

Individualized Funding

First Choice Option for Developmental Services

Individualized Funding Coalition for Ontario

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Introduction - The Problem

Some people with disabilities and their families need extra supports to deal with the challenges in their lives. The cost of meeting their needs through the traditional social service system is high, yet existing services have serious shortcomings. In Ontario, the Ministry of Community and Social Services spends more than \$110,000 per person per year, on average, to keep people in institutions which are generally considered to be dehumanizing. Within its developmental services program, it spends an average of \$29,000 a year per person for services for 30,000 people, but many of these services are not effectively addressing individual needs or achieving any significant community involvement. Thousands of people with critical needs cannot access any support at all. These shortcomings, occurring in times of severe fiscal pressures at all levels of government, draw attention to the urgent need to make the developmental services program more accountable to consumers and more cost-effective.

These problems are chronic. Twenty-five years ago, when the progressive *Comserv Ontario* initiative was established, the *Comserv* brochure identified the following problems: “We are faced with:

- Program orientation rather than individual orientation. If the individual cannot ‘fit’ or if the program is ‘full’, he may be referred repeatedly, put on waiting lists, and often not served at all.
- Inappropriate and ineffective use of scarce resources. Agencies seem ready to serve (sometimes over-serve) those who fit in easily, while those in most serious need of services may not fit in, and thus not receive services.
- Inefficient use of scarce resources. Dollars are tied to buildings and agencies, which is less productive and more expensive than tying resources to individual needs.”

Today, these statements still ring true. Thousands of people still live in institutions in Ontario. Many are locked in services which offer them little or no control over what they do with their lives, over whom they live with, over where they live, and over how they spend their time. They are locked in because funding is not portable within the province, but is tied to buildings and agencies. Leaving one service leads to going to the bottom of a long waiting list for another. Rigid bureaucratic practices prevail over the need for supports adaptable to individual needs.

There are many whose needs are simply not addressed by the current system. An important example is the increasing number of families who want to establish their sons/daughters in residential supports that are more individualized, more community-oriented, and more flexible than traditional group homes. These families are prepared to assume responsibility and to exercise control with their daughters and sons. Similarly, there are adults living in institutions or group homes who would like to live somewhere else but who have no flexibility to move out with their funding.

A recent report on the Individual Approaches Project (1994) funded by the Ministry of Community and Social Services, indicates that the problems persist. It states (p.2) that “That [service] system, for all its positive achievements, has grown in size and professionalism [in the past twenty years] and has surprisingly produced or perpetuated some of the issues inherent in institutions. Concerns about segregation, labeling and control are raised on a regular basis...’ *today’s crisis is the unintended result of the transfer of institutional patterns of service development and delivery to community programs*”.

These problems persist in spite of good intentions and plans, on the part of all stakeholders, because the existing service delivery system is not flexible and is not directly accountable to consumers. The Ministry of Community and Social Services perpetuates this system through its policies, its funding practices, and its arbitrary and discriminatory categorization of people and their needs.

Consumers who are not well served by the current system are neglected and forgotten; some have been on hopelessly long waiting lists for many years; there are even some whose severe and chronic needs are not documented and unknown to the Ministry and to service providers. The problems identified by *Comserv* are as real today as they were 25 years ago.

It is time for a fundamental change of approach.

Individualized Funding

The answer to these problems lies in empowering the consumers to decide what supports they need and what they want to do with their lives. The system would then be accountable to consumers. An essential component of empowerment is *consumer control* of the resources allocated for supports.

We define the expression “individualized funding” to mean funding determined according to individual need and controlled by the consumer. The consumer may manage the money directly, or may designate/hire a manager or an agency to manage it, but the consumer ultimately decides how it is spent. For those consumers who need assistance in making choices and decisions, this assistance can be provided by family and friends who are the most highly committed people in those consumers’ lives, and/or significant others.

Funding provided directly to persons with special needs is very cost-effective and can be applied directly to address individual needs and to increase community involvement. Individualized funding empowers consumers, and offers flexibility to achieve personal goals. It can support personal values which are sometimes different from the values of service-providing agencies. It can capitalize on the high degree of personal commitment of people with disabilities, their families, and their personal advocates. Individualized funding is inherently portable, giving individuals and their families opportunities to seek out new places, new jobs, and new environments according to their changing needs at various stages of their lives. Individualized funding is inherently fairer than the prevailing system, as people would get supports in proportion to their needs, rather than according to who was first in line.

The Ministry of Community and Social Services is currently preparing to implement a plan for the years ahead – the Developmental Services Framework. We want to make it clear that any new Developmental Services Framework must recognize that virtually every individual will have needs for some form of community support for some period of their lifetime. A commitment to equitable support for individuals necessitates a fundamental change in the way government resources are allocated to all individuals and their families.

Individualized planning and funding are essential to eliminating the perpetuated inequities of the existing funding system. It will enable the planning and allocation of resources to all individuals in an equitable manner that respects individual requirements but within the available resources.

