research

Self-Managed Care and Individualized Funding: Not the Same Thing!

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Introduction

It is easy for the labour movement to be suspicious of government initiatives in social programs. Our history has taught us that improvements in social policy have to be won through concerted effort and struggle. This has been why the Canadian labour movement has joined in solidarity with equity and justice seeking organizations to work together for progressive change. Another lesson from this long history is that sometimes there are conflicts and contradictions in the agendas between these different social movements.

Over the past decade we have seen some conflict between the disability rights movement and the labour movement on the question of alternative models of service delivery. In many ways a false antagonism has been created between the right of service-users to direct and manage their own care and workers' rights. On the other hand, as in all such perceived conflicts there is enough of an element of truth to merit discussion. This paper is intended to address the potentially thorny issue of a labour perspective on one increasingly popular alternative model of service delivery – self-managed care.

From the onset it must be established the two pillars on which a labour perspective on the issue must stand:

1. The labour movement's commitment to protect and expand upon workers' rights. This includes the right to organize and collectively bargain and protection from unjust treatment in the workplace.

2. The right of disabled people to be full and active participants in Canadian society. There is a collective responsibility to provide equal access, and the supports necessary to achieve this, to all citizens.

If we work from these two guiding positions we should be able to develop a progressive and positive perspective on alternative models of service delivery. Yes we may hit a few bumps along the way – but the road will get us to where we need to be!

This paper is going to look primarily at the Self-Managed Care/Individualized Funding model of service delivery that is becoming increasingly popular in Canada.

The Context

There are two main identifiable trends in the development of these programs in Canada. The first is the adoption of neo-liberal policies of fiscal restraint at all levels of government in Canada. Secondly is the growing, in size and influence, of the disability rights movement.

Government Downsizing

Canada witnessed a major growth in the social services sector in the late 1960s and throughout the 1970s. A key factor resulting in this growth was the introduction of the federal government's Canada Assistance Plan (CAP) in 1966. CAP was a federal/provincial fiscal arrangement whereby the federal government provided provincial governments with fifty cents for every dollar they spent within the social services sector. These 'federal 50¢ dollars' provided provincial governments with a significant incentive to expand social security, services and programs to protect those vulnerable citizens who, through no fault of their own, were not able to fully participate and benefit from economic growth taking place in our country. CAP ensured that the sharing and caring values of Canadians formed a part of our country's overall prosperity. CAP also provided a strong signal that the state had a collective responsibility for the well being of all citizens.

The first years of CAP saw the expansion of social services take place mainly through a centralized delivery system under the direct administration of provincial Ministries of Social Services. In the late 1970s and throughout the 1980s, however, the social safety net showed some signs of stress as governments began to adopt neo-liberal public policies such as wage and price controls through anti-inflation policies, caps on public spending and reductions in corporate taxation. In many provinces, governments continued to fund social services, but downloaded the responsibility for delivery by creating a host of non-profit agencies.

The rate of growth of the social services sector slowed significantly in the 1990s. Provincial governments have been either eliminating, privatizing, and/or downsizing social services. The most significant factor that has led to the contraction of Canada's social safety net was the 1995 federal budget. That budget eliminated the federal CAP program and its 'federal 50¢ dollars' for social services spending, in favour of the Canada Health and Social Transfer (CHST), a federal block funding scheme that greatly reduced federal funding for social services, health care and education.

The result has meant a significant shift in the funding and delivery of social services. In order to cope with the additional burden brought about by the CHST, provinces which have less money for services have begun to restructure their own delivery of social services by downloading the responsibility to municipalities, community-based organizations, the private sector and individuals.

Disability Rights Movement

Another impetus for the shift of government funding of health care out of more traditional settings into home and self-managed care models has been the rise of the disability rights movement. In particular agitation over the past decades, for de-institutionalization, normalization/community integration, civil rights and independent living has lead to a significant shift in the manner in which services for people with disabilities are conceived.

Historically, the charity model was the primary means by which people with disabilities received support. Inadequately funded and prone to abuses and warehousing charity proved to be a poor model for meeting the needs of these citizens. Responding to pressure from the popular movements, an important component of which were the trade unions, social programs overall shifted more to state-funded and provided services. While never fully sufficient there was at least an acknowledgement that social programs, including those for people with disabilities, were a collective responsibility.

It could be strongly argued that the expansion of the “welfare state” helped facilitate the growth of the contemporary disability rights movement. Improvements in supports provided for people with disabilities meant increased presence in the classroom and workplace. Demands for full and active participation in all areas of public life became a rallying cry for people with disabilities.

The first targets for change were those institutions that isolated and segregated people with disabilities from the broader society. This was also accompanied by a growing recognition of the exploitation and abuse that occasionally occurred in some traditional care settings. People with disabilities were demanding more input and control over the services they needed. It has also been that case that government’s have taken advantage of the very real and tangible aspirations of people with disabilities for control over required supports, in their home communities, to engage in an attack on social services. In the majority of cases the shift from an institutional to community based setting was not accompanied by equal and adequate funding. In many cases the marginalized and oppressed conditions of people with disabilities were exacerbated.

The American Independent Living Movement helped to spark a Canadian counterpart in the 1980s. After intensive lobbying they managed to secure stable funding from the state, Human Resources and Development Canada, to establish a network of Independent Living Resource Centres (ILRC) across the country.

Self-Managed Care Programs

> *"Self-managed care is totally unlike conventional programmed attendant and home care services. All decision-making and most of the administration of self-management is performed by the disabled service-user. This occurs at considerable saving to the skeletal remaining system which, virtually, becomes a monitor/cheque writer; having dispensed with concerns related to items like personnel and contingency management, scheduling, needs assessment and similar kinds of resourcing."*[1]

The above quote expresses the position of many disability rights organizations approach to a self-managed care model of service delivery. Advocates of these types of alternative models of service delivery argue that it provides nothing but benefits to the service-user.

> *"Yet without wishing to cast aspersions on those requiring programmed services for whatever reason; with the development of self-managed care systems, we have finally evolved to the point where, from the disabled person's point of view, all vestiges of the medical model of care end, and true person-hood begins."*[2]

The fundamental arguments used in favour of self-managed care service programs can be grouped as:

1) **Individuals with disabilities (or their guardians) are themselves their best spokespersons.**

   Individuals with disabilities have the right to participate in making the decisions that affect their lives. No 'non-disabled' expert or collection thereof can understand the aspirations of a person living with a disability. People with disabilities, and their families, should be able to participate in the planning of services and programs they need and how those services and programs are structured and delivered. Their input can only hasten their eventual integration and full participation in all aspects of society.

2) **The needs of persons with disabilities are not static, and therefore services and programs must be provided based on a 'continuum of care' model.**

   From the time they are born through to adulthood, persons with disabilities require a wide variety of different personal services and support programs. These services and programs should evolve along with persons with disabilities, as they themselves develop different interests and goals they

[1] The CCD Health Inspector. "Self-managed and programmed services; Threats and opportunities". Council of Canadians with Disabilities, September 14, 1998.
[2] Ibid.

would like to achieve, or decide to make changes in their daily lives. These situations also apply to family members and/or support groups caring for an individual with severe developmental and/or physical disabilities.

3) **Quality personal services and support programs must be accessible and readily available in a seamless manner to meet the needs of individuals with disabilities in their communities.**

   Basic access to services is often the biggest obstacle to the independence and full participation in all aspects of society for a person living with a disability.

