

The Self-Manager

CILT • Centre for Independent Living in Toronto

Winter 2012

Direct Funding Expansion

IN SEPTEMBER, 2011, WE received great news! The Government of Ontario is investing \$1.7 million new dollars annually in the Direct Funding program. This means that up to 50 additional people, like Angela, (please see Angela's story on this page), can become self-managers of their own attendant services.

We are very grateful to the Ontario Government and the Toronto Central LHIN (TCLHIN). This investment will bring life-changing benefits to many of the new self-managers. This investment will also help the greater health care system.



PHOTO: AVAVA

Angela's Story

ANGELA, 51, IS A WONDERFUL person accustomed to living in the country, north of Kingston, with her husband Doug.

A year ago Angela was diagnosed with Multiple Sclerosis (MS) when she suddenly could no longer walk. Her MS came on like a stroke. She went to the hospital, then completed rehabilitation and was subsequently moved to a long-term care (LTC) facility.

Life for both Angela and Doug had become extremely difficult. Angela only went home once every three weeks

from the LTC facility because there weren't appropriate community options in her rural area. The family was out of cash and had to turn to their RRSP savings to make the co-payments charged by the LTC facility. Sometime last year after Angela's MS diagnosis, Doug had a heart attack. After evening visits with Angela at the LTC, he would find it heart breaking looking back at his wife sitting in the window waving goodbye and neither of them knowing whether this was forever their new normal.

Last summer, at his wit's end, Doug happened upon the local Independent

Please see **ANGELA**, p.8

Integration of the Direct Funding program with the LHIN System

Important *This update describes a transition process underway and is for information purposes only. You do not need to take any action. This is essentially an administrative change at the highest level that will not affect the day-to-day workings of the program or be felt by Direct Funding (DF) participants or applicants.*

Local Health Integration Networks (LHINs) and what they do

Ontario's system of LHINs was created in April 2006 by the Ministry of Health. LHINs are not-for-profit corporations that work with local health providers and community members to determine the health service priorities of their regions. LHINs are responsible for planning, funding and managing health services in their communities. They took on full authority on April 1, 2007. LHINs don't provide services directly; instead they are responsible for integrating services in each of their specific geographic areas. •

Provincial Programs in 2007

Four years ago authority for many health programs and attendant services (Outreach and Supportive Housing) was shifted from the Ministry of Health to the 14 LHINs. However, provincial programs, including the Direct Funding program, remained under the direct authority of the Ministry. This allowed provincial programs to stay intact and not be split up among 14 LHIN areas. Single organizations, like the Centre for Independent Living in Toronto (CILT), could continue administering a provincial

program across all regions of Ontario. DF could keep its unique features, such as portability that enables participants to move about anywhere in Ontario, or relocate from one LHIN area to another without any effect on their DF status. In some other provinces with regional systems, moving across a boundary line involves dealing with a new health authority that may apply standards and funding levels differently.

Lead LHIN Model

Earlier this year CILT received word that the Ministry has been working on a way to devolve provincial programs to the LHIN system without splitting up province-wide programs. They have created a "lead LHIN" mechanism in which one LHIN can be given responsibility for a program on behalf of all the other LHINs. The remaining 13 LHINs sign an agreement with the "lead LHIN" agreeing that a program of one LHIN can provide services to people in all LHIN areas.

The Ministry signs an agreement with the lead LHIN setting out responsibilities. The Ministry's ongoing involvement includes providing the funds to the lead LHIN for the provincial program, setting standards and provincial policies and reviewing the reports that the lead LHIN must regularly submit to the Ministry.

Transfer of Some Provincial Programs in 2011

With this new mechanism, three provincial programs were devolved from the Ministry. One of them is the Direct Funding program. CILT's contract for DF has been transferred from the Ministry to the Toronto Central LHIN (TCLHIN),

as the lead LHIN. This administrative shift means that CILT will receive its Ministry funds through the TCLHIN and will be accountable and report to the TCLHIN instead of directly to the Ministry.

