A New Life-Style for Persons with Severe Disabilities: Supported Independence

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Abstract

This article presents the first descriptive data on an innovative approach to persons with disabilities so complex and serious that the traditional services have given up. The model, supported independence using individualized dollars (dollars allocated to the specific client), emerged when the Calgary Association for Independent Living, a small self-help group of disabled persons, was asked to help a multiply disabled, aggressive, young man to stay in the community. Because the Board had made a commitment to serve all disabled persons and had stated their priority as preventing unwanted institutionalization, they agreed. This is the first of five published accounts about the first severely disabled persons who, with their families, friends, and CAIL, are true Canadian pioneers of supported independence.

With the goal of maintaining a young man with severe disabilities in supported independence, the Calgary Association for Independent Living (CAIL) "broker" raised private funds and used summer staff and her own apartment to buy time while CAIL put together a funding mechanism and a clinical advisory team to compliment their self-help base. These supports offered "Larry" a last chance. His "last chance" opened the door to many others. To date 27 persons requiring exceptional funding have received support from the CAIL supported independence model, and another 120 have received support in using their disability allowance benefits more effectively. This is the first of five published accounts about the first severely disabled persons who, with their families, friends, and CAIL, are true Canadian pioneers of supported independence.

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, not the person 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 (MacLean, H., Marlett, N., & Goldenberg, S., personal communication, May, 1987). 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.

This paper focuses on the changes in behavior, the need for supervision, personal decision-making, and funding patterns over a two-year period.

All five persons in the study were considered to be moderately to severely mentally handicapped, behaviorally aggressive, and had been diagnosed as exhibiting psychotic behaviors. In addition, three had experienced severe brain damage. The behaviors which led to their expulsion from programs included: destruction of property, aggression toward staff, regression, and high risk social behavior. CAIL was seen as the only alternative to institutionalization.

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).

Accommodation and Personal Support

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

5. isolated; no intervention possible; removal of most human contact;
4. restrictive 24 hour program; 1:1 staff in highly structured program; restrictive procedures used prn (i.e., as needed); designated facility for behavior problems;
3. structured program with obvious contingencies; staff trained in behavior modification; restrictive procedures part of program; group home or natural environment;
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);

Table 1
Changes in Accommodation and Personal Support During Two Year Experience in Supported Independent Living Situation

Client	Status at referral	Level	Status at 3 months	Level	Current status	Level
1	24 hour supervision for Behavior (2 staff) Terminated from institution	4	in own apartment full time; p.s.s.*	2	sharing home with 2 room mates (peer and p.s.s.)	2
2	isolated at home; no intervention/no contact	5	in own home full time; support from skilled clinician	3	sharing home with peer room mate and p.s.s.	2
3	24 hour level of supervision in group home; 1-1 worker	4	living with family with p.s.s.	3	family situation	1
4	unit in Provincial maximum security institution	4	trained staff in home; 24 hour supervision	3	living with peer and p.s.s.	2
5	isolated in duplex; no contact	5	apartment with p.s.s.	2	apartment with room mate/staff	1
$\bar{X}$		4.4		2.6		1.6

(n=5) *p.s.s. personal support staff

1. sporadic support for guidance or refocusing as needed within a consistent supportive base; in natural environment (i.e., own home or apartment);
0. personal support only when requested.

Table 1 describes the situations at the time of referral to CAIL, the situation three months later, and the current status. All persons were in restrictive settings (levels 4 or 5) at the time of referral. Within three months, the pattern of support shifted to 2 and 3. Currently, the situations can be described as levels 1 or 2. Little further movement is expected for those with serious brain damage because of the severity of their perceptual, motor, or memory limitations. The changes in mean level of support, although only nominal data, suggest a profound change

Table 2
Presenting Behaviors and Current Status after Two Years* of Supported Independence

Client		Present	Present reduced	Absent	Last Occurred
1	- Physical aggression to staff and trainees			✓	July/85
	- Severe agitation—pacing			✓	March/86
	- Disturbed sleep patterns			✓	Sept./86
	- Suicidal		✓ (Minor recurrence April 87 during physical collapse		
	- Incontinence			✓	March/86
	- Total motor collapse		✓		
	- Echolalic			✓	
2	- Severe aggression—not prompted—to staff			✓	Nov./86
	- Severe aggression when others in personal space			✓	Jan./87
	- Self stimulation		✓		
	- Echolalic			✓	
	- Severe sleep disruption (nocturnal seizures)		✓		
3	- Verbal aggression—hitting out			✓	
	- Destruction of property			✓	
	- Psychotic outbursts			✓	
4	- High risk sexual behavior		✓		
	- Verbally abusive		✓		
	- Physically aggressive to staff			✓	
5	- Abusive language			✓	
	- Psychotic approaches			✓	
	- Frightening behavior			✓	
	- Inappropriate conversation			✓	
		0 0%	6 28%	16 72%	

*Descriptors taken from files

in the quality of life for these five individuals (X [referral]: 4.4; X [current]: 1.6).

Presenting Behaviors

There was some difficulty in describing presenting behaviors of the clients because the graphs of behavior generated during the initial phases became irrelevant as the situations stabilized. That is, the initial presenting behaviors disappeared. Agency documents, school reports, government documents, and physicians reports were analyzed to identify major presenting problems. Only descriptors that were present in more than two documents were included. These descriptors were compiled in a chart and were rated by persons familiar with the client at this time. Descriptors were rated as *present, present but in a significantly reduced state,* or *absent.* The date of the last occurrence was also noted.

