

Direct Funding's 15th Birthday

Robert was in an intolerable situation. Every day, he was forced to accompany his mother to her workplace. He wasn't an employee there. In fact, he had very little to do there all day. But Robert had no choice but to sit there, in his wheelchair, until his mother was ready to go home. Robert had no attendant services, and being with his mom at work was the only way he could get help for essential tasks like eating or using the washroom.

This had been going on for months. Robert's grandmother had been assisting him before that, but she had died. And Robert's mother was already helping him a great deal while simultaneously trying to hold down her job. A young man with Duchenne muscular dystrophy, Robert lives in rural Ontario. Because he requires special care when transferring due to very brittle bones, and because of other complex personal needs, Robert's assistants have to be people who know him really well. They have to be completely consistent and reliable. It was critical that Robert have personal control of his own service.

Happily, personal control is a cornerstone of Direct Funding. And this program was able to help a family out of crisis.

Fifteen years after Direct Funding was given the go-ahead by the provincial government as a pilot project, it's gratifying to observe how far we've come. In the past 15 years, we've managed to secure permanent program status and an expansion of the program. In the past 15 years, Ontarians with physical disabilities have had an unprecedented opportunity to hire, train and manage their own attendants, allowing them more choice, control and flexibility with their services. In the past 15 years, Direct Funding has made a dramatic difference in the lives of almost *one thousand* people.

Thanks to Direct Funding, men and women with physical disabilities have been able to live where they want, travel, get jobs, look after their children, look after an aging parent – all because there were flexible supports in place that allowed them this level of independence. This newsletter shares with you a few of the generous submissions we received from self-managers this fifteenth year.

Before 1994, there was no program in Ontario like Direct Funding. In fact, there was almost nothing like it in Canada. Those who used attendant services were forced to struggle with agency-delivered models that didn't always meet their needs. With those models, it might mean having to wait until an attendant could help you, because he or she was busy helping someone else. It meant little or no control over the timing of normal, everyday activities like getting up, dinner or even bedtime. It might mean living in a designated apartment building instead of a home and neighbourhood of your choosing, because that was the only place where you could receive services. It might mean being unable to attend college or go to work because you had no assistance there with the washroom or your lunch. It might mean never going on holiday because your attendants were obligated to stay behind and help others. And it might mean relying on people who didn't get along with you for your most basic personal and intimate needs.

We people with disabilities knew that there could be a better way of life. A model of self-managed attendant services could enable people with disabilities to select and hire their own attendants. Getting from dream to reality in Ontario was neither fast nor easy. In fact it took over eight years of hard work and determination, working together with consumers, government officials and other community organizations, and persevering through a change of government and the setbacks that came with that. From the initial commitment, in 1990, by Liberal Minister of Community and Social Services Charles Beer to pilot direct funding, we finally heard in 1994 the announcement we had been working towards and waiting for. At a provincial consumer conference, New Democratic Party Minister of Health Ruth Grier announced the immediate start of a 2-year pilot for 80 to 100 self-managers of attendant services. It would be administered by the Centre for Independent Living in Toronto in partnership with the Ontario Network of Independent Living Centres.

I will never forget the huge cheer that arose from the crowd. We were all so joyful to hear this great news... to finally get the green light to start. We had been through so much hard work and dead ends. Yet through it all we were supported by many fine allies from government officials and other community organizations. This experience bonded many of us into lifelong friendships. One of my government friends has said, "Direct Funding is the best thing we ever did!" An independent evaluation of the pilot project proved so successful that in 1998, Progressive Conservative Minister of Long Term Care Cam Jackson announced that Direct Funding would be a permanent program and expanded to 700 people. We had done it!

One of the successful offshoots of this program is the contribution it has made to a growing awareness of the capabilities of people with disabilities. It has meant many more people with disabilities are visible and participating in their communities and workplaces.

We have always maintained that the desire for self-management is not related to a person's level of services. Three people in the pilot project who used ventilators proved that self-management can work really well for people with complex needs. Today, no fewer than 40 self-managers use ventilators.

