg. "she was not really a problem in the first place".

### **STEP 4 ADVOCACY**

Because the personal support staff is intimately involved in the progress and the emergence of new competence, he / she may feel that the natural supports and other agencies involved don't appreciate the abilities of the person or recognise the changes. This can cause stress unless the natural supports are kept abreast of the progress and are helped to deal with the implications of the person's desire to take control. During this time the staff and person develop a closeness as they often feel alone in trying to get others to understand the changes.

### **STEP 5 FRIENDSHIP**

During this time there is a developing reciprocity of support and a genuine preference in sharing time together. There is a new understanding of each other's needs, personal interests and stresses. There is an expansion of supports as each develops outside interests.

### **STEP 6 REALIGNMENT**

As the friendship base becomes established there is often a major realignment of the situation—in some situations the clinical support base is no longer needed and the staff moves on to allow another relationship emerge, in others the person may feel ready for a roommate and the person then becomes a support for the next person in the situation.

During times of stress the friendship base may be replaced by earlier phases. Staff turnover in this approach has been extremely low—an average of 2 and a half years to date. The staff have made life changes during this time – eg gone back to school, developed new hobbies, or new personal relationships but the because the SI situation is a partnership, changes in the situation have been possible .

# PART 4: RESEARCH STUDIES

## BROKERAGE REVIEW RESEARCH STUDIES

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The Director of the Calgary Association for Independent Living initiated a study through the Dinsdale Centre that would be a participatory study involving disabled people, staff and parents/guardians and the relevant stakeholders in the community

The purpose of the study was to:

- *Document the natural history of the pioneers of brokerage / direct payment and record the impact of supported independence on the lives of those involved*
- *Assess consumer satisfaction with supported independence and brokerage*
- *Evaluate the success of brokerage from the perspective of the key stakeholders in the community ie. government and other emerging brokerage alternatives.*

### DESIGN

Throughout the study, questionnaires were developed by consumers and students, reviewed by the focus committee and administered by students and volunteers. As there was no funding to carry out the study, the focus committee and the research coordinator spent a great deal of time ensuring that research protocol was adhered to re. confidentiality and objectivity. Each section was the responsibility of a separate researcher who analyzed the results and prepared their preliminary report for the focus committee. The research coordinator then assumed responsibility with the chairpersons of the committee, and an outside technical editor to prepare the final document.

This section contains the four research components of the project: a file review of the impact of supported independence on the life style of those affected, a consumer satisfaction survey of consumers, their families and the personal support staff, a review of the process by the government officials most involved and a review of brokerage by the other emerging brokers in Calgary.



## **SUMMARY OF THE FOUR RESEARCH STUDIES**

### **1. Social and Financial Impact of Supported Independence**

This section used a research framework of an earlier study conducted to evaluate the changes in the lives of the first five persons supported by CAIL through brokerage. The original study looked at the behavioral, social and environmental and financial impact of Supported Independence. The current study focussed on changes in living arrangements and financial allocations of the 28 persons using the exceptional considerations funding route.

### **2. Consumer satisfaction of Disabled Persons / Guardian and Staff:**

This was the central research study commissioned by the director and board of CAIL. Over 50 persons were interviewed using a combination of standardized questions and open-ended questions which encouraged elaboration. The responses were recorded in detail and then analyzed to identify common themes. Sixteen situations were reviewed in depth and their responses analyzed.

The questionnaire and the covering letters are included in appendix two.

### **3. Social Services Review Team:**

The special considerations review team which consisted of the supervisors of the AISH Unit, the client coordination unit and the program division of the Calgary district of Alberta Social Services was interviewed by Elaine Kuhlemeyer, graduate student of the University of Calgary.

A twenty four page report was compiled. For the purposes of this report, a summary will be presented. The original report can be obtained through the CAIL office.

### **4. Calgary Brokerage Service:**

Six (6) Calgary Services were interviewed by a graduate student. The results have analyzed twice, once by Pam Ranelli as a summary for this report, and by Denise Getz – a full report available through the CAIL office.

### 3.1 Social and financial impact of supported independence situations

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extracted and adapted with permission from Marlett, N.J. and MacLean: *New Life Styles for Persons with Severe Handicaps* in Baine et al (ed) *Alternative Futures for Education of Students with severe Disabilities*.

This report deals only with the changes in living situations and funding. The reader is referred to the full article referenced at the end of the report. It describes the behavioral, communication and personal decision-making changes that occurred in the first 5 situations.

#### background

In order to keep a young man with severe disabilities in Calgary, the Calgary Association for Independent Living (CAIL) "broker" raised private funds from car companies, used summer staff and her own apartment to buy time while CAIL put together a funding mechanism and a clinical advisory team. This makeshift arrangement offered him a last chance. His "last chance" opened the door to many others. To date 27 persons requiring exceptional funding have received support from a CAIL supported independence model, and another 120 have received support in using their disability allowance benefits more effectively.

This independent living approach stresses consumer control and choice. This differs dramatically from service models that allow control only when the individual demonstrates competence. In independent living, the individual, no matter how disabled, is assumed to know best his or her own disability and his or her own needs. Control is assumed, and once accepted, competence manifests. The social environment is adapted to support the person, the person does not have to adjust to the environment. The disability is accepted and seen as secondary. Independent living assumes that desire to change precedes change, and the desire must come from within the person.

A customized plan and specialized funding are facilitated by a service broker, acting on behalf of the individual. The key to the model lies in the partnership between the person with the disability and the personal support staff who works for him or her. This is a dramatic shift from the traditional balance of power between the professional and the client. It frees the skilled staff to enter into a creative, dynamic, if at times, taxing relationship.

Funding requests were prepared and approved (MacLean, 1987) and individual situations were created with the assistance of natural support networks known as Joshua Committees (Hicks, 1987).