CILT – TCLHIN Agreement

Over the past 11 months CILT has been working with TCLHIN to finalize a three-year agreement that describes the Direct Funding program, its conception, spells out its unique features and advantages and provides demographic statistics so the program will be protected in writing and continue as it is now. Included are such fundamentals as:

- that the Independent Living (IL) Movement and philosophy are recognized as the foundational and ongoing guiding principles of the DF program. The concept of DF arose from IL principles and the Movement's mandate is to allow individuals with disabilities to achieve self determination, take risks, and achieve greater quality of life through:
 - Consumer control
 - Choice
 - Individual responsibility
 - Full participation in community life

This philosophy provides an alternative to traditional medical and institutional models which view the person with a disability as a "patient" who is "sick," "dependent" and needing to be "cared for" by professional health care experts;

- that DF is operated and controlled by an organization that is run by and for people with disabilities, is community-based, non-profit and consumer-governed;

Please see **INTEGRATION**, p.4

Integration

Continued from p. 3

- that DF is administered province-wide by one organization (in partnership with others) undivided across all LHIN regions;
- that CILT continues to carry out sole administrative management of the program including selection of participants and management of the applicant waiting list, determining adjustments and termination of DF contracts with individual consumers;
- that CILT continues to protect the privacy and confidentiality of all personal information of program participants and applicants, both current and archived;
- that the level of program funding will not decrease and will be recognized as protected funding and;
- that other fundamental features will remain unchanged such as portability that allows participants to move from one LHIN area to another without any effect on their DF status.

Work to Date

In addition to frequent meetings between CILT and TCLHIN representatives, in July, 2011, a TCLHIN official discussed the transition at a meeting of all Ontario's Independent

Living Resource Centre Executive Directors and stressed to them the LHIN's goal of keeping DF as it is.

We have experienced a very positive working relationship both with the Ministry and with the TCLHIN in all of this. They have shown strong commitment to working in collaboration with CILT to achieve a smooth transition and continuation of DF. They recognize the great success of this program. We also have the benefit that one of the TCLHIN officials is familiar with the program from his previous 20 years of working at the Ministry and with our former Ministry program consultant.

• http://www.health.gov.on.ca/english/public/legislation/lhins/lhins_faq.html



Looking Forward

CILT SIGNED THE AGREEMENT with the TCLHIN on Dec 1, 2011. Other work will involve us in 'knowledge transfer' or education about the Direct Funding program to all the other LHINs.

We have been given assurances that the transfer will allow CILT to administer the program much as it always has in partnership with the other Independent Living Centres. As far as self-managers are concerned, we expect there will be little or no observable change.

History of Direct Funding

WHILE THE SELF-MANAGED Attendant Services – Direct Funding program is 17 years old, its underlying philosophy and principles date back more than 50 years. It was in the 1960s that a handful of student 'consumers' (people with disabilities who use, or 'consume' services related to disability needs) attending the University of California defined a non-medical, non-charity approach to disabilities.

Consumers, the students argued, are not sick or in need of a cure. They developed Principles of Independent Living associated with attendant services:

- 1) Consumers should be integrated as fully as possible into communities.
- 2) Those who best know the needs of consumers and how to meet those needs are consumers, themselves.
- 3) The needs of consumers can be met most effectively by comprehensive programs, which provide a variety of services.

The principles and philosophy spread throughout North America and the world, leading to the establishment of independent living resource centres (ILRCs) established with federal government funding. There are now 12 ILRCs in Ontario and a total of 28 across Canada.

Only a few decades ago, users of attendant services in Ontario were generally limited to two options: residing in supportive housing or using Attendant Outreach Services. Some consumers, wanting greater choice, control and flexibility than they were receiving from these programs, began strategizing about a consumer-driven partnership between consumers and the provincial



Audrey King

government that would allow funds for attendant services to flow directly to individuals. Such an arrangement, they felt, would more fully meet consumers' needs to exercise full responsibility, independence and self-determination regarding attendant services; to live outside designated housing or catchment areas; to have more control over who would provide the most personal of assistance on a daily basis and over the human relationships involved; and to receive the amount of service needed, as well as exercise flexibility over scheduling their services.