No program, of course, is perfect. And Direct Funding continues to experience challenges. These include, for one, the current limitations of government funding. The resources we receive are simply not sufficient to meet consumers' increased needs as they age or as their disability progresses. They don't provide consumers with adequate and competitive wage levels for recruiting and retaining employees. They do not allow for applicants to start on DF immediately after demonstrating their need; instead, they must wait many years and find precarious sources of support, like aging family members.

This underfunding has a huge impact. In a recent survey, we found the active waiting list of applicants had experienced a dramatic drop in numbers (from 473 down to 260). Unfortunately, many applicants had fallen out of contact or died while waiting to get on the program, or had been forced to move into alternate arrangements such as institutional services. Other eligible people with disabilities aren't even bothering to apply because they know they'll languish at the bottom of an impossible list. Even with the list down to 260, the wait is long. Do the math: With only 30 spots coming open per year, a new applicant must wait for over eight years, unless there is an increased investment in the program.

Despite the challenges, the fact remains that almost a thousand people in Ontario have seen their quality of life dramatically improve, thanks to Direct Funding. This is living proof of the value of a program that so many men and women worked so long and hard to achieve.

It is our hope that this program is reinforced and carries on to make the same difference to many more people with disabilities in future years.



Audrey King's Cartoon

Thankful Every Day

Ethel Dubeau

I was born with FSH Muscular Dystrophy. I was diagnosed in 1989 when I was 52 years old.

I received a form letter from Muscular Dystrophy re: Independent Living Direct Funding. I filed it (never to find it again) until 2 or 3 years later. When I did, I questioned, "Will I or won't I"? Within a week or two I received a second form letter. Was that a sign????

I finally decided it was for me.

Even though my two children and their families are great they have their lives and I need more help than they should have to provide. Over the past 6 plus years I have been able to stay in my own home quite comfortably because of that decision, the super attendants and bookkeeper's that I have and have had and still my family. Also I can spend more time writing (my passion, see below) and am in control of hiring and directing my own personal care. Also, working with numbers keeps my mind alert and me active.

My house is perfect for me in my situation (I am in a tilt wheelchair)-1500 square feet very open, wide doors, ramp and accessible deck. I have bought myself a walk in tub, and a heavy scooter for outside because I live in the Country. I have 4 attendants who help me with my bath and hair, help me keep my house clean and attractive, do laundry, help to prepare meals, (many ahead of time) and who help me get out and about among my flowers and in the fresh air.

Happy and Relieved

Julie Lemieux

I am thankful every day that I can still stay in my own home and that there are programs like this to enable that to happen.

The Direct Funding is the greatest thing that happened to me. When I got accepted into the program, I was happy and relieved knowing that I was in charge of my own care.

The program changed my lifestyle. It gives me the freedom to hire the personal support workers I want and have the same ones to work for me. It also gives me the flexibility to change the schedule when needed but I kept the same routine. It's good to know that it's the same people that know what needs to be done every day and do not need to explain my routines to new workers. The only thing I didn't like was to fire a worker, but I had to do it.

I hope this Direct Funding program stays on for many more years since I am sure it helps a lot of other people with disabilities across Ontario. Keep up with good work. Thank you.

Time Flies

Ethel Dubeau

A bright Monday morning
And I'm fully dressed
Weeks plan in my left hand
I begin with full zest.

But I blinked and week's over
I blinked and week's gone
I blinked and it's Friday
Evening news coming on.

For my sink needed plunging
Had to shovel my walk
A Chiropractor appointment
A friend needed to talk

My head is a buzzin
My pen's skipping ink
Water pressure's a dribble
A dish mountain in my sink

Two afternoon meetings
An insurance man
My vacuums out of baggies
Not one thing's on my plan

So it's wait until next Monday
Last week's plan once again
Double laundry tops my list, Lord
Lord, Please, hold the rain.



Ethel DuBeau

My World was Falling

Giuseppe Inserra

Sometime ago all my world was falling over me, I was getting less assistance time over time due to “budget”, and my days were getting darker and darker.