It is important to distinguish between self-managed care and the means by which these services can be offered. The labour movement must support the right for people with disabilities to exercise control over the services they receive. But, the means by which governments can provide these services must be done in a way that respects the rights of both the service-users and the service providers as well as ensuring equality and high standards of care. There are three principle models in which self-managed attendant services could be offered by a province.

The first is an agency-sponsored but user-directed service. Under such a model a central organization would oversee/support the hiring, training, supervision and payment of an employee. The service-user would interview and negotiate a personal support regime with the employee based on their individual needs. A familiar example of this kind of model would be the current practice of forming a relationship with a family physician in Canada. The individual seeking regular medical attention chooses a personal physician from among the number of locally available practitioners. Payment for the service provided is overseen by the provincial government and various regulatory bodies. Province wide standards and fee schedules are established and the physicians have gained, to a large extent, collective bargaining rights. A variation of this model is currently in place in the province of New Brunswick and a number of US jurisdictions.

The second model, the one most often referred to when discussing these types of programs is the individualized funding approach. A more complete discussion of this model constitutes the majority of this paper and follows this section.

The third is a brokerage model involving a middle person acting between the government, which funds the personal programs, services and support, and the individual who receives these personal programs, services and support. The broker doing the purchasing for the clients keeps a fee off the total funding amount. The province of Quebec currently practices a brokerage type of model.

Individualized/Direct Funding

Most self-managed care programs in Canada are based on an Individualized Funding (IF) relationship between the provincial government and the service user. Individualized funding refers to a transfer of money from governments directly to individuals or their support group for the purchase of personal programs, services and support. The direct dollar model is individualized funding in its purest form. The money goes directly to individuals or their support group, who then purchase the personal programs, services and support. Support groups can include but are not limited to, families, advocacy groups, and micro-boards.[3]

In most programs, the service-user, or their support group, assumes an employer-employee relationship with the attendant. Participants in these programs must recruit, hire, train, supervise and pay, including payroll deductions, their employees. Funding allocations are determined after a needs assessment with the applicant. Usually the eligible applicant must establish a separate bank account and all the necessary payroll deduction arrangements. As a means to ensure accountability, the province conducts periodic audits of the service-users books.

Other restrictions to the program may apply depending on the province. Most programs prohibit the hiring of family members as attendants. The rationale for the prohibition is to guarantee family members respite from providing personal care. Some concern has been expressed that the hiring of a family member could contribute to the economic exploitation of vulnerable individuals (the statistics of abuse of the elderly and disabled by family members is significant). Both of these are legitimate concerns but most likely the reason is that the total provision of care is extended through the use of unpaid family members, overwhelmingly women, which might not happen when family members are hired.

When IF programs are cited in reports on self-managed care programs the overwhelming justification for these types of funding schemes appears to be perceived cost-savings to the system. Given that the money is provided directly to the service-user to oversee the funds, it is assumed that fewer administrative personnel are required. Similarly, as the individual service-user is in a position to recruit and hire staff it is thought that they will be able to contract for service with employees at a rate of pay lower than that paid in home care agencies. This is achievable only if the individual hired to provide attendant services is not as well trained as other support providers and that established standards of care are not strictly adhered to.

[3] A microboard is a non-profit society. It is a group of people who have been chosen by, or on behalf of, the individual, whose primary focus is to provide support for the individual. Microboards negotiate with the government for money needed for services. Microboards reflect the needs and wishes of the individual. They represent one way of implementing individualized funding. Report on the Individualized Funding Conference, June 8-9, 1997, Vancouver, British Columbia.

Both of these assumptions should be taken with a grain of salt. Indeed there are some indications that these programs will more likely transfer the administration of employee payment to private sector companies and out of the public service. Most IF programs in Canada provide for, and in many cases actively encourage, the service-user to utilize third party organizations for managing their employees. Also, there is evidence of difficulties in recruiting attendant care workers in all regions of the country based on the low wages and poor benefits these programs offer. It is unlikely given the shortage of home care workers that people will opt for a lower paid self-managed care relationship over a higher paid and protected agency position. As in many aspects of health care market forces prove to be a poor impetus for service provision.

The fact that home care and IF are cheaper for governments to provide is more a consequence of being inadequately funded and not universally available than any real organizational benefits. Were governments to ensure that workers in this part of the health care system received decent wages and benefits and that the services provided were complete and adequate it is unclear whether the savings promised would materialize to the extent suggested. This does not argue against the importance and beneficial nature of home care/self-managed care but rather the motivations of elected governments.

A number of authors point to the differing rates of unionization as a significant determinant in the wage gap between the traditional health care and home care settings. One of the outcomes of IF schemes, possibly a major motivation for governments, is the virtual denial of organizing and collective bargaining rights for workers.

Self-Managed Care in Canada

National Policy Directions

It could be argued that both the provincial and federal governments are showing a renewed interest in implementing policy pertaining to people with disabilities. The 1998 paper by the Federal, Provincial and Territorial Ministers (representing all Canadian jurisdictions with the exception of Quebec) is entitled *In Unison: A Canadian Approach to Disability Issues*. Part of the Social Union initiative (see Appendix I for more on the Social Union) the paper indicates a push by these governments to act on disability issues.

Where the *In Unison* document represents a small step forward is that it recognizes and highlights the unevenness of services provided for people with disabilities. On paper the document was everything that disability activists could have hoped for. But, as in many similar initiatives the mechanisms for implementation were far from clear.

“While the spelling out of the situation of Canadians with disabilities that the paper provided, the recommendations it proposed, were everything they could reasonably hope for from a government production. ‘In Unison’ includes no mechanism tasked for either getting the process underway or keeping its diverse components in some order once it was.””[4]

To date very little has been done with regards to the implementation of the recommendations. Where the report is relevant to the discussion of Individualized Funding schemes is that it does highlight that this may be a viable addition to the range of services provided for persons with disabilities. The theme of “consumer-directed and managed” services is a strong one throughout the paper. There is no doubt that all provinces will be shifting more services for people with disabilities and seniors into a self-managed/IF model.

In addition to provincial efforts the federal government released a draft of its proposed national strategy in January of 1999. Under the working title of “Federal Disability Strategy: Working in Partnership for Full Citizenship”, the document was distributed to national organizations representing persons with disabilities for comment and feedback.

The rapid expansion of home care services, of which self-managed care is usually considered a component, has generated a very real need for research and national policy coordination. With federal government announcements of increased funding to health care, a significant portion of which will be allocated for home care programs, there has been a considerable increase of activity in the sector. Health Canada convened a **National Roundtable on Home and Community Care** in February of 1999. The roundtable was comprised of representatives from a host of organizations with an interest in home care, with the notable exception of the trade union movement. The goal of the meeting was to commence the process of creating a national home care system.

Within many of the provinces a similar process of research and advocacy is gearing up. Again with the promise of increased spending many organizations are scrambling to have input into the manner in which expanded services will be offered. Recently reports on IF were released by the **Ontario Coalition for Individualized Funding** (OCIF) and the **Ontario Federation for Cerebral Palsy** strongly advocating for IF.[5] The report from the OCIF arose from a Roundtable discussion they hosted in May 2000. Again the absence of labour representation is noteworthy.

It is important that the labour movement develop a position on self-managed care and IF as a first step in its efforts to have input into policy formation.