**Table 1: Changes in Accommodation and personal support  
frequency of persons at each level of support at the time of referral and in  
Nov.**

**1987**

The following scale was created to describe the range of available alternatives (levels) for accommodation and personal support (Marlett, 1974):

<b>levels of support needed</b>	<b># persons at referral</b>	<b># persons Nov. 1987</b>
<i>5. isolated; no intervention possible; removal of most human contact;</i>	3	0
<i>4. restrictive 24 hour program; 1:1 staff in highly structured program; restrictive procedures used as needed : designated facility for behavior problems.</i>	14	1
<i>3. structured program with obvious contingencies; staff trained in behavior modification', restrictive procedures part of program; group home or natural environment;</i>	7	1
<i>2. consistency in structure but structure natural and developed with the person; systems in place for behavioral emergencies; in natural environment (i.e., own home or apartment);</i>	1	11
<i>1. sporadic support for guidance or refocusing as needed within a consistent supportive base; in natural environment (i.e., own home or apartment);</i>	1	6
<i>0. personal support only when requested.</i>	1	8
<b>Total</b>	<b>27</b>	<b>27</b>

## Accommodation and Personal Supports Patterns

Table one presents the dramatic changes in living situations for the 28 persons surveyed. The table describes the situations at the time of referral to CAIL, and the current status as of Dec. 1988. Most persons were in restrictive settings (levels 4 or 5) at the time of referral. Within three to six months, the pattern of support shifted to 2 and 3. Currently, the situations cluster around 1 or 2 for most individuals apart from those with serious brain damage because of the severity of their perceptual, motor, or memory limitations who tend to cluster around level 2 and 3.

Table 2 presents the actual situation of all 28 persons at referral and one and a half to two and a half years later.

The changes in mean level of support, although only nominal data, suggest a profound change in the quality of life for these individuals (mean at time of referral: 4.0 ; current mean : 1.2).

## Funding Patterns

Perhaps the most stringent indicator of progress in this model is the direct reduction in funding which was made possible by the changes in the living situation. It must be stressed that the underlying etiology has not been erased; the situation has been modified to support the person to grow.

Table 3 presents the initial contract costs and the current contract costs (Dec. 1988). The differences in these figures are dramatic when one considers the severity of the presenting problems.

Tables 4 and 5 compares cost estimates for the range of living alternatives available at the time of the study for the initial 5 persons.

The marked differences in costs between traditional system and SI exist because CAIL makes extensive use of community resources and natural supports. The provision of safety nets and information supports that are provided by the Centre for Independent Living have not been included in the costs. However agency overhead charges are eliminated because the money available goes directly into services, not into administration.

If this model is to develop further there will need to be core funding for the safety nets provided by Independent Living Centres such as brokerage, attendant care registries, Joshua committee facilitators, peer support. An employment infrastructure will be essential as the numbers served in the community through individualized dollars increase. This will include relief services for support staff, opportunities for sharing experiences, and for mutual support.



**Table 2**  
**Changes in Accommodation and Personal Support**  
**for those Accessing Direct Payment**

Initial	Current
1. 24 hour supervision for behavior (2 staff) terminated from institution	sharing home with 2 room mates (peer and p.s.s.)
2. isolated at home - no intervention/no contact	sharing home with peer room mate and p.s.s.
3. 24 hour level of supervision in group home. One-to-one worker	family situation
4. unit in provincial maximum security institution	living with peer and p.s.s.
5. isolated in duplex - no contact	apartment with room mate/staff
6. restrictive program - 24 hour care	in structured training program
7. lived with family 1:1 support with training program	left to a restrictive training
8. lived in apartment required funds for personal support	employed health care costs cancelled
9. in home but outreach agency unable to supply health care	in and out of hospital for past two years but hires support as needed
10. chronic care unit of acute hospital. No other referral possible	married, living on their own (with child care support) and physical care
11. supervision exceeded 1:1 for key times in restrictive behavior home	living on own with some support re: finances
12. highly structured program restrictive behavior group home	ready for 1, but still has natural support shares home with friend/support person
13. in psychiatric acute care under heavy sedation	shares home with friend/support person
14. in highly structured setting for severely disabled	lives with family with 24 hour care. In day program
15. rejected from residential setting	ready for 1, but with support in family
16. in home, residential	shared accommodation with natural supports
17. in group home with terminally ill	returned home for hospice

**Table 2 con't**

<b>Initial</b>	<b>November 1987</b>
18. in treatment centre for disturbed adolescents	living with benefit allowance - support as requested. No consistent living or work arrangements
19. provincial institute for mentally handicapped	living on own - emotional support when requested
20. in 24 hour treatment centre	managing own attendant care
21. in group home for severely retarded	sharing accomodation with PSS and 3 others
22. rejected from services	in regular group home
23. in mental health group home	at home waiting for funding to be reestablished. threatened with institutionalization
24. in behavioral group home for mentally retarded	living with boyfriend and PSS and family
25. in home -- threatened with institutional care	own attendant care in home
26. in nursing home	own apartment...own attendant care
27. at home, threatened with with family breakdown	in regular group home
28 at home, in crisis	still in family situation



**Table 3**  
**Exceptional considerations contracts: Personal support staff wages.**  
**Does not include the personal budgets for living allowances**  
**because of variability.**

	Initial Monthly Wage	Monthly Wage (Nov. 1987)	Comments re Funding Status
1.	1,936.00	900.00	
2.	3,126.00	2,190.00	managed by management company,
3.	1,820.00	834.00	now on AISH, support of Joshua committee
4.	3,958.00	1,320.00	funding cut after one year by citizens appeal committee...being investigated by ombudsman
5.	1,456.00	1,100.00	
6.	2,000.00		moved out of region
7.	2,100.00		moved out of country for training
8.	800.00		employed, no funding allowed
9.	1,640.00		temporarily hospitalized for treatment
10.	2,400.00	1,350.00	funding shared with two other people in family situation
11.	2,581.00	720.00	government refused funding court ordered assessment for service costs
12.	1,520.00	1,520.00	
13.	1,232.00	1,232.00	
14.	550.00	550.00	

**Table 3 con't**

	Initial Monthly Wage	Monthly Wage (Nov. 1987)	Comments re Funding Status
15.	800.00	800.00	
16.	880.00	880.00	
17.	1,423.00		deceased
18.	1,520.00	720.00	consumer turned down direct payment after 6 months.
19.	1,214.00	720.00	consumer turned down direct payment after 4 months.
20.	1,640.00	1,640.00	
21.	1,334.00	990.00	
22.	1,700.00	720.00	original contract with handicapped children's services in regular group home.
23.	900.00	720.00	funding cut by citizen's appeal committee after one year.
24.	1,120.00	1,120.00	
25.	500.00	720.00	
26.	500.00	500.00	
27.	1,456.00	720.00	found placement in group home.
28.	700.00	700.00	handicapped childrens servcies.