Amid this period of strategizing, the government commissioned a review of Ontario's attendant services in 1988. Among other recommendations, the report, "Independence and Control: Today's Dream, Tomorrow's Reality,"

indicated the need to provide a direct funding option.

In May 1990, the Attendant Care Action Coalition (ACAC), the Centre for Independent Living in Toronto (CILT) and London Cheshire Homes organized the first-ever provincial attendant services consumer conference, at Woodedden Camp near London, Ont. It brought together consumers and their attendants, researchers, Independent Living Centre members, government officials and service providers.

ACAC/CILT completed a position paper and a proposed model for direct individualized funding for attendant services. Together with the Canadian Association of Independent Living Centres, they sent a summary letter to the government.

Please see **HISTORY**, p.6

HISTORY

Continued from p. 5

During the summer of 1992, the Minister of Health met with the Coalition and indicated a commitment to test this service model, with Independent Living Centres playing a key role in managing the proposed pilot project. A steering committee consisting of government policy people, political staff from three ministries, and consumers of attendant services worked collaboratively on the government policy paper for the direct funding pilot.

In 1993, after years of negotiating by consumers and their advocates—

through three provincial election periods and as many different parties in power—the Ministry of Community and Social Services Act (Bill 101) was amended to enable direct funding.

The following year, at a consumer conference on attendant services held at Woodedden Camp near London, Ont., the Ontario Minister of Health announced that funding had been approved for a pilot direct funding project to be run by the Centre for Independent Living in Toronto (CILT) and the Ontario Network of

Independent Living Centres.

The provincial government allocated \$4.4 million for the two-year pilot project starting in 1994. CILT, an organization run by and for people with disabilities, was chosen as the administrator of the pilot due to its experience with large-budget projects and helping consumers find suitable attendant services. By 1997, 102 consumers were participating in the pilot; all participants took a leap of faith by giving up their rights to use other types of publicly-funded attendant

Please see **HISTORY** on page 8

DIRECT FUNDING TIMELINE

SSLU pilot projects established

Funded by Ministry of Community and Social Services, Support Service Living Unit pilot projects are established to provide 24-hour, consumer-directed attendant services in designated apartments and clustered settings.

1975

Legislation amended

After years of negotiating by consumers and their advocates, the Ministry of Community and Social Services Act (Bill 101) is amended to enable direct funding

1993

Pilot becomes program

Ontario government increases Direct Funding budget to \$18.7 million, allowing the program to fund approximately 700 Ontario self-managers

1998

Early 1990s

Strategizing

Users of attendant services begin strategizing about a consumer-driven partnership between Ontario consumers and the provincial government

1994–95

Government funds pilot program

Ontario Minister of Health announces funding approval for a Direct Funding pilot program, to be run by the Centre for Independent Living in Toronto (CILT) and the Ontario Network of Independent Living Centres. Government allocates \$4.4 million to enable pilot, later providing an additional \$750,000 to CILT, allowing 102 consumers to participate.

2011

Program transfer to LHINs

Provincial Ministry of Health and Long Term Care announces intention to transfer administration of the Direct Funding program to the Toronto Central Local Health Integration Network (TCLHIN). CILT worked successfully with TCLHIN to finalize a three-year agreement to ensure the integrity of the program is protected in writing and can continue as it is now.

Staffing update

TO MEET THE UPDATED NEEDS of the Direct Funding program some roles and titles have shifted: **Ian Parker** is now Senior Advisor and **Leisa DeBono** is Acting Program Manager. **Susan DeLaurier** continues to serve as Accounting Clerk (Auditing), however Julia Fice, former administrative facilitator, is no longer with the department. **Victoria Pica**, Direct Funding Support, has been on medical leave since September, 2010. We are pleased to introduce the following four people who joined the Direct Funding staff team in Toronto in the last year. Please join us in welcoming them.



LEANNE LARMONDIN

Acting Administrative Coordinator

Many of you have spoken with Leanne since she began working with Direct Funding in October 2010. Leanne is an award-winning writer and editor with 20 years of journalism and communications experience in the not-for-profit sector. She has been published by *USA Today*, the *Irish Times*, Religion News Service and Ecumenical News International.