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[4] Graham, Mel. “FPT … It’s Not an Automotive Supplement!” Abilities Magazine Forum, Fall 2000.

[5] “Linking Individualized Supports & Direct Funding: Making Money Work for People,” Report of the Ontario Round Table on Individualized Funding, May 2000. “More Choice and Control for People with Disabilities: Individualized Support & Funding,” Ontario Federation for Cerebral Palsy, July 2000.

Programs Across Canada

There are self-managed care programs in most provinces with a fairly limited number of participants.[6] The majority of these programs operate on an IF model of payment. The following is intended to provide a thumbnail sketch of self-managed care programs available with some elaboration where relevant.[7]

New Brunswick
There is a self-managed care program available in New Brunswick. In 1997-98 there were, approximately, 500 people in self-managed care, the majority of whom are people with disabilities, and for most the Department of Health directly pays for the services. In a small number of cases the service-user pays the entire cost of the service and a few receive a financial allocation from the Department to purchase services related to home support.

Newfoundland
In December of 1998 the Newfoundland and Labrador House of Assembly passed Bill 56, the *Act Respecting Home Services Provided to Persons in Self-Managed Care*. This legislation established a direct funding program and explicitly stated that people who utilize the program are considered employers of their own workers.

The program implemented in Newfoundland is unique in the broadness of its application. Currently, approximately 80% of people with disabilities use services provided for through self-managed care and only 20% use an agency. A serious concern for both staff and participants in the program is that workers are not covered by workers' compensation. In case of injury the worker may have no recourse but to sue the employer. Apparently the 1997 budget allocated $1 million to extend coverage to these workers but as yet it hasn't been implemented. Even if implemented the amount established is insufficient to fully cover workers' compensation claims by these workers.

The province of Newfoundland perhaps best exemplifies that home care provision may be increasingly shifted to an IF model. Most provinces with self-managed attendant services apply them to a small segment of the population who requires home care services. Newfoundland has gone one better and is adopting it as a model for all home care services – from support to seniors to persons with disabilities. This has been quite a fractious dispute in the province, including a supreme court challenge, and has led to the de-unionization of home support workers (see Appendix II).

[6] The information contained here is as current as reports provided allow. Given the rapid expansion of home care programs the information may be dated for some jurisdictions.

[7] For a more complete survey of self-managed care services available see "Best-Practice Models of Self-Managed Care: Their Application for Seniors" report prepared by Canadian Home Care Association, 2000. As well there is a report from Health Canada entitled "Home Care Development: Provincial and Territorial Home Care Programs – A Synthesis for Canada", June 1999.

Nova Scotia
In 1994, Halifax's Metro Resource Centre for Independent Living Resource initiated a self-managed care pilot program. Following the pilot project the Metro Resource Centre submitted a proposal to increase the service province-wide between 1998 and 2003. Over these five years the program will be introduced in Nova Scotia's four health regions with the goal of adding 200 additional service-users by 2003.

Prince Edward Island
While not formally available in PEI there are a small number of individuals, less than five, involved in self-managed care as part of a pilot project.

Quebec
A self-managed care program has been in effect in Quebec for a number of years. Eligible participants are responsible for recruiting, hiring and supervising attendants, but the funds are not directly provided to the service-user. Instead the Centre Locale de Services Communautaires (CLSC) informs the Employment Service Cheque (ESC) Processing Centre of the need to pay the attendant. The service-user then completes a record of hours worked to submit to the ESC.

While the program is available to seniors the majority of users are people with disabilities, as is the case in all provinces. In 1997-98 there were approximately 6,000 people using this service.

Ontario
Ontario has what is probably the most comprehensive of the self-managed care programs in Canada (see Appendix II for criteria and program details). After a 1994 pilot project the provincial government announced that it could serve as a possible model for self-managed care (direct funding) of attendant services. In the program the province provided funds to persons with disabilities to hire, train, supervise and pay for their own attendants. In July of 1998 the program was declared a success and the provincial government made it a permanent program and announced expansion. During the 1997-98 year there were 102 participants in the program, almost all persons with disabilities.

Manitoba
In 1994, following a two-year pilot project (1991-93), the government of Manitoba expanded its self-managed care program across the province. The Self-Managed Care Option is operated through the provincial Home Care program. Eligible individuals receive direct funding to make arrangements for their assessed needs. The service-user is considered the employer in the relationship.

Most researchers on the topic acknowledge that the 1996 strike by home care workers in the province contributed to an increased emphasis on the program by

the previous government. Reports suggest that the current government is re-examining the provision of home care in the province.

Saskatchewan
There is a self-managed care program being designed in Saskatchewan but not, as yet, implemented. One Health District does offer a self-managed care option to its home care service-users of which there are less than five participants, all of whom are persons with disabilities.

Alberta
The Alberta Home Care Program implemented a self-managed care option in 1993. It followed a two-year pilot project, 1991-93, as a response to growing demand from consumer organizations and disability rights groups. Between 1997 and 1998 approximately 1,130 people participated in self-managed care, the majority of whom were people with disabilities (the program is open to seniors and others but these appear to constitute a minority of service users).

It is a true IF program as eligible service-users receive a monthly transfer of funds with which to pay their attendants. The service-user is considered the employer and must pay all payroll deductions, train and manage their employee. Under the program the service-user may purchase administration services from an agency.

British Columbia
British Columbia's Regional and Community Health Authorities offers a self-managed care program through its Choice for Supports in Independent Living option. The program was embarked upon in 1994 to provide personal care and home support to persons with severe disabilities living in the community. Funds are provided directly to eligible individuals who then recruit, hire, train and pay their attendants.

There are about 300 individuals participating in the program, the majority of whom are people with disabilities.

Northwest Territories
Currently self-managed care is not available in the Northwest Territories.

Yukon
Currently self-managed care is not available in the Yukon.

Evaluation of Self-Managed Care Programs

The conclusions reached on self-managed attendant service programs most often depends on the perspective taken by the researcher conducting the report. Most advocacy organizations for people with disabilities report that this form of program is highly effective. Studies have tended to be case studies utilizing anecdotal evidence and may be biased to reporting favourable accounts. Having said that, the bulk of evidence seems to suggest that users of self-managed attendant services are happier with this arrangement than past agency-based models.

There is very little research done focusing on the experiences of the workers in the system. The evidence that does exist tends to be less enthusiastic, though not entirely hostile, about working directly for an individual employer. Almost universal is the concern about low wages, poor working conditions, and the quality and consistency of service providers.

It is important to remind the reader that self-managed care and IF are not necessarily connected. As has been previously mentioned there are other possible models of funding self-managed care programs. That IF is the most common model of providing these programs in Canada reflects political priorities of various levels of government and not best practice decisions.

When looked at as a body a number of topics arise both in favour of self-managed care/IF and in criticism.

Strengths of the programs:

- Improved individual choice and control.
- Flexibility of services provided.
- Enabling individuals to be more independent and autonomous.
- Client satisfaction.

Difficulties with the programs:

<u>Workplace Issues</u>

- The rates of pay and conditions of employment show no uniformity or consistency within jurisdictions, indeed sometimes between service-users. While in a few jurisdictions workers in IF/self-managed care programs have slightly higher income than their agency home care worker counterparts this is only comparing bad pay with worse.[8] The wages paid to attendants is still

[8] While some research suggests that IF/self-managed care workers make more money than there agency counterparts this is not the situation in all jurisdiction. For example, according to an article in the Montreal Gazette, November 20, 2000, "Help for handicapped comes too cheap, group says" by Charlie Fidelman, workers in the province of Quebec make between $5-$6 less than their agency counterparts.

considerably lower than that paid to workers in traditional health care settings. This is largely a result of the constraints placed on funding than anti-worker attitudes held by the service-user.