**Table 4\***  
**Initial and Current Contract Costs for Supported Independent Living**

Client	First Contract - 1985		Current Contract - 1987	
	Support Staff per Month	Living Costs per Month	Support Staff per Month	Living Costs per Month
1	\$1,936	\$675	\$900	\$541
2	3,126	682	2,190	678
3	1,820	682	834	680
4	3,958	684	1,320	689
5	1,459	693	1,000	689
Mean:	2,459	683	1,249	653

**Table 5\***  
**Yearly Estimates of Per Day costs in Institutional/Community Group Home and Supported Independence**

	Staff Costs	Facility/Administration Costs	Total
Institutional costs (estimated for those in project)	\$52,000.00	\$8,000.00	\$60,000.00
Group home costs of persons	19,500.00	4,360.00 Facility 4,300.00 Administration (5,110.00 paid by client)	33,356.00
Costs of supported independence (initial)	29,508.00	8,196.00	37,704.00
Current costs of supported independence	14,988.00	7,836.00	22,824.00

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Current costs of supported independence	14,988.00	7,836.00	22,824.00

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## Summary

These situations were high risk, and yet the model used was one compatible with independent living. Persons lived in ordinary apartments, with staff they had hired themselves, supported by volunteers and natural supports with a voluntary advisory team as backup. Such a stand was possible only because of the commitment of the Board of CAIL. Each board member had experienced the risks while living in the community with their disability. Their willingness to risk gave others a chance to prove that disabled persons could succeed.

### ingredients of success

There was a unique combination of ingredients operating at the time of the implementation of the CAIL model

- *existence of a consumer controlled Independent Living Centre with a staff trained in consumer controlled service;*
- *commitment of the family, personal support staff, and friends of the persons who provided ongoing support and group advocacy with funders and service providers;*
- *local social services management who were willing to adapt policy to allow persons with behavioral and intellectual disabilities to use an income security funding route to provide ongoing support*
- *a brokerage advisory team of rehabilitation and community development professionals committed to the principles of independent living who volunteered their time to support Centre staff in developing the model; and*
- *the existence of guardianship legislation which appoints a legal substitute decision-maker for those unable to speak on their own behalf.*

### cautions

Some cautions must be stated regarding the model. There has arisen an optimism and a simplistic belief in the power of individualized dollars to remedy the current crises caused by the breakdown of institutionalized services and the growing shortage of resources. Money is only a tool for changing environments and developing community and personal resources.



Without a coherent philosophy of consumer empowerment and inclusion of natural and community resources, individualized dollars can be a costly, oppressive, and isolating alternative. One service estimated \$90,000 to serve an individual in the community but this would have provided all supports by paid staff. The plan transferred an institutional service to a institutional service in the community. No community or natural supports were developed.

In any new model, there is a lack of natural history that can be used as reference or refuge. One of the authors was a participant observer and member of the clinical advisory team. This afforded a unique opportunity to provide feedback and suggest changes as the situations evolved.

This type of external conceptual backup is important when starting into uncharted waters for without such an external anchor, consumers and staff can easily become engulfed with the day to day crises.

## **implications**

While this model may not be easily replicable, it is vital that we attend to the implications it raises;

- *an affirmation of the strength and untapped competence of persons with the most serious disabilities;*
- *a challenge to those who are inadvertently creating behavioral problems through frustrating environmental restraints;*
- *affirmation of the effectiveness of environmental supports as an alternative to behavioral intervention;*
- *the potential to allocate money directly to persons with disabilities; and*
- *the effectiveness of consumer controlled services.*

## 3.2

# Consumer Satisfaction

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analyzed by Pam Ranelli, conducted by the students of EDPS / SOWK 205

Of the 28 persons receiving customized or direct funding by October 1987, 20 used the AISH plus route. Of these 16 were interviewed, 2 had moved from the region, one moved to a group home and one recently died in a hospice situation.

Parents, guardians, and in some cases, Joshua committee members were also interviewed. The questionnaire and the letters involved are in the appendix.

A summary of the results for each question are presented for two groups; disabled person and family—called **consumers** and **staff**. **Sixteen situations answered the consumer questionnaire (37 persons) and 13 staff answered most questions. Where staff numbers are different they are included in brackets after the staff notation – "(n= xx)"**

### WHAT SITUATION PRECIPITATED THE NEED FOR FUNDING THROUGH EXCEPTIONAL CONSIDERATIONS?

**consumer:** Eighty percent (12) of those surveyed were in group homes at the time of the first contact. Most of these (9) were in jeopardy of being terminated due to behavior problems which were severe enough to preclude all other service options. For these persons direct funding and customized services posed the last hope for a community based service.

The other group within the survey, those with progressive medical conditions, saw a brokerage alternative as a way to ensure more control over their extensive medical needs and to live as independently as possible where they chose.

## WHAT MADE YOU APPLY TO WORK FOR A DISABLED PERSON • WHAT IS YOUR BACKGROUND • HOW HAS IT HELPED YOU IN YOUR PRESENT SITUATION?

Almost all the respondents became involved due to a strong belief in independent living and improved quality of life for the disabled. The majority (8) had formal experience or training in the rehabilitation field with backgrounds including working in group homes, institutions, summer camps etc. Six (6) had achieved formal university or college training in rehabilitation. The remainder (3), became involved to check out rehabilitation as a career choice and felt it would be a good way to gain direct experience.

This is in keeping with the results from community colleges which indicate that approximately one-third of those graduating from Calgary programs are looking at direct service provision as opposed to the more traditional group home and institutional routes of the past.

## HOW WAS THE CONTACT MADE • WHAT WAS THE WORKING RELATIONSHIP • WHAT OTHER RESOURCES DID YOU CALL ON IN DEVELOPING THE INITIAL CONTRACT?