One day someone came into my house to see me. I believe it was an angel. We were talking for ten minutes, when she asked me if I ever heard about “C.I.L.T.”, “no” I answered and she added “Mr. Inserra, the more I look at you , the more I get convinced you would be perfect for this program”. She talked to me about this program and before leaving, she gave me the phone number. When she left, I phoned C.I.L.T., from that first call I could understand that I was entering another dimension. The person that answered the phone was very polite and gladly send me the application. When I went for my interview, it went very smooth.

Sure enough I was admitted in the program and everything changed. I was my own “boss”, now I could choose who to help me, my employee, and not depend upon the agency to send me someone that usually was a retired lady. Of course she didn’t look that strong, therefore I was scared to fall if I didn’t want her to fall after me and find her over me, and that wouldn’t have been a pleasant thing, I assure you of that. Now instead my helper is stronger and most of all I can talk to her and be understood because now she is of the same generation. She is very helpful, she treats me as a human being and she would help me no matter what because she is a simple person who needs to work and value the money she makes. But most of all I feel she “depends” on me. What a change, not too long ago I was who “depended” on the mercy of others. This is the most beautiful thing that has happened to me in a long time.

Finally to put the icing on this gorgeous cake, are the people working at C.I.L.T. What can I say about this “Angelic” people, my English is so poor that it doesn’t permit me to find the proper words to describe them. Therefore I use the words I know. They are helpful, down to earth, also they understand very well someone’s needs. They are always there when you look for help. They are full of LOVE for anyone who needs it. This is why every night before I go to bed, they are always present in my prayers.

A Ticket to Freedom

Don Barrie

I've been a Direct Funding self-manager since 2005. Being part of Direct Funding has been a godsend these past four years. It has transformed my life in ways I couldn't have imagined! Hiring and maintaining a group of attendants has contributed to me living more independently.

Prior to coming into Direct Funding, I had received services from an agency. It worked out well for a few years, but when the agency began to make changes, over which I had no control, I put in an application for Direct Funding. This was when the program intake was full, so I waited two-and-a-half years before a vacancy became available for me.

When I activated my service, I was excited because I saw it as a ticket to more freedom. However, I was nervous about finding attendants who would be reliable and understand how the Direct Funding system works. I'm glad to say that the majority of the people I've hired have worked out well.

Having the capability to control and manage my own attendant services is both empowering and a confidence-booster to me.

I am very grateful that Direct Funding exists. Here's to another 15 years!

Living Life

Anita Berglund

As someone born with a physical disability (Spinal Muscular Atrophy type 3) I can say that nothing ever took me by surprise. It was made very clear to me at about seven years of age, I was going to die by the time I was 20 years old (they misdiagnosed me at the time with Duchenne's Muscular Dystrophy). As well it was clear I would lose my muscular abilities slowly and eventually stop walking. For me, no big deal because it was a slow process.


At 13, I was lying on my back recovering from a Harrington rod surgery (my parents were told I would be dead in 6 months if I didn't have scoliosis surgery!) at Sick Children's in Toronto, when my Dad informed me that I was re-diagnosed with SMA. In my morphine induced haze, that was all I could remember. It meant nothing at the time because no one told me the prognosis was any different or so I thought!

Because I had believed I was going to die by the time I was 20, I never made any future plans. It was clear I was a very lost soul during those days. At 17, I was able to move into my first apartment that was supported by 24 hour personal care attendants. The apartment was fully wheelchair accessible and I loved it!



Anita Berglund's Artwork

I pursued one of my first loves which had always been making art. When it was clear I didn't think I was going to die I obtained actual written information about SMA type 3. Well the brochure said, "Life expectancy can be normal!". A shock to me. I shared it with my family and I have to confess even 20 years later, I still struggle with accepting that I may live to be an older person.

During these years, I was appreciative of the 24hour on site (personal care attendants) but I have to tell you the attitudes and behaviour of some of them were what caused me to consider Direct Funding. .