- In some instances, unreasonable expectations are placed on workers.
- There is evidence of the denial of employment standard provisions to workers primarily as a result of lack of knowledge of the employer. For example, in Newfoundland there was recent evidence of a worker not being paid for statutory holidays.
- Many home care workers are individuals who previously worked in the more traditional health care sector. This is undoubtedly true for self-managed care attendants. Overwhelmingly these individuals report a decline in salary and working conditions when moving into these programs.
- Often workers in self-managed care programs are themselves vulnerable people subject to abuse and exploitation.
- There are serious concerns about the health and safety of attendants. Often inadequately trained and working alone they are highly likely to injure themselves doing heavy lifting or using equipment. In some jurisdictions they are not covered by worker's compensation.

<u>Problems for the Service-User</u>

- The level of training for self-managed care providers under IF is usually considerably lower than for agency based workers resulting in a lowering in the quality of care. Furthermore, in the absence of established standards of care there is no collective recognition of best practices in the provision of support.
- The turnover rate for workers is high. Often trained employees will opt to work in better paying agencies or in more secure settings. This has meant that the process of recruitment, hiring and training of personnel has to be an ongoing process. Recent reports favouring IF have advocated the creation of support services to assist people with disabilities with these roles. This would seem to beg the question why replace existing agencies with new ones?
- In smaller rural, northern and remote communities the availability of funding does not necessarily mean that there are potential workers.
- Increased responsibility of recruiting, hiring, supervising and administering the program. While many said that the benefits outweighed this problem the repeated references to these concerns indicates that it is not an insignificant issue for the user.
- Lack of back-up services.
- As the service-user must provide training for their attendant a number of studies have highlighted the lack of adequate education as a problem.

Conclusion

It is a reflection of the current policy directions being adopted in this country that IF is becoming the dominant funding model for self-managed care programs. Neo-liberal policy analysts and right-wing political parties have been strongly advocating similar programs in almost all areas of public policy. For example, the voucher system in education, replacing the CPP with an RRSP scheme, and individualized subsidies in childcare. The goal is to replace a pre-existing system of service delivery, in this case the health/home care system, with individual purchasers of service. This does not negate the potential benefits of self-managed care but should raise alarm bells for all of us who value a healthy and vibrant public sector.

The predominant theme of this paper is that self-managed care and IF are not the same thing. When you examine the strengths attributed to self-managed care the list does not immediately suggest that service-users must assume an employer relationship with their attendant. Indeed there are indications that people find the bureaucratic elements of the program an obstacle to overcome. This is not entirely surprising. For the overwhelming majority of people full citizenship and societal participation is not dependent on being able to hire, supervise and pay employees. Also, the employee-employer relationship is always a slightly antagonistic one and it is naïve to think that it would not be the case for persons with disabilities in an IF relationship with their personal support staff.

Claims that self-managed care and IF represent a paradigm shift in the provision of personal supports to people with disabilities are very much overstatements of the facts. The paradigmatic shift in health care provision is the move from the hospital setting to the community. Moving from a medical model of diagnosis and treatment of people with disabilities to one of providing self-managed community support has been a considerable step forward in respecting human rights. Individualized funding is simply reintroducing market considerations into the system. It is not that long ago when people with disabilities, who could afford to do so, hired personal servants. In fact, if a paradigmatic shift is coming, it is hoped that it would be one where the rights and needs of the attendants were also entered into the consideration!

It is quite easy to envision alternate models of funding self-managed care programs. One that was mentioned earlier is similar to that which most people utilize to form a relationship with a family physician. Under a model of this type:

- A roster of qualified individuals authorized to provide attendant care for a region could be established.
- Standards of care could be set and enforced by regulatory bodies.
- A high level of initial training and skills development could be assured the individual service-user prior to the more individual specific orientation.
- Workers rights to collectively organize and bargain would be provided for.
- Province-wide rates of pay and benefits would be established and enforced.

- The burden of recruiting, hiring, managing, and paying (including associated payroll obligations, is removed from the individual.
- The provision of services for people with disabilities remains a collective obligation for society and not an individualized market relationship.

A model of this type, it is believed, provides for all the benefits of self-managed care without the problems associated with Individualized Funding.

Appendix I

The Social Union

The debate about Canada's Social Union refers to the distribution of powers, responsibilities and resources between the federal and provincial Governments. Following the establishment of the CHST the provinces met with the purpose of hammering out a new arrangement between themselves and Ottawa.

The provinces motivations for the Social Union talks are quite easy to see. While the five principles of the *Canada Health Act* were retained in the CHST, and two new standards were added (no user fees or extra billing) only the federal Government can judge whether a province is complying with these national standards. Dramatically reduced funding made it far more difficult for provincial Governments to deliver programs as they were in the past. The provinces were irritated that the federal Government was giving them so much less, while binding them to national standards and retaining the exclusive right to police the system.

At the beginning of the Social Union debate, the provinces wanted the federal Government to be barred from introducing new national programs without provincial approval. They wanted an end to the right of the federal Government to decide whether provincial spending, on health care especially, was living up to national requirements. The provincial Governments also wanted an assurance that federal transfers would not be cut unilaterally.

When the talks appeared to be going nowhere, the federal Government simply purchased the Social Union agreement to the tune of $3.5 million per province in the form of a trust fund for health care.

On February 4th, 1999 the agreement was reached without any public consultation and without approval by Parliament, or any of the provincial legislatures. The Social Union framework is still unclear on a number of issues. The agreement stipulates that it will promote equality of opportunity for all Canadians, however there is no mention on how this will be achieved. The five principles of Medicare are mentioned but the new principles under the CHST, namely no user fees and no extra billing are not referred to. The deal also talks about "monitoring outcomes of social programs and reporting to constituencies on the performance of these programs", but is very vague as to what that means.

The $3.5 million trust fund that was referred to earlier in the report is a one-time supplement to the CHST. In effect, it was a bonus for signing the Social Union framework. This money will be put into a trust fund for the provinces to draw on over three years, although if they choose they can take all the money in year one.

However, under the CHST, the federal Government can no longer ensure that the provinces will actually spend these funds on health care. Consequently, the

provincial Premiers stated, by way of letters, that they would spend the money exclusively on health care.

Community-based services such as home care are not included in the *Canada Health Act*. Hence, the CHST money and the $3.5 million trust fund are not going towards these types of services. This is unfortunate because the point of entry into the health care system in Canada is increasingly community-based rather than institution-based.

In every province, there has been a decentralization or regionalization of services. If Governments wish to put the health care system back on its feet, they need to look at a new foundation for the proposed system, and where they want to go with it, rather than come up with band-aid solutions tailored for the old structure.

Appendix II

The Newfoundland Supreme Court Challenge

national
union
analysis

A Legal Analysis of Individualized Funding

The Gray and Stanford Case in Newfoundland

December 1998

Introduction

The National Union of Public and General Employees sponsored a Working Session on Individualized Funding in April 1998. During the Working Session, Sheila Green, staff lawyer at the Newfoundland Association of Public Employees (NAPE), gave the participants a briefing on a Court case in Newfoundland where two individuals living with severe mental challenges were deemed employers for purposes of certification. The following is a summary of how the case was decided at the Labour Relations Board, as well as at the Newfoundland Supreme Court.