**consumer:** While all persons/guardians made the initial contact with the broker themselves six (6) had the assistance of their group home or outreach staff. Three (3) came with the assistance of public guardians or parents.

Only one of the consumers was able to handle the procedures required for the first contract on their own. The rest of the sample had help from either public guardian or Joshua Committees in developing the first contract with the broker.

**staff:** Seven (7) were recruited from the DIBS Line. The screening process was initially done by disabled persons. Once on the DIBS line they were prescreened by the broker or support network before meeting with the individual. Three (3) were contracted directly through the broker's personal network and two (2) were identified by the disabled person themselves without any assistance of the brokerage service. One had been a former Joshua member and left the committee to take her into his home.

## HOW EFFECTIVE WAS THE INITIAL CONTRACT?

**consumer:** Half of the contracts were still in place without major revision after the two year time period. The parties expressed satisfaction with all aspects of the initial contract and staffing model. The other half, seven (7) found that the contract needed revision, mostly due to alterations in the first staff match. The second contract for all those interviewed were still in effect at the end of the survey with the persons and family expressing satisfaction with the model as revised.

**staff:** All but two (2) felt the initial contract was effective. The other two felt there was a lack of clarity in the expectations in the employment contract. Staff were also asked what was the most difficult aspect to adjust to. All indicated that it took time to adjust to a supported independent situation in which the staff behavior had to adjust and adapt to the clients personal and training needs. Four found it difficult to adjust to the lack of freedom and being on call. One expressed difficulty in adapting to the lack of outside supports or collegiality.



## WHAT CHANGES OCCURRED IN THE FOLLOWING AREAS

**consumers:** All felt that they had maintained or increased their social networks and interactions, in particular, their interaction with non-handicapped persons. All said they had increased their independence in the community and at home, and in fact, started to see themselves as part of a neighbourhood. Ten (10) of the fifteen are involved actively in day programs and most are involved in leisure activities. Three are employed full or part time.

**staff: (n=11)** All felt that the disabled person, their employer, had increased their independence in the home and all felt that their employer had increased their independence in the community.

Those staff members that were involved with clients experiencing behavior problems, indicated a dramatic decrease if not disappearance of major presenting problems. All felt that the disabled persons had maintained or increased their social networks and many indicated that they felt quite comfortable including their employer in their own personal network of friends.

## WHAT ARE THE MAJOR STRESSES IN THIS TYPE OF SITUATION?

**consumer:** Although a number of categories were identified, all respondents but one indicated one major stress was financial. Most expressed ongoing and critical fear of having funding pulled which would precipitate institutionalization. In addition a number felt they would like to have more friends, one indicated a problem finding accommodation for wheelchairs. One expressed a concern with the fear of potential staff turnover.

**staff: (n=12)** All but two felt that they needed more support. They would like support groups for attendants to share ideas and concern and they would like a relief system so they don't have to be on call 24 hours a day. In addition, four were unhappy with shared accommodation, preferring more privacy. However, none indicated a desire to return to a traditional staffing relationship.

## HOW INTACT ARE YOUR SUPPORTS AT THIS TIME • WHAT REVISIONS TO EXISTING SUPPORTS AND NEW SUPPORTS DO YOU REQUIRE TO CONTINUE IN AN INDIVIDUALIZED SITUATION?

**consumer:** It should be noted that these situations were being handled by the individual or family/support network. The uncertainty and the temporary nature of the situations was felt by all. They indicated the need to establish funding security as the key to continued independence.

Eight felt insecurities: requesting more community based support on an ongoing basis i.e., attendant on call, increased funding to hire relief and a broker on call to handle crisis situations. This is particularly important given the reluctance of the CAIL board to provide ongoing management which could be seen as a direct service. While there was a lack of clarity in the responses to this question, the majority of both staff and consumers felt that they could handle their own needs given greater security in the funding base and greater access to supports

## WHAT ARE YOUR PLANS FOR THE FUTURE?

**consumer:** All felt that the changes in their lives were positive and this was reflected in a number of ways. Seven indicated that they wanted further training and job experience to become economically contributing individuals in society and more fully independent. From a staff perspective, the major comments in this section indicated that disabled peoples lives had positive changes and increased independence due to brokerage.

The majority of responses about the future revolved around the desire to become more independent than they were at present. Twelve of the thirteen staff would like to continue to work in rehabilitation or special education. Five expressed interest in returning to school and obtaining more training.

## WHAT ARE YOUR HOPES FOR THE FUTURE OF EXCEPTIONAL CONSIDERATIONS • WHAT WOULD YOU LIKE TO TELL THE PROVINCIAL GOVERNMENT?

All expressed satisfaction with brokerage and supported independent situations. It was felt that the government should make individualized funding easier to obtain and more stable. A number were also concerned that attention be directed to day activities and competitive job opportunities, so that once their living situations were stabilized, they could become more active in their community. Of the staff, all thirteen that responded felt that this was the best alternative for the disabled person that they had experienced and they are willing to work towards continuance of the supported independent situations.

## SUMMARY

- The most dramatic finding in the study was that disabled people, no matter how handicapped, have the capacity and the ability to achieve a life of dignity within their communities with the help of their families and friends
- The situations established were managed and supported directly by family, friends and peers as opposed to traditional agency structures or outreach programs. While there were stresses, the ability of informal networks to manage and monitor the situations, with the support of the IL Centre, affirms the strength of families and neighbourhood resources. They did not ask for a professional service management unit but felt they could cope if support was available when needed.
- The funding level for the situations was modest by any standard and yet it achieved dramatic changes in behavior in the level of independence and the development of social networks and community integration.
- From a staff perspective, the model has a number of problems which need to be addressed i.e. lack of collegial support and relief backup etc. Nevertheless, all staff felt that it was a model that encouraged their personal creativity and enhanced the development of natural working relationships with their employer.
- A community support base is essential for the families, disabled persons, and networks. From a brokerage perspective this is particularly essential when adjustments need to be made to the supported independent situation or when negotiations are required with the government.