It took a lot of trial and error trying to figure out how to make the hours work and how to interview the right people and train them but it all easily fell into place. I always tell those I interview that I am seeking someone to be my "arms and legs" which means I will be directing you as the brain. It is important to me that I hire people who can grasp that concept and not those who want to "help" me or tell me how they do things in their home. In fact the best persons I have hired are those who I have trained from scratch, no previous PSW certificates or nursing, just someone who wants to listen to direction, isn't grossed out if they need to clean, well, you know, something up.

I know to some outsiders they would think that I am not independant because I need assistance with all things, but in my heart, I am totally independant thanks to being able to be a Self Manager.

[Attendants] ... help me to provide a clean and beautiful home for my husband and on those days my husband is too tired to run an errand, I can do it instead via one of my gals! I could go on and on...not to mention some of these great ladies become life long friends and a part of your family.

I would be lying if I said it was always a breeze, hiring and managing my own personal care attendants. There are challenges during different seasons, but like my sister once said when I was having a hard time finding the right person and whining, "Remember the old days!"

Thank you to all of those whose hard work and lobbying the Government paid off, not to mention the politicians with the right attitudes. Now we get to reap the benefits of what you all did for us. I know it isn't easy fighting for change, but just know it is very appreciated. I get to live my life like everyone else with my wonderful husband and friends and family each and every day because of what you all did. Thank you for 15 years of freedom!



Anita Berglund

Comment [IP1]: undelete

Comment [IP2]: undelete

Comment [IP3]: undelete

A Great Storm

Betty Charles

I am so blessed to be a part of your program. Your program kept me from having a nervous breakdown when storms came my way and things are not so good physically, emotionally and spiritually. I remember the day when I came for an interview with my daughter who was just recently diagnosed with breast cancer, I believe in 2004. She was diagnosed when she was pregnant with Zoe, who is now 5 years old. I was diagnosed with Rheumatoid Arthritis in 2000. I am looking after my husband who is disabled with minimal mobility. My daughter became palliative in 2006, she was in and out of the hospital. Then in January 2008 she was admitted to the hospice and eventually died in July 2008. She left me her children, 2 boys ages 14 and 10 and a girl 5 yrs. Old. Her daughter is staying with her father half time and stayed with me the other half. The boys are staying full time with me.

So, you see how the program assisted me with the great storm I have had in the past several years. If I did not have the program I don't know what would have happen to me, my husband and grandchildren. I hate the thought of them being in a foster home because of my inability to look after them. I also thank you that my husband did not end up in a nursing home. Because of the program me and my family are enjoying a little bit of quality of life, and I have time to spend quality time with my grandchildren. I am able to do my personal needs because I have the support around me when I needed.

I don't know if I would have survived and been able to faced my circumstances if the program did not exist.

Direct Funding Program is worthwhile and I experienced the benefit of my family being together at our own home.

DF Makes It Easy

Tamra Ricci-Moretton

Direct Funding has changed my life and how it has enabled me to flourish in my roles as a wife, an entrepreneur, and a mother. I started on Direct Funding when it began as a Pilot Project in the early 1990's. Back then, I was completing my PhD in clinical psychology and living in Toronto.

I have Juvenile Rheumatoid Arthritis and have used a motorized scooter for many decades. I was nervous and a little wary when I first started in the DF program. I didn't



Tamara and family

realize how independent and how much freedom the program would provide me.

As a result of Direct Funding, both my husband (who is also physically disabled) and I are able to work, live in our own home, and raise our child. We have attendants help us with day-to-day activities. The flexibility that Direct Funding provides is incredible. Our attendants have traveled on a cruise with us, assist us with grocery shopping, and have accompanied us to our son's skating lessons, swimming lessons, gymnastics, diving lessons, and hockey. Despite our disabilities, my husband and I lead 'normal' and productive lives. We work full time, travel, parent, and visit family and friends out of town. We go on picnics, to the movies, concerts, and NHL hockey games.