When the Gray and Stanford case reached the Supreme Court of Newfoundland, the Court was called upon to decide whether a prior decision by the Labour Relations Board of Newfoundland was patently unreasonable in finding mentally challenged persons to be "employers" under the *Labour Relations Act*; whether caregivers could be Government employees if funded and directed to a large extent by the Department of Social Services but not hired through the Public Service Commission or approved by the Treasury Board.

What is Individualized Funding?

By way of background, individualized funding refers to a transfer of money from governments directly to individuals with special needs or their support group, for the purchase of personal programs, services and support. The direct dollar model is individualized funding in its purest form. The money goes directly to individuals or their support group, who then purchase the personal programs, services and support. Support groups can include but are not limited to, families, advocacy groups, and microboards[9].

In an agency model scenario, the agency gets the money from the Government and allocates it to the individuals through client-centered planning where a support group decides on the amount of money

[9] A microboard is a non-profit society. It is a group of people who have been chosen by, or on behalf of, the individual, whose primary focus is to provide support for the individual. Microboards negotiate with the government for money needed for services. Microboards reflect the needs and wishes of the individual. They represent one way of implementing individualized funding. Report on the Individualized Funding Conference, June 8-9, 1997, Vancouver, British Columbia.

needed, and the use of that money.

The brokerage model involves a middle person acting between the Government, which funds the personal programs, services and support, and the individual who receives these personal programs, services and support. The broker doing the purchasing for the clients keeps a fee off the total funding amount.

The purchase of personal programs, services or support through either one of the previous mentioned models, can be done by going to a publicly funded agency, a private for-profit agency or a community-based agency.

The concept of individualized funding is at different stages of implementation across the country, for the simple reason that some governments have been moving faster than others in introducing this funding mechanism[10].

De-institutionalization

In the Mid-1980s, the Government of Newfoundland and Labrador announced its intention to integrate people living with a disability into the community by moving them out of large institutions. The Department of Social Services (DOSS)[11] closed several large institutions and moved the former residents into Group Homes and Co-op Apartments. NAPE represented employees of these large institutions. The Government was the direct employer, the workers were unionized in large bargaining units and well paid under the province-wide Hospital Support Staff Collective Agreement.

Community management boards were established to administer DOSS funding and each board was incorporated to manage and operate a group home. Counsellors and support workers were considered employees of a Group Home Board and were designated public service employees under the Public Sector Collective Bargaining Act (PSCBA). NAPE

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[10] For further information on Individualized Funding refer to Individualized Funding. Destruction of our Social Services Support System, NUPGE, February 1997 and The Hard Truth About Individualized Funding, NUPGE, May 1998.
[11] The Department's name was changed to the Department of Human Resources and Employment on April 1, 1997.
[12] In view of legal proceedings.
[13] Legal guardianship.

continued to represent these employees who were covered by the General Service Collective Agreement and received many benefits including workers' compensation benefits.

In the early 1990s, Government started to set up Individual Living Arrangements (ILAs), which are usually rented apartments occupied by one, sometimes two persons and supported by a live-in support staff. ILAs are 100% funded and financially controlled by Government. Each ILA operates under the "sponsorship" of an Operating Committee consisting of family members, advocates, social workers and behaviour management specialists. The Operating Committee functions within policies and procedures as set by DOSS. The DOSS Policy and Procedures Manual contains regulations covering staff support, qualifications and recruitment of staff, staff salaries, job descriptions, hours of work, requirements for confidentiality, and other working conditions.

The ILA setting - The Factual Background

Prior to Ms. Gray and Ms. Stanford being moved into an ILA setting, a social worker placed an ad in the newspapers for a live-in supervisor and support staff to be employed at the ILA. The ad did not mention DOSS and directed the applications to a post office box. The social worker, along with the behaviour management specialist and Ms. Gray's sister, which are all members of the Operating Committee, interviewed and selected several job applicants for the position of live-in supervisor. The interviews were conducted at the Department of Social Services. The supervisor then participated in the interviews for support staff. The supervisor, who was not hired through the Public Service Commission process, receives a salary that was set in accordance with DOSS regulations and has disciplinary powers over the support staff. The social worker delivered the training and told the newly hired employees that they, for "administrative purposes" were employees of Ms. Gray.

The social worker also initiated the rental of the house in which Ms. Gray and Ms. Stanford moved in. The lease was signed by the live-in supervisor and DOSS pays the rent directly to the landlord. DOSS also purchased the furniture and the insurance for the

house. The employees' pay cheques were generated by Central Accounting Services (CAS) which is a book-keeping/payroll company with Ms. Stanford as the employer. Ms. Stanford was given a Revenue Canada number to register her as an "employer". The employees' hours were submitted to the accounting company, which in turn invoiced DOSS for the gross amount of the payroll and cheques issued to employees.

The Case Before the Labour Relations Board

The Issues

People living with a disability or developmentally challenged persons can now receive money from the Government to purchase personal goods and services. The funds are either allocated directly to the persons or to somebody acting on their behalf. From a legal perspective, the identification of the "employer" has become the key issue for organizing and bargaining. For the purposes of certification, is the employer the Government, the third party or the person receiving Government funding?

Who is the employer?

According to NAPE it had become quite obvious that the use of a payroll company was evidence of the Government's deliberated and orchestrated attempt to obscure its true identity as the employer.

NAPE's Arguments

NAPE argued that the true employer is the party who:

- determines the structure of the organization or the vehicle for the provision of services;
- establishes the mode of service delivery and puts the vehicle in motion;
- directs the provision of services and controls the operation of the service mode.

The answer to the above is clearly DOSS, not the individuals who have no capacity to contract and who are recipients of the service, regardless of whether they have employer numbers issued in their name by Revenue Canada. It is not the Operating Committee, whose existence emanates from the DOSS policy and whose primary and full time participants are the social workers, employees of DOSS, and members of NAPE.

Government's Arguments

The Government relied on a series of cases involving Government entities or agencies, where funding and employment related functions are provided by the Government who is not considered the employer.

Kelowna Centennial Museum Association and CUPE

Waterloo County Roman Catholic Separate School Board

Province of Ontario Board of Internal Economy

Government also relied on high level cases which deny jurisdiction to a Labour Relations Board in finding a *de facto* public servant. In Canada and PSAC 1989 FCA and 1991 SCC, it was found that the Board lacked jurisdiction to find that the concerned employees were employed by Government in the absence of formal appointments to the Public Service in accordance with the *Public Service Commission Act*.

Government justified its actions by claiming that it was committed to reach the goal of de-institutionalization and integration of people living with a disability into the community, by "getting out of the business of providing direct care to such individuals in institutional settings".

Test adopted by the Labour Relations Board

The Labour Relations Board asked who has fundamental control over the employees by adopting the following test from York Condominium Corp. and LIUNA Local 183 (1977), OLRB.

- who's exercising direction and control?
- who's bearing the burden of remuneration?
- who's imposing discipline?
- who's hiring the employees?
- who has authority to dismiss the employees?
- which party is perceived to be the employer by the employees?
- is there an intention to create the relationship of employer and employee?
- who benefits from the work performed?