## 3.3 Government review of Brokerage

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by Elaine Kuhlemeyer, Program Coordinator at the Salvation Army Children's Village and graduate student at the University of Calgary.

As part of the review process an independent interviewer conducted a structured interview with the Review Committee for Alberta Social Services. The committee members were David Dewar (Chairperson), Mary Kay Russell and Yvonne Schmitz. The verbatim transcript of that interview consisted of some twenty-four typewritten pages. This report is an attempt to summarize briefly several key concerns of Social Service members about direct funding using a brokerage process.

### GENERAL CONCERNS ABOUT THE DIRECT FUNDING ROUTE

Many of the concerns revolved around the problems which arose from the use of an income security funding option to provide specialized services for disabled persons who require ongoing assistance.

- The funding route being used is designated as a short term expedient directed at exceptional needs - i.e., needs that cannot be met in any other way. This means that only those persons whose needs have been found unmanageable by all other alternatives should be considered. In addition, only short term solutions should be funded if the guidelines are followed diligently.
- The funding route, opened as a precedent, soon became a popular solution to many problems faced by "hard to serve" individuals. This created extreme pressure on an already taxed system. This route causes new work for AISH workers, Program Supervisors and Public Trustees. New approval procedures have had to be established, monitoring and accounting routines developed.
- The combination of policies and practices of social allowance and social service have caused uneasiness. The established practice has been to serve disabled persons through program / agency routes and Supported Independence crosses the boundaries between service and benefit programs.
- There is a general concern about the exclusion of particular groups of persons with disabilities. While Social Allowance is open to all Albertans, there is a historical basis for funding services to specific groups. eg. Mental Health, brain-injured, mentally handicapped.

There is tension between historical, categorical approaches and the current cross disability approach. There is a possibility that some specific groups may be denied access to direct funding through Social Allowance because of this.

### CONCERNS ABOUT THE CALGARY ASSOCIATION FOR INDEPENDENT LIVING



While the committee recognized the hard work of CAIL and the impact of Supported Independence on the lives of persons with serious and complex needs the following were the concerns expressed:

- The primary concern was that CAIL over extended itself in trying to respond to the expectations placed on it in the early stages. There were concerns that CAIL should establish a policy of accepting / rejecting those they work with.
- Because CAIL operates from a self-help base it does not have an agency image - i.e., attending inter-agency meetings, creating a public profile, a clear management image, etc.
- CAIL should increase their consumer profile by having more consumers on community committees and by having more consumers involved in brokerage.
- There is confusion about CAIL's mandated clientele. This relates to the cross disability nature of CAIL and their openness to all ages and any disability.
- There is confusion about the nature of Information and support services of an Independent Living Centre as opposed to those of a direct service provider.

### **CONCERNS EXPRESSED BY INDIVIDUAL COMMITTEE MEMBERS**

- One committee member (CM) questioned the fairness of giving additional funding to selected clients ie. only those with knowledge or advocates realize that the funding route is available. Many others who may need the service do not access it. The possible inequities that could result were noted.
- One CM expressed concern about the accountability of money given directly to the client. There was also fear that those incapable of handling money might "throw cheques away".
- There was concern that if the majority of government dollars were supplied directly to individuals, there would not be enough funding to continue to support agency operations.
- There was concern that CAIL has a bias against traditional services. This CM felt CAIL left little or no room for the traditional agency or group services; that all effort are focused on individualized and direct funding for clients in the community.

**Although there was uneasiness in the early stages of supported independence because of the radical nature of the shift in philosophy and approach, the most serious concern of the model now lies, not in it's value or effectiveness but with the extreme pressures that a new model places on the structures which must stretch to meet the demands.**

**If it is to be successful, government policy must recognise and support the government structures most affected.**

## 3. 4

# Calgary Brokers Survey

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by Pam Ranelli, Special Education teacher and graduate student at the University of Calgary.

A number of organizations, agencies, companies and individuals perform brokerage functions. To gain a broader perspective from other brokerage services, the focus committee recommended interviewing all six Calgary alternatives that offered some or all of the functions of brokerage.

The following organizations were interviewed:

- **Bow Point Alternative:** A government funded agency whose mandate is to promote economic self-sufficiency and the work abilities of disabled adults. They act as employment brokers for the developmentally disabled and they design service plans to enhance a client's employability. They use an individualized funding route.
- **Behavior Support Team - University of Calgary:** This unit serves behaviorally disturbed clients who are mentally handicapped. This team performs many brokerage functions and negotiates some government funding, particularly through Handicapped Children's Services. The unit utilizes both individualized and direct funding routes but does not normally manage funds.
- **The Calgary Association for Independent Living:** This is basically a self help unit with a professional broker who is available to any person with a disability who wishes support in securing personal support. CAIL uses only direct payment and does not handle any persons funding although it is available to assist persons to manage their funds .
- **A Private Broker:** The person interviewed said she works exclusively for the individual. She is not associated to any other agencies. She also manages supported independent situations.
- **Calgary Association for Community Living:** An agency developed by the parents of children with special needs who want small, home like alternatives for their children. This association uses individualized government funding but also accepts those with direct funding.



- **Community Options:** A company hired by Community Living to handle their services. Although Options is not a brokerage team, it does perform some brokerage functions.
- **Canadian Paraplegic Association:** This organization deals mainly with the physically disabled. They do not view themselves as true brokers; however, if a client experiences difficulties accessing services, they will appeal their case or assist in negotiating funds.
- **Easter Seals Ability Council of Calgary:** This organization specializes in securing funding to assist persons to purchase technical aids through charitable organizations. It is not a brokerage agency but submitted a written report.

The following is a brief report on the responses received from interviews of other Calgary brokerage services. A full report is available through CAIL.

## HOW DO YOU DEFINE BROKERAGE?

Most brokers define their role as accessing service for the individual. They see it as securing the necessary funds and supports for individuals so they may live in the community. All see empowerment of the individual as a key issue. "It helps to have one main contact to help the consumer walk his way through the hoops."

## HOW SHOULD BROKERAGE BE FUNDED?

The answers were as varied as the brokers themselves. Three brokers felt that salaries should be provided through government grants. Two felt that service organizations such as the United Way may be an alternative until the funding issue is resolved. One broker felt that there should be a fee for service.