Table 2 presents the information obtained. None of the descriptors were still present, 28% were present but in a significantly reduced state, and 72% were absent. Most behaviors that disappeared did so within the first three months. This leads one to speculate that some of the more dramatic behaviors were the direct result of, and maintained by, environmental frustration.

Personal Decision-Making

The following rating scale allowed for rating levels of personal decision-making:

4. no decisions made; not a party to even minor daily decisions;
3. expresses dislikes and wishes; attempts made to include the person in decisions;
2. involved in decision process; makes concrete decisions within limited choices;
1. directly makes daily decisions; involved in decision process for major decisions; directs staff; and
0. functional decision-making with alternatives; makes major decisions; monitors process; supervises staff.

Table 3 indicates rated changes in personal decision-making over the two years of the project. It also includes the initial intervention strategy used to support and reinforce control. All individuals were at the most restrictive level of decision-making at the time of referral with no input in minor, day-to-day decisions. Despite this, all were involved in hiring their own staff. In one situation, the person interviewed over 20 poten-

Table 3
Initial Intervention Strategy, Personal Decision-Making, and Rated Changes over the Two Year Period

Client	Initial Level	Initial Intervention	Current Situation	Current Level
1	4	All behavioral controls and medications removed under supervision; escalation of behavior in first 3 months; language developed in first 6 months; involvement of neurologist	Makes major and routine decisions with support, e.g., fired support staff and Joshua Committee; chose room mate	1
2	4	Skilled clinician established routines and reinforced personal control; 6-8 month process; alternate staffing model then introduced	Makes routine decisions with support; Joshua Committee no longer functioning; limitations due to "group home" staff model	2
3	4	Placed in home setting of skilled staff; Joshua Committee instrumental in reinforcing personal control; acceptance; subtle structure and community exposure the focus; Joshua Committee provided clinical support	Much more in control; considering a move to live with sibling; within situation expresses likes and dislikes	2
4	4	Moved into home with 24 hour supervision because of high risk behavior; progress made in own home then move to group situation broke down; move to IL situation with skilled but untrained staff and room mate with similar problems; initial involvement of full psychiatric team—withdrawn after first failure	Natural controls in shared accommodation; included in day-to-day decisions; transfer to internal control just starting; involved in independent day alternative, therapeutic intervention starting	2
5	4	Person spent 2 months choosing staff who could support emotional and behavioral needs as well as lifestyle; emphasis on companionship and doing things together; strong psychiatric support during process	Making decision to live independently with staff as neighbor; controls all daily and most major decisions; psychiatric support continues; dramatic decrease in medications	1

Table 4
Initial and Current Contract Costs for Supported Independent Living

Client	FIRST CONTRACT - 1985 Support Staff per Month	FIRST CONTRACT - 1985 Living Costs per Month	CURRENT CONTRACT - 1987 Support Staff per Month	CURRENT CONTRACT - 1987 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	1,456	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 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

tial staff before the "right one" was hired. Three of the initially hired personal support staff are still in the situation two years later, one staff model changed, and one (the only one with a clinical team directing the situation) experienced two major changes before a supported independence (SI) model was tried. This SI situation is still in place after one year.

The changes in language competence have also been dramatic. Three of the clients were considered incapable of intentional communication because of echolalic speech (those with brain damage). Their language has become both goal directed and functional. Persons whose language was confused or delusional also made dramatic changes toward coherent, intentional speech.

Funding Patterns

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

Table 4 presents the initial contract costs and the current contract costs. The differences in these figures are dramatic when one considers the severity of the presenting problems. Table 5 compares cost estimates for several living alternatives.

The marked differences in costs between the 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. Overhead charges of agencies are eliminated because the money available goes directly into services, not into administration.

If this model develops further there will need to be core funding for the safety nets provided by Independent Living Centres. At present, there is no core funding allocated for core functions—information services, peer support, or brokerage in provincial or federal policies. This employment infrastructure will be essential as the numbers served in the community through individualized dollars increase.

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 one was personally aware of the risks he or she had faced

living in the community with a disability. Their willingness to risk gave others a chance to prove that disabled persons could succeed.

There was a unique combination of ingredients operating at the time of the implementation of the CAIL model, thus allowing for success of the model:

1. existence of a consumer controlled Independent Living Centre with a staff trained in consumer controlled service;
2. commitment of the family, personal support staff, and friends of the persons who provided ongoing support and group advocacy with funders and service providers;
3. local social services management willing to adapt policy to allow persons with behavioral and intellectual disabilities to use an income security funding route to provide ongoing support;
4. 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
5. the existence of guardianship legislation which appoints a legal substitute decision-maker for those unable to speak on their own behalf.

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, in an Independent Living model and this would have meant contact with only paid staff in a single dwelling house.

This model cannot be undertaken without safety nets and a strong support base. At the very least, there is a need for core funding to support emerging employment infrastructure which individualized dollars are predicated.

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 directing the broker in all of the initial situations. This afforded a unique opportunity to provide feedback and suggest changes as the situations evolved.

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 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.

References

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