1. Ms. Gray and Ms. Stanford do not communicate verbally, but do make known their desires and

The Board's Findings

intentions and their likes or dislikes of food, activities or persons, to the employees by various means of non-verbal communication. They are unable to independently pay employees, hire, discipline or dismiss, without assistance from others.

2. Ms. Gray's mother and Ms. Stanford's sister play a supportive role in assisting with activities in the community, such as banking and shopping. But these roles, while important, are secondary to the role played by the social worker and behaviour management specialist.

3. The social worker plays a dual role in that she facilitates the integration of Ms. Gray and Ms. Stanford into the community, while at the same time ensuring that DOSS's regulations and policies are enforced, and that there is financial accountability for funds spent on behalf of Ms. Gray and Ms. Stanford.

4. On one occasion, when an employee was dismissed for theft, the live-in supervisor recommended dismissal to the social worker and after the decision was made it was communicated to Ms. Gray's mother.

5. The supervisor controls day-to-day activities, supervises staff, maintains records and reports to the Operating Committee.

6. The support workers do not perceive their employer to be Ms. Stanford because they do not believe she has the mental capacity to be their employer. They believe DOSS is their employer, but would likely agree that the purpose of the Operating Committee is to act on behalf of Ms. Gray and Ms. Stanford.

On the basis of these factors, the Board concluded that CAS, the social worker, the live-in supervisor, the Operating Committee and others assisting, were doing so on behalf of Ms. Gray and Ms. Stanford. The Board found that fundamental control over the employees in the bargaining unit is exercised by Ms. Gray and Ms. Stanford "or persons acting on their behalf", and that they are employer of the employees.

Because the Board found that DOSS does not exercise

fundamental control over the employees, the Board decided it was unnecessary to address whether or not the employees could be employees of DOSS in the absence of an appointment by the Public Service Commission complying with statutory requirements.

Concerning the legal capacity of Ms. Gray and Ms. Stanford to be an employer, the Board noted it had not received any medical evidence with respect to the mental capacity of Ms. Gray and Ms. Stanford. The Board accepted that Ms. Gray and Ms. Stanford could not fulfil their responsibilities under the *Labour Relations Act* as an employer without assistance. The Board pointed out that this is no different from the obtaining assistance to do their banking or other daily activities.

On the appropriateness of the bargaining unit it was submitted on behalf of Ms. Gray and Ms. Stanford that, since they have no choice but to arrange for persons to assist them to live in their own homes, it would never be appropriate to certify a bargaining unit there. The Board noted that the *Labour Relations Act* does not specifically exclude the application of the Act to domestics employed in private homes, an exclusion that exists in some other jurisdictions. The Board concluded the issue under the Act *is* not whether the work is "suitable" but whether employees are properly included in the unit or not. The Board decided that to conclude a bargaining unit was inappropriate solely because it was in a private home would be to exceed its jurisdiction by in effect amending the Act.

Supreme Court of Canada Rules

Prior to the decision in Gray and Stanford, the Supreme Court of Canada ruled in City of Pointe-Claire (Québec). A temporary services agency placed an employee with the City. The agency recruits, hires, trains, has a Revenue Canada number, pays the employee and then invoices the City at the rate determined between the agency and the City. The employee is supervised by the City who sets the hours of work, as well as non-monetary and non-disciplinary terms and conditions of employment. Any problems with the employee is dealt with by the agency.

The Labour Commissioner, the Labour Court, the

The Impact of City of Pointe-Claire

Superior Court and the Court of Appeals found the City to be the employer. The impact of this decision on individualized funding is disastrous because Labour Boards can now with confidence certify unions to an employer who does not determine wages which will lead to meaningless bargaining, which is exactly what happened at the Newfoundland Labour Relations Board regarding the Gray and Stanford case.

The Gray and Stanford Case Before the Newfoundland Supreme Court

Submissions of the Parties

Ms. Gray and Ms. Stanford, by their guardians ad litem[12], applied for judicial review, submitting the Board's decision is patently unreasonable, as they do not have the legal capacity to contract. They submitted also that the Board unreasonably exercised its discretion in determining the appropriate bargaining unit, since unions should not be certified for caregivers in private homes of people with severe mental disabilities.

NAPE also sought judicial review of the decision, submitting it is absurd and patently unreasonable, in that, since Ms. Gray and Ms. Stanford are not capable of negotiating a collective agreement, the Board should have found the employer was DOSS, as it is that Department which allegedly exercises the greatest control over the caregivers' work.

DOSS submitted the Board had no jurisdiction to determine whether a position had been created within government, as that is the function of the Treasury Board. Also, to have government employees, the Public Service Commission must fill the positions, says DOSS.

The Newfoundland Supreme Court's Findings

On Fundamental Control

The Supreme Court Judge did not accept NAPE's submission that the evidence showed DOSS exercised overriding control over the employees. According to the Judge, the Board carefully considered all relevant evidence and noted the manner in which the

mechanisms of an operating committee sought to remove direct control from DOSS, and provide as much autonomy and independence as is reasonably possible to disabled individuals such as Ms. Gray and Ms. Stanford.

The Judge did not think that the ILA arrangement was a sham. In his own words, "the participation of family members on the committee, the payment of gross amounts by DOSS to Central Accounting Services, disbursement of payroll cheques by Central Accounting Services, and the other evidence considered by the Board was properly evaluated in the context of the fundamental control test in York Condominiums. I do not find the Board's decision patently unreasonable in this respect."

The Judge did not find anything unreasonable in the Board's decision finding that the social worker played a dual role in facilitating the integration of Ms. Gray and Ms. Stanford into the community and thereby working on their behalf, while at the same time, ensuring compliance with DOSS policies and regulations.

Once the Board concluded DOSS did not exercise fundamental control over the employees, the Board had no obligation to consider the then hypothetical question of whether the employees could be employees of DOSS in the absence of compliance with legislation relating to hiring through the Public Service Commission. The Judge added that this may change if the Newfoundland Supreme Court concludes, following Charter arguments, that Ms. Gray and Ms. Stanford could not be employers.

On the Appropriateness of the Bargaining Unit

While the parens patriae[13] jurisdiction of the Newfoundland Supreme Court may, in certain cases, permit intervention to prevent certification of bargaining units in homes of persons living with disabilities, the Judge believed, in the circumstances of the case, the question of whether certification would be too great an intrusion into the private lives of Ms. Gray and Ms. Stanford should be determined in the context of the protection afforded by the Charter, an issue to be considered later.

The Judge also believed that the Board was correct that “appropriateness” in the *Labour Relations Act* refers to the scope of the bargaining unit, rather than to whether the workplace is “suitable” for collective bargaining.

On the Legal Capacity of Ms. Gray and Ms. Stanford

The Board decided to impose legal obligations upon Ms. Gray and Ms. Stanford. The Board decided that they could engage the assistance of *de facto* guardians to help them fulfil these obligations, or apply to the Newfoundland Supreme Court to have a legal guardian appointed. The Newfoundland Supreme Court Judge believed the Board was correct in so deciding. He added “indeed, if the Board had decided it could not grant certification because of the legal incapacity of Ms. Gray and Ms. Stanford, it would have been deciding without proper evidence. The Board decision noted: “No evidence of a medical nature was presented”, it is the practice of this Court normally to require medical evidence before making a declaration of mental disability or mental infirmity, under the *Mentally Disabled Persons' Estates Act*. Subject to what may be presented on the Charter argument, I see no reason to deviate from that practice in the present case.”