A reoccurring theme seems to be that wherever the funding comes from it must allow the broker to remain as independent as possible, to prevent conflicts with funding sources.

## DO YOU USE ANY SPECIAL FORMAT OR FORMS WHEN DEALING WITH GOVERNMENT?

All stated that sometimes the "red tape" of going through government departments was frustrating. One broker found that dealing with a number of different AISH workers or civil servants, all wanting proposals written in different ways frustrating.

Sometimes the lack of clinical knowledge on the part of officials can be frustrating. All stated that it is extremely important to know the workings of government departments and regulations.



## **HOW DO YOU HIRE STAFF • HOW DO YOU MATCH ?**

Most brokers act as the pre-screening device for hiring staff. They may interview, screen or recommend certain applicants as service providers. Ultimately the final decision is up to the individual and his/her network. The matching of staff to client is usually done in agreement with the individual and their support network. Indeed they feel that all parties involved must be aware of their role in the contract. (i.e., that of employer or service provider)

## **HOW ARE YOUR CONTRACTS AND STAFFING REVIEWED?**

Funding contracts vary as to the amount of monitoring that is done. Some contracts are reviewed every 3 months, every six months, or on a yearly basis. This depends on the type of funding that is being provided to the individual. Joshua Committees and individuals may do ongoing evaluation of funding, service needs and staffing contracts in direct funded situations.

## **HOW SHOULD THE ISSUE OF ACCOUNTABILITY BE HANDLED • WHO DO YOU SEE YOURSELF ACCOUNTABLE TO?**

All brokers, regardless of the model that they were working under felt that the broker must be accountable to the individual first and foremost, then the support network. As well, brokers felt that they were accountable for their own professional ethics .

Indeed, a number mentioned the constraints that some brokers face working in certain models (i.e. agency brokers are accountable to their boards. However, agency brokers felt that they were accountable to the individual first, then to the board.

One broker felt that even though constant monitoring of funding on the part of government was time consuming, it did keep all parties involved on top of the accountability issue.

## **SHOULD BROKERS MEET A SPECIFIC SET OF STANDARDS OR TAKE SPECIFIC BROKERAGE TRAINING?**

All stated that a broker must have a good background in clinical rehabilitation and they must be competent in dealing with other professionals and government. The brokers were split as to specifics of training. Some felt that training could just be creating another group of professionals. Others felt it would be a good way to ensure competent service.

A number felt that the standards should be monitored by the brokers themselves, as well as the disabled persons and their support networks. If a person is not happy with the service he is receiving, he does not continue the service of that broker.

## **DO YOU SEE A NEED FOR A BROKER SUPPORT NETWORK?**

Yes, the majority of brokers would like a network or group in which they can share ideas and concerns.

## **WHAT DO YOU THINK THE FUTURE HOLDS FOR BROKERAGE AND SUPPORTED INDEPENDENCE?**

All the brokers were optimistic that independent situations were here to stay. They have seen the positive changes that have resulted from deinstitutionalization. As more disabled people are made aware of their options, this model of service delivery will blossom. As one broker put it, "the government will, in the government's way of handling all financial changes, evaluate it-- a part of that evaluation may look at our competencies ... and if brokers can come up smelling okay, then I think there is a good future for us".

# PART 4: CHALLENGES UNMET

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## The last word from the focus committee:

Supported Independence using direct payment, is still in its infancy and many challenges remain.

### ENSURE RIGHTS TO INDIVIDUAL CHOICE AND DIGNITY :

The focus committee recognized the struggles of consumers, their families and friends in establishing a precedent for others. Now that there seems to be an accepted process for obtaining direct payment the committee was concerned that this innovative alternative might become another "program" with an increase of regulations which could reduce the ability to respond to individual situations.

### ENSURE CONSUMER INVOLVEMENT AND CONTROL OVER DIRECT PAYMENT:

The committee encouraged government to ensure that direct payment not become a mechanism to fund agencies – that the central control of the consumer be maintained and strengthened.

There is a concern that brokerage, when connected to a service, can (as it is in some brokerage models) promote privatization without accountability to the person or his family. For example if the broker negotiates funds and then runs the services identified, he has the perceived ability to control the person / family through controlling money.

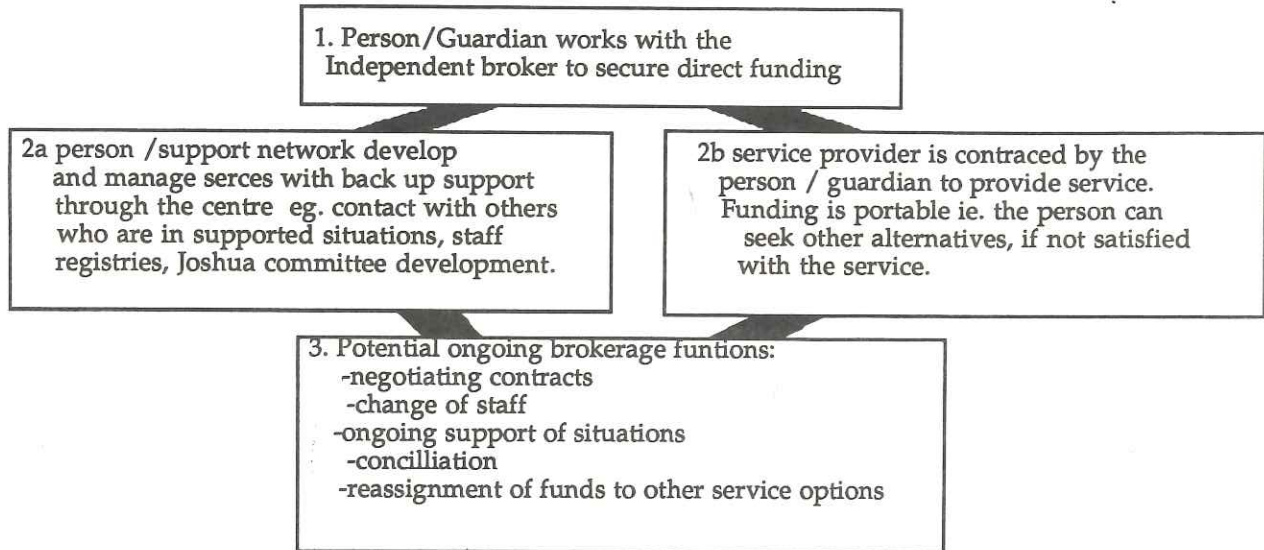
To ensure portability of funding i.e. *dollars attached to the person not the service*, care must be taken to separate the two functions: securing funding and providing the service.