Program effectiveness

Individualized funding gives the consumer maximum flexibility and control, making it possible to address individual needs effectively. If the consumer chooses to shop around for existing services, he/she will be in a position to negotiate the price, the schedule, the location, the quality, etc. If a suitable existing service cannot be found, the consumer may bargain for a new service, or hire a person directly to provide the necessary support. If needs change, the funding can be adjusted accordingly. Choice also brings the advantage of encouraging personal responsibility and planning.

When professional services are needed to implement a plan, they can be purchased. Planning, administrative, and clerical skills can also be purchased. The main function, that of overseeing and assisting a person with major decisions related to personal supports, is best left to family or caring personal friends.

With consumer-directed individualized funding, the consumer is the judge of the quality of the service or the supports. Service providers become fully accountable to the consumer and become more responsive to the consumer. Because individualized funding can be used very creatively and flexibly, it can overcome gaps or inadequacies in the service system.

The Special Services at Home (SSAH) program, which is the prime demonstration of individualized funding in Ontario since 1983, has been proven to be highly successful. Lord, McGeown, and Ochocka (1993) have found that families and other stakeholders agree that the program is a success in general family outcomes, community integration, family life, and skills and behavioural development outcomes – “Three mixed stakeholder focus groups agreed that these outcomes are positive and an excellent fit with the stated purpose and hoped for outcomes of SSAH. These focus groups also emphasized the preventative nature of these outcomes.” The SSAH program can be considered as a successful pilot program which can serve as the basis for a more comprehensive individualized funding program.

Cost-effectiveness

Personal supports based on individualized funding have less overhead because home and public facilities are used more extensively. Family members contribute their own time and effort free of charge, and activities are tailored to provide the exact level of support needed, exactly when it is needed (no more, no less). Flexible individualized funding also encourages frugality. Savings in

other less important areas according to personal priorities can compensate the extra cost of some personal supports. Families who receive needed supports are less likely to seek more costly institutional placements for their sons/daughters. We also strongly believe that children who are provided with supports at home and who experience interaction with the community are likely to have less demanding needs when they become adults.

Individualized funding can increase cost-effectiveness of the whole service delivery system. As explained by Rioux and Crawford (1994), putting the dollars in the hands of the consumers will tend to make the service providers more responsive, more effective, and more efficient. If they have to rely on user fees for their services, their viability will be related to consumer satisfaction.

System accountability

Rioux and Crawford (1994) of the Roeher Institute reviewed the basis of social services in Canada and recommended that individualized funding be the basis for supporting the needs of individuals with disabilities. They define *demand-side funding* as dollars flowing to consumers who purchase the supports and services they need, and *supply-side funding* as dollars flowing directly to service providers.

They state (p.7) “[demand-side funding] has proven to be an effective means of making social services more responsive and accountable to consumer demand. It introduces market forces and related efficiencies, lacking at present, into the social service sector. It is a means of containing costs in the sense that funds are allocated to actual requirements of individuals and over-serving is avoided. Demand-side funding has the advantage of providing enormous social and economic flexibility to the individuals being funded”.

They recommend demand-side funding and state (p.54) “The proposed reform would put a delivery system in place that would respond accurately to individual requirements in a timely fashion and adapt as these requirements change. It would maximize flexibility in order to address community and individual circumstances. Correspondingly, the proposed reform would ensure responsiveness through individual and community planning.”

The concept of individualized funding is also discussed in another publication of the Roeher Institute (1993), *Direct Dollars*.

Other benefits of individualized funding

A shift to more individualized funding in Ontario would be partly offset by lower costs to the health care system, as families would have more opportunities to avoid costly and sometimes unnecessary placements in psychiatric hospitals and others, such as Bloorview Children's Hospital. We are aware of families who would prefer individualized funding for a fraction of the cost of such institutional placements which are currently offered to them as the only option.

The experience of the SSAH program has been that individualized funds are often used to create jobs, including summer jobs and part-time jobs for students.

Conclusion

We support the self-determination of persons with disabilities. We believe that they should have the decision-making authority over what they do with their lives. They should have control over decisions concerning where they live, with whom they live, with whom they associate, and how they spend their lives.

Individualized funding is not new. It already exists in Ontario in the form of the SSAH program. The experience with SSAH can serve as the foundation for a broader approach to individualized funding. Indeed, the new Long Term Care Ministry has recently announced self-directed funding for people with physical disabilities.

The inescapable conclusion is that consumer-directed individualized funding should be the first option. Some people will no doubt choose to buy the formal, traditional services now offered by transfer payment agencies. They should have that option. Those who feel they are already well served may appreciate the flexibility of features such as portability of funding from one agency to another, anywhere in Ontario. The process of transforming a service delivery system funded on the supply side to an individual support system funded on the demand side needs to begin now. The Ministry of Community and Social Services needs to adapt its funding priorities and mechanisms to reflect the wishes of the consumers.

Finally, as the Ministry of Community and Social Services implements its long range plan “**Making Services Work for People**”, it must respond to the wishes of consumers and the Individualized Funding Coalition for Ontario by recognizing the advantages of individualized funding. The necessity of shifting funding to give consumers more power over the direction in which services evolve must be recognized. Through consumer empowerment, the whole service delivery system will become more responsive, more effective and more efficient.

References

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