The Implications of the Gray and Stanford Case

The implications of this case are far-reaching. The fact that Ms. Gray and Ms. Stanford were deemed employers by the Newfoundland Supreme Court impacts greatly on the bargaining process involving NAPE members employed at the Gray and Stanford home. Ms. Gray and Ms. Stanford cannot negotiate with the Union, unless they engage the assistance of legal guardians. In other words, it is the Operating Committee, made up of family members and government workers, who will be mandated to bargain on behalf of Ms. Gray and Ms. Stanford. This case thus sets a precedent by allowing negotiations with a party other than the true employer, which denigrates the basic principles of collective bargaining.

With the increase of individualized funding arrangements for people living with severe mental disabilities, the chances for a bargaining unit to ever be able to negotiate a contract with the true employer are all but impossible to achieve. Government is taking advantage of this loop-hole at the detriment of

unionized home support workers, and more generally at the expense of one of the tenets of trade unionism, namely collective bargaining.

Appendix III

Ontario's Self-Managed Care Program

Funded by:
Ontario Ministry of Health

Administered by:
Centre for Independent Living in Toronto (CILT)

In Partnership with:
Ontario Network of Independent Living Centres (ONILC)

Note that this has been excerpted from a booklet by Centre for Independent Living in Toronto (CILT) to provide a general outline of the Ontario program, Self-Managed Attendant Services - Direct Funding.

1. What is the Program?

Many adults with physical disabilities want to live independently and take charge of all aspects of their lives. They wish to take full responsibility for the attendant services they need by employing their own attendant workers and managing their own funding.

The option of self-management is supported by the Independent Living movement. This international movement promotes an independence that allows individuals to take responsibility for their lives, make choices, take risks, and participate fully in community life.

Self-Managed Attendant Services — Direct Funding is an innovative program that enables eligible adults with physical disabilities across Ontario to receive funds individually to recruit, manage and pay for their own attendants, i.e. become an employer with all the associated responsibilities of being an employer. The program is funded by the Ontario Ministry of Health and is administered by the Centre for Independent Living in Toronto (CILT) in partnership with the Ontario Network of Independent Living Resource Centres (ONILC).

This program was developed by consumers and government as a pilot project in 1994 to test direct funding as a self-managed model for adults with physical disabilities who need attendant services. The pilot was independently evaluated over a two-year period. This new, consumer-driven service model was so successful that in July, 1998, the Government of Ontario made it a permanent program and announced that the program would be expanded to reach a total of 700 participants.

New participants will be selected each year to receive funds in lieu of agency-delivered attendant services for which they would otherwise be eligible.

This program differs from, and is intended as an *option to*, agency-delivered attendant service programs. In Ontario's *delivered* service models (Supportive Housing (SSLUs), and Attendant Outreach Services), an agency is the employer and provides attendant services to the consumer, sending attendants to the consumer's apartment or house. In the self-managed model, however, it is the consumer who is the employer and takes full responsibility for securing and managing his/her own attendants. There is no other manager... there is no one else in charge.

2. What are Attendant Services?

Attendant services are consumer-directed, physical assistance with routine activities of living which the individual would do for him/herself if it were not for physical limitations. The consumer takes responsibility for the personal decisions and training involved in his/her own assistance. The assistance is provided by another person and involves a positive human interaction.

Note: Attendant services *do not* include services such as physiotherapy, rehabilitation, life-skills teaching, active nursing, socializing, etc. Some of these professional services are provided through Community Care Access Centres (CCACs).

3. What is Self-Management?

Self-managed attendant service is an option in which the consumer assumes full responsibility for recruiting, hiring, supervising and/or dismissing, if necessary, his/her attendant workers. The consumer receives funds and undertakes all responsibilities associated with being an employer. These responsibilities must be undertaken by the consumer him/herself (i.e., the person who is receiving the services); they may not be assumed by any other person on behalf of the consumer. Management by a family member, or via power of attorney, is not permitted.

4. How Much Attendant Service will be Funded?

The amount and kind of attendant service funded will be comparable to Homemaking/Personal Support/Attendant/Respite Services provided by Ministry of Health-funded agencies.

The amount of service required will be determined individually with each applicant. The amount of service funded for any one individual will not exceed 180 hours per month (or 186 hours for months of 31 days) of attendant services (an average of 6 hours per day). Please note the paragraph in this section on flexibility of coverage.

Ministry of Health guidelines regarding monthly service maximums are currently under review, especially with respect to service levels for persons who require assistance in the maintenance of an airway or who use a ventilator at all times. When new policy is known, applicants and participants will be advised. Except for cases defined in Ministry guidelines, additional services or funding will not be granted.

It should be noted that this program enables great individual flexibility. While attendant hours are paid for at a regular hourly wage rate for direct service, flat rates of pay may also be used for indirect service. This enables a participant to arrange overnight coverage by an attendant or the attendant's carrying of a pager for unscheduled needs. Room and board may also be used as a means of extending coverage for more hours in the day.

5. What are Some Aspects of Funding?

· under most circumstances, program funding will be the participant's only source of government-funded attendant services;
· those living in Supportive Housing, e.g. Support Service Living Units (SSLUs), who are selected to participate in the program must move out within three months in order to receive ongoing direct funds. This gives other people an opportunity to move into, and receive service from, the participant's former SSLU;
· participants may not hire immediate family members to provide services. These include parents, children, siblings, spouses or the equivalent;
· participants are responsible for training their own attendants. However, if special training is required, participants may use training support available free of charge in the community.
· Participants may call their local Independent Living Resource Centre (ILRC) for information about resources;
· services are funded for use within Ontario but are not tied to any place. This enables participants flexibility to meet their personal needs in various locations, such as at home, in the community and while travelling in the province;
· funds are portable if a participant wishes to move to another community in Ontario;
· funds are provided monthly to participants, while participants report quarterly on their expenditures. All expenditures must be in accordance with the contractual Agreement
between CILT and the participant. Reports of expenditures are closely monitored and the Agreement is strictly enforced. This program is accountable for public monies;
· participants are encouraged to hire qualified assistance for bookkeeping, payroll preparation and financial reporting responsibilities. Funding for this support is included as part of a participant's budget.

6. Who is Eligible?

To be eligible for the program a person must be a resident of Ontario, hold a valid Ontario Health Card and must meet ALL the following criteria:

(These eligibility criteria reflect the *Regulation Made under the Ministry of Community and Social Services Act: Grants for Persons with Disabilities*, which stand as the final authority.)

"Attendant services" means assistance with activities of living referred to in 1) to 8) under (c) below.