The following independent brokerage model is proposed to overcome the tendency to combine brokerage and service provision:



## INDEPENDENT BROKERAGE MODEL

THIS IS A PROPOAL FOR AN INDEPENDENT BROKERAGE PROCESS THAT IS ALIGNED WITH A COMMUNITY RESPONSE CENTRE. (ILC)



## SUPPORT A COMMUNITY RESPONSE BASE THAT INFORMS CONSUMERS ABOUT ALTERNATIVES FOR SUPPORT AND FUNDING

The committee recognized that if consumers and families were to assume resonsibility for developing and managing and monitoring complex service packages that they would need a resource that could provide information, assistance and a way to meet others who shared their concerns and dreams.

The information base should include a full range of alternatives including traditional group programs, individualized alternatives, staff and relief registries that are up to date.

## **ACCESS TO AN INDEPENDENT BROKER FOR THOSE WHO REQUIRE ASSISTANCE IN MANAGING THEIR OWN SITUATIONS.**

At present all brokers, apart from CAIL are tied to service provision -either as staff brokers in agencies or through combined brokerage / service provision because of funding.

*CAIL, although not official service providers, do support the situations when needed on a voluntary basis. This has caused considerable stress on limited resources and the board is investigating a way that even these support services--ie facilitating Joshua committees, monitoring situations, clinical backup, referral to other resources and changes in staff or accommodation might be funded or made available through an independent but affiliated service contractor.*

The fee for service that is available through exceptional consideration situations means that brokers currently can only work for those persons who require exceptional considerations. (only 40% of CAIL brokerage cases are for exceptional considerations). The committee felt that an independent Broker was essential but that the funding for such a broker must not compromise the relationship between the broker and his / her client. If funding for an independent broker, apart from fee for service, is not the found many persons who could manage on the current benefit package will be forced to request additional monies just to secure the services of a broker.

*CAIL is attempting to secure funding for an independent broker through corporate donations, United Way and other foundations. There is also the possibility that funding, if attached to the information component of IL centres may provide a "free from service conflict" funding alternative.*

## **SECURE A NEW, HYBRID FUNDING ROUTE**

While this was of top concern for the consumers, the focus committee felt optimistic that recent developments in the funding availability in other regions indicated that the current situations were less in jeopardy than when the study was conducted.

The committee recommended the establishment of hybrid funding route with the non discriminatory access and flexibility of the 'AISH plus social allowance' route but without the restrictions of a welfare benefit program.

The committee felt there should be a route which :

- accepted the need to fund those who choose their own lifestyle (not just those who have been denied all other services)
- would open the way to a cost effective alternative for persons with the ability to be more involved in their own plans.

## **ENSURE STABILITY OF FUNDING AND ACCOUNTABILITY:**

The committee felt that it was essential that the month to month uncertainty of the present system needed to be changed to provide some security that funding was possible for an ongoing period of time.



No one, not the disabled persons, guardians, staff, government officials or brokers suggested that accountability should be reduced but all felt the tenuous nature, and indeed the stated intent to reduce or remove funding, was counter productive.

## **SEPARATION OF THE NEED FOR SUPPORT FROM THE ABILITY TO PAY**

As it stands presently 'disability' translates to 'poverty' if the person requires customized services. As it is now a person requiring exceptional services must prove eligibility for welfare (i.e., depletion of assets and savings, no income) to qualify for subsidies. This has recently improved so that the asset level is not such a hardship.

## **SECURE "DIRECT FUNDING" AS AN OPTION FOR ALL PERSONS WITH DISABILITIES REGARDLESS OF THE DIAGNOSIS.**

The committee recognized the pressing need to work across government, agency, social services mandates to ensure that some groups are not excluded from access to direct payment because of diagnosis - e.g., brain-injury and dual diagnosis, those in services that are not adequate etc.

Within the current review, the only persons who were denied funding were those with mental health concerns. There seems to be a continuing discrimination against those with dual diagnoses and yet these are the very people who require a customized alternative.

## **SHARE RESULTS WITH OTHERS**

The committee recommended that the Calgary experience be shared with other regions and other provinces and that an attempt be made to inform federal government reviews of social policy about the success of direct payment for consumers with serious and complex needs. While there was recognized that some government officials still seem concerned about the implication of such a precedent, the results of this review and the continuing success of emerging Calgary alternatives within direct payment can no longer be ignored. If the model can work for those with the most serious and complex needs it has great potential as an alternative for those with less serious concerns.

**The Dinsdale Center and CAIL welcome comments about the report, the process or ideas for future directions. An order form and evaluation are enclosed with all orders. If your form is missing address ideas and / or orders to CAIL. #610 839 5th Ave S.W. Calgary Alberta.**



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## PART 5:

## References and Related Reading Materials

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Brown R.I. , Bayer, M.B. and MacFarlane, C.M. **Rehabilitation Programmes: A commentary on Performance and Quality of Life of Adults with Developmental Handicaps.** Lugus Productions, 1989, Toronto

*Describes the needs and perceptions of developmentally disabled persons in rehabilitation programs with over 100 recommendations for change in rehabilitation programs. This first hand account forms the base of a future volume that features individualized alternatives.*

Brown. R.I., **Quality of Life for handicapped people.** London: Croom Helm, London.available in Canada through Hughson and Brown, Inc. 3040 7th St S.W. Calgary T2T 2X5

*Presents papers by international authors covering theoretical and practical approaches to the challenges facing service providers and families in addressing the current lack of quality of life and the need for change. Deals with a wide range of disabilities and life domains.*

DeJong, G, **The Role of the Academic community in Fostering Independent Living Alternatives for Persons with Disabilities,** 1982, paper. available through CAIL

D'Aubin, A. **Defining the Parameters of Independent Living.** Coalition of Provincial Organizations of the Handicapped, 1985. available from COPOH 926 - 294 Portage Ave. Winnipeg Man. R3C 0B9.