MELISA (MEL) DELL

Direct Funding Accountant

Mel brings to Direct Funding a background in human resources and accounting, with specific experience in payroll and employment standards. She is currently working towards her Certified General Accountant (CGA) designation. Mel has also been involved in the deaf-blind community for 10 years, both in administrative roles, and currently as an intervenor. More excitingly, Mel is recently engaged, and is working hard planning her February 2012 wedding.



KATHERINE JANICKI

Direct Funding Clerk

Since June, Katherine has been providing administrative support to the Direct Funding team and acting as a resource for applicants and is excited to continue learning and become more involved with every aspect of the program. Katherine brings to DF 10 years of administrative experience in a wide range of industries, including human resources, venture capital, and even fitness! A born and raised Toronto girl, Katherine attended the University of Toronto and can be seen and heard around the city as an active political organizer and a musical theatre performer.



ABDULLAH DURANAI

Direct Funding Support Coordinator

Abdullah brings to DF an extensive background in customer service, business management and human resources from working as a general manager at McDonald's Restaurants. He also has experience in the not-for-profit sector, working with new immigrants and refugees in settlement and sponsorship matters. He is eager to assist self managers, drawing from his education and experience in accounting, bookkeeping and payroll administration.

Angela

Continued from p. 1

Living Resource Centre near his workplace in Kingston. He spoke with Neil, a representative of the Self-Managed Attendant Services Direct Funding program. Doug had certainly come to the right place to talk about his and Angela's desperate situation. On hearing how Direct Funding works, Doug saw that it could be their lifesaver, giving them an opportunity to get their lives back.

Recently Angela left the LTC home and moved back to her own home to be reunited with her family – a very exciting time for them all. Neil and the Centre for Independent Living in Toronto (CILT) provided Angela with lots of support and information about how to arrange the transition to managing her own services. After interviewing job applicants, hiring and training her own attendant workers Angela is now employing her own attendants is happier, healthier and once again a full, participating member of society.

Government investment in the Direct Funding Program allows for real benefits on many fronts, for example:

- Angela can access attendant services in this South-East LHIN rural area where there are no other suitable options.
- She can become re-integrated back in her own community and reunited with her husband, family and friends instead of languishing alone in a far-away institution;
- As employer she will choose who comes in to assist her and when, allowing her privacy, dignity and



PHOTO: IKO

flexibility compared to conditions in a LTC facility with its many workers;

- Living in her own home again, she and her husband can stop paying twice for accommodation that is depleting their RRSP savings; and
- Supporting Angela's needs through Direct Funding has a positive impact on the broader health care system. It has freed up a LTC bed. Furthermore, DF will provide a vastly better option for Angela at significantly less expense.

Over the next months watch for further Direct Funding stories as more of the 50 new participants come onto the program.

History

Continued from p. 6

services in favour of hiring and managing their own attendant services through direct funding.

In a subsequent evaluation of the pilot self-managers reported increased self-determination in all aspects of their lives, a reduced sense of vulnerability, greater independence, a stronger sense of self-esteem, more fulfilling personal relationships and greater social participation.

In 1998 the Ontario government increased the Direct Funding budget to \$18.7 million and transformed it from a pilot to a full-fledged program with approximately 700 participants. The number of participants has remained at about 700 since 1998, with about 300 on the waiting list. A funding increase announced in late 2011 was aimed at reducing the wait list and enabling 50 more consumers to become self-managers.

In 2011, the Ministry of Health announced plans to transfer the administration of the Direct Funding (DF) program to the Toronto Central Local Health Integration Network (TCLHIN). This administrative shift means that CILT will receive its Ministry funds through the TCLHIN and will be accountable and report to the TCLHIN instead of directly to the Ministry.

CILT successfully negotiated a three-year agreement with TCLHIN that describes the Direct Funding program, its conception, spells out its unique features and provides demographic statistics so the program is protected in writing and can continue as it is now.