An "attendant worker" means a worker who provides any of the attendant services referred to in 1) to 8) under (c) below.
A person is an eligible person for the program if he/she:

(a) is at least 16 years old;
(b) requires attendant services as a result of a permanent physical disability;

(c) requires the attendant services referred to in at least two of 1) to 8) and at least one of them is from 1) to 4) of the following:

1) turning in bed, lifting, positioning or transferring;
2) washing, bathing, showering, shaving or personal grooming;
3) dressing or undressing;
4) catheterization, emptying and changing a leg bag, using the toilet, urination or bowel routines;
5) breathing, or caring for a tracheostomy or respiratory equipment;
6) eating;
7) meal preparation, dish washing, laundry or other housekeeping tasks; and
8) essential communication;

(d) has attendant services requirements that have been stable over a period of at least one year;
(e) has service requirements that can be met while residing in his/her home;

(f) understands the nature of his/her disability and its impact on his/her ability to carry out the essential activities of daily living;

(g) is aware of the type of attendant services he/she requires and when, how much and how assistance should be provided;

(h) is capable of scheduling his/her attendant services as well as making alternative arrangements to ensure that his/her requirements are met in case an attendant worker is not available at a scheduled time;

(i) is capable of training or arranging the training of, supervising, instructing and communicating with attendant workers;

(j) is capable of recruiting, hiring and dismissing attendant workers;

(k) is capable of understanding and carrying out the responsibilities as an employer of one or more attendant workers;

(l) is capable of managing and accounting for the expenditure of the funds that would be granted to him/her;

(m) is capable of evaluating the attendant services he/she would receive and of communicating his/her evaluation; and

(n) is prepared to undertake the functions referred to in clauses (h) to (m) and to assume the responsibility and risks inherent in undertaking those functions.

As defined in the Regulation, it is a condition of the Ministry of Health grant to CILT that CILT "shall not transfer the grant to anyone other than an eligible person."

7. Who will be Selected?

This program is open to eligible persons in Ontario. Participants will be selected from across the province, with a wide range of service needs, ages and backgrounds. To be selected, a consumer must meet all of the eligibility criteria. This program differs from agency-delivered attendant service programs by requiring the participant to self-manage all aspects of his/her services; therefore, special attention must be paid to the self-management eligibility criteria listed above as j) to m).

Self-Managing as an Employer:

Participants will be selected according to their demonstrated ability to understand and undertake employer-related responsibilities, and their willingness to assume full responsibility for self-managing their attendant services.

Note: As the participant is undertaking the role and responsibility of an employer, and the attendant worker enters into an employee role, this relationship is subject to the laws of Ontario and Canada. The participant/employer must follow all legal requirements and must manage and maintain good relationships with his/her employees.

8. What is the Application and Selection Process?

If you (the consumer) are interested in applying to this program, you should contact your local Independent Living Resource Centre (ILRC) (a list is attached), if you have not already done so, and ask for a Direct Funding Information Package (which contains this *General Information Booklet* and other material).

Note: A Letter of Intent is no longer required by the Program.

After you have reviewed the information (in particular the eligibilty criteria), you should then contact your ILRC and ask for *Application Materials*. They describe how to do a self-assessment of your needs, how to plan your attendant services, and how to prepare a direct-funding budget, all of which must be part of your application. After you have sent back a completed application, you will be invited to an interview/negotiation with a Selection Panel in your region, at the next available time.

The selection panel interview is very important. You, the applicant, present your application, are asked detailed questions concerning your application, negotiate your proposed service plan and budget, and discuss your knowledge and experience that demonstrate your capability of self-managing attendant services. A Selection Panel usually includes a consumer of attendant services from your region, a representative from an Independent Living Resource Centre in the region, and a representative from the program administration (CILT). A Selection Panel recommends participants for the program and determines individual funding levels.

If you are selected for Direct Funding, you are sent an Agreement to sign. You also receive resource books which show you, step by step, how to get started and how to manage your own attendant services successfully.

Note: Because the Application/Selection process consists of a number of steps, please be prepared for a short wait before hearing back regarding the next step. Selection Panel interviews will be held at different times throughout the province. All applicants will be advised of the dates of the next available interviews to be held in your region.

9. What are the Applicant's Responsibilities?

Consistent with the self-management requirements of this program, you are responsible for fulfilling all the requirements in the application and selection process strictly on your own initiative, and in your own words. You may receive physical assistance in writing if necessitated by your disability. However, submissions made by professionals, family members or others on behalf of an applicant are not acceptable. Your responsibilities include contacting your local ILRC, filling out the Application Materials and attending a Selection Panel interview, which are detailed as follows:

Application Materials:

In filling out the Application Materials, you, the applicant, must:

· state that you have reviewed the eligibility criteria;
· verify that you are a resident of Ontario and provide a valid Ontario Health Card number;
· indicate that you are an adult with a permanent physical disability;
· provide a description of your current attendant services useage;

· self-evaluate your attendant service needs under Direct Funding;
· develop a proposed service plan and a budget;
· provide evidence of management skills: describe your experience, education or understanding regarding the responsibilities of becoming an employer and self-managing attendant workers;
· declare your preparedness to accept the responsibilities and risks of self-managing your own services;
· provide all requested documentation; and
· mail back the completed application.

Selection Panel Interview:

At a Selection Panel interview, the applicant must:

· come, in person, to the scheduled interview location;
· be prepared to spend at least one hour at the interview;
· bring a copy of your application;
· present and negotiate the application by yourself alone;
· be prepared to discuss your disability and its impact on service need;
· be familiar with the details of your application and be prepared to discuss them;
· present a clear picture of your current services and of your proposed services plan;
· be prepared to discuss the details of your proposed budget;
· be prepared to discuss self-management functions, including those listed below.

Self-Management Functions:

To become a participant in the program, an applicant must learn and be capable of properly doing a number of employer-related functions, including the following:

· recruiting, hiring, training, managing and possibly dismissing attendant workers;
· managing money, time and personnel;
· applying for a business number from Revenue Canada and complying with Revenue Canada requirements;
· making payroll deductions (CPP, EI (formerly UI), Income Tax, WSIB (formerly WCB);
· keeping records for employer/employee tax purposes;
· complying with Ontario labour standards and human rights; and
· following occupational health and safety standards, and workplace safety and insurance requirements.

Note: Funding is available for payroll and bookkeeping assistance.

10. Are Support and Information Available?

You may request assistance in applying for the program from one of the Independent Living Resource Centres (ILRCs). A list of ILRCs is included with this booklet.

Participants can rely on their ILRC for ongoing support and information. The ILRCs may also assist with orientation sessions, peer networking and advice, as well as general disability information and referral. In addition, they provide information to attendants and others.

Some further information about the program is included in the Application Materials. Complete resource materials, including a start-up package and two comprehensive handbooks that address issues related to employing attendants and managing finances, will be sent to participants on the program. These "how-to" resource and training materials give explanations on, for example, recruiting attendants, employer/employee relations, employment and tax laws, payroll issues and accounting.

11. How are Participants Accountable?

Agreement:

> Participants must sign a comprehensive Agreement, which is a legally binding contract regarding the terms and conditions of funding. It spells out a participant's requirements, including:
> · keeping the funding in a separate, special bank account, and making all transactions by cheque;
> · maintaining and keeping all records, including bank statements of deposits and payments, time sheets and invoices of the attendant services provided, and employment records;
> · keeping the employment and financial records required by Revenue Canada;
> · preparing and submitting to CILT a Self-Manager's Report on expenditures every three months, including bank statements and bank reconciliation; and
> · keeping all records available for audit on one week's notice.

Renegotiating the Agreement:

> If a participant's needs change, he/she and the program administration will review the situation. The administration may consult the selection panel and may amend the budget portion of the Agreement, if appropriate.

Ending the Agreement:

> Use of funds is closely monitored by CILT. Where there is misuse of funds or

other breach of the Agreement, the participant will be subject to legal action and the requirement to withdraw from the program.

Voluntary withdrawal from the program may be arranged by a participant at any time. The participant generally will be responsible for making suitable new arrangements with a service delivery agency.

Liability:

Under the self-management direct funding model, liability related to attendant services rests with the participant as employer. He/she will require suitable insurance coverage.

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