*A user's guide based summarizing personal perspectives and COPOH resolutions and commentaries. It also includes an interesting description of early centres.*

Hampshire Centre for Independent Living. **Source Book towards Independent Living, Care support ideas.** 1985. Available from HCIL Books c/o Mark Walsh 31 Churchfield, Headley, Bordon, Hampshire, GU35 8TF ..four pounds



*Although this is a British reference it is an excellent guide to securing and managing attendant care staff. It includes how to secure funds, how to advertise for and interview care staff and sample job descriptions, contracts, insurance etc.*

Canadian Mental Health Association. **Building A Framework for Support Series.** • Participating • A Framework for Support for People with Severe Mental Disabilities • Listening: To People Who Have Directly Experienced the Mental Health System • From Consumer to Citizen

available from Canadian Mental Health Association, National Office, 2160 Young Street, Toronto Ontario 416-484-7750

*This is an excellent resource for those working within an Independent Living approach with persons with Mental Health concerns. It deals directly with changes in public and system attitudes to promote citizenship.*

Hicks, James H. **Joshua Committees: An Introduction to Personal Support Networks**, 1985. unpublished document for distribution. available from CAIL

*An excellent resource covering the roles of Joshua members as well as the duties and expectations.*

Hicks, James, H. **Joshua Committees: An examination of the Use of I.P.P.s in a self help model**, 1985 . unpublished document. available from CAIL

*There is often confusion about the relative responsibilities of IPP teams and Joshua committees and this paper describes clearly the separate roles that persons with disabilities play in each.*

Clutterbuck, Peter, **A Statement of Purpose and Principles.** working document of the National task force on service brokerage and Individualized funding, 1988. available from Peter Clutterbuck, c/o Secretary of State.

*A description of the the task force and a set of working definitions and critical components of service brokerage. It also presents a set of principles that underlay service brokerage as a tool of empowerment.*

Marlett, N.J. **Impact of and Alternatives to Corporate Business Models in Rehabilitation.** In R .I. Brown, (Ed) **Management and Administration of Rehabilitation Programmes**, 1986, Croom Helm, London.

*Presents the rationale for moving to small business models through direct and individualized funding from the current models which emulate corporations.*

Marlett, N.J. **The Dynamics of Consumer Control** in D'Aubin, ed **The proceedings of the first annual Canadian Association of Independent Living Centers**, Ottawa, 1987

*This paper , covering the personality dynamics of consumer control and the role of Independent Living centers in supporting the achievement of consumer control, has been extracted and adapted from the original proceedings. available from CAIL*



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*Describes the various models of service brokerage, some of the challenges to social policy and the steps that need to be taken to make brokerage a reality eg. legitimizing of funding for individual needs, salaries for service brokers, development of community resources and ways to overcome the loneliness .*

MacLean H. **A Challenge to Social Policy. The Rights of the Individual or Due process and Equality.** unpublished paper, 1986

*The paper describes the rationale for movement from due process and equality to individualization of support based on need. It also is a case study of the change which occurred through CAIL's experience as a precedent setting agency.*

MacLean, H. Marlett, N.J. and Goldenberg, S. **Supported Independence--One more step in the evolution of individualized services.** prepared for the DIGNITY OF RISK CONFERENCE, Nov. 1987, Baltimore.

*This paper outlines the ecological and independent living roots of the supported independence model, the process of service brokerage and the evolution of the staff / employer( person with a disability) relationship*

Lord, J. and Osbourne-Way, L. **Toward Independence and Community. A Qualitative Study of Independent Living Centres in Canada.** Secretary of State, 1987. Ottawa

*Describes the evolution of the Kitchener Waterloo, Winnipeg and Calgary Centres for Independent Living. It also deals with the core functions, and management of the centres. It addresses some of the barriers to implementing a consumer driven support service.*

Rioux, M. and Crawford, C. **CHOICES: The community living society. New Methods of Responding to the Individual with a Handicap.,** 1983, Community Living Society, 1983. available from Community Living Society, 102 - 395 West Broadway, Vancouver, B.C. 604- 873-4733

*This excellent resource describes the evolution and practice of the Community Living Society of*

## APPENDIX 1:

## EXAMPLES OF BROKERAGE CONTRACTS

### A. EXAMPLE OF A REQUEST FOR DIRECT FUNDING : TO PREVENT INSTITUTIONALIZATION.

Date of Submission: May 2, 1988  
Submitted by: Heather Maclean  
Name of Consumer: Tim Goal  
AISH Worker: Pat O'Brien

Proposal submitted to the Department of Social Services, AISH unit for consideration: Program Type 1 with 52 benefit.

The proposal was developed, by Tim, Mrs. Goal, the attendant, his medical doctor (letter forwarded earlier) and the Calgary Association for Independent Living.

#### I. Support Needs (Supports needed to provide security and potential for growth.)

Tim's need for support has increased over the past year due to developing obstructive sleep apnea, and a gain of weight.

Dr. Hall's letter confirms Tim's multiple congenital abnormalities. As a result he has undergone a number of orthopedic procedures in addition he has severe congenital.

Tim requires total assistance in several of the activities of daily living. This includes bathing, personal hygiene, housing, laundry and night time continuous oxygen therapy overnight.

#### II. At present he requires support with:

Bathing: Sometimes needs assistance with total care

Dressing : Putting on and taking off shoes and socks. Assistance with other dressing - i.e. pants etc.

Housekeeping : Unable to stand for any length of time at present. Because he tires very easily, sometimes short of breath and gets back-aches and uses a cane he requires assistance to:

- \* pick things up from the floor
- \* Vacuum
- \* Wash floors (kitchen and bathroom)
- \* Wash or iron floors
- \* Lift objects or carry them (back problems)
- \* Change bed sheets