I never realized how independent and productive I could be before I had the opportunity of being involved in the Direct Funding Program. I own and operate a successful psychology practice, I am married, and I am a mother. I enjoy life with few limitations. I recognize that without Direct Funding my life would be much more restricted and much less productive and enjoyable.

I am so grateful for the opportunity to live life with flexibility, independence, and few limitations. Being on Direct Funding makes it easy to forget my disabilities and allows me to focus on my abilities. Thank you to all those that have made this possible for me and the many others like me.

Mobility Means...

Ruth Burns

Muscular Dystrophy is my permanent disability. My arms, hands and leg muscles are getting weaker as time goes by.

I can remember the great feeling I had when I read in a disability magazine, that Toronto was accepting applications to the Direct Funding Program. I immediately applied and was accepted. I was the first participant in South Timiskaming District to be accepted. It was with great enthusiasm that I hired my attendants and was ready to start on the program January 2nd, 1999.

I was asked by Direct Funding Program to sit as a consumer on the interview panel. We presently have twelve participants on the program in South Timiskaming. I was and still am very happy to tell others how great the program is for persons with disabilities and how much it will help them and their care givers. The program helps the care givers not to have "burn out".

In the beginning I was able to do most of my transfers by myself and was able to open my door and go outside, do most of my shopping and banking. I needed help with my personal care and meal preparation. My MD has deteriorated, I now need help to do all of the above tasks. One of my attendants has been with me since the first day I was on the program. She is a great asset to me.

Our three children live in Kitchener and Marathon and my husband died Dec. 26th, 2001. I live alone. My children have peace of mind knowing that I am being cared for by the attendant I have chosen to hire. It is because of this program that I am able to live and be cared for in my own home.

This program has given me back some of my independence and control of my life. My life is less stressful. The hours on Direct Funding are so much more flexible and I can hire the attendant whom I wish. I feel like I am contributing to society by providing employment. I can't stress the importance of keeping your independence, this helps greatly with your attitude. "Mobility" means more than just

getting around. It really refers to every aspect of daily living – from sliding a key into a lock, to opening a door, carrying groceries, reaching for something out of normal reach, or opening a child proof container and all aspects of personal care.

The Direct Funding Program is a terrific program, and I can't thank you enough for starting it up. I only hope that the Government will put more funding into the program, so that the wait won't be so long for others to get on the program.

A Whole New Life

Angie Ryan

It's challenging, exciting, and stimulating! "A whole new life" – That's what Independent Living has been for me!

My name is Angie Ryan. I am 56 years of age. I have Friedrich's Ataxia (one of the Muscular Dystrophy) My disease was diagnosed when I was 14 years old. The progression has been a very slow decline and I started using a wheelchair full time at age 35.

I have been on the Direct Funding program since January 2002 Because I have more than twice as many home care hours, it has opened the doors to many possibilities.

Now my home care helps me with grocery shopping, personal shopping and banking needs, overnight needs and events and holidays.

I feel like a truly independent person. Having the time and energy as well as the extra support from my personal support worker, I have been on our Independent Living Board as well as the Co-op Board where I live; I am involved with my church {P.P.C;RCIA; and I'm a Greeter there! As well I'm involved in a positive thinking wellness group.

Its so great to go to family and friends homes over night; plus holidays [just like other people!]

Two years ago I went on a Caribbean Cruise with a Support Person. And I'm going to the Tulip Festival in Ottawa this May 2009!

I find the structure and support from my Independent Living Centre very prompt and supportive. I have only praise for this wonderful life enhancing program, and I truly hope the Direct Funding program will be made available to other disabled Canadians in need

In Praise of Direct Funding

Georgina Wheeler

I'm enjoying seeing the birds at my new feeder outside my dining room. My helpers fill it once a month. It's possible for me to stay in my home because the "girls" do so much for me. I'm very appreciative of the program.



Georgina Wheeler



Georgina sent us this handmade booklet with tributes and pictures for all of her attendants.

In Charge

Harvey Ewing

I came on the program in 2001 from a rather restrictive home care program, which frustrated me [and gave no]... regard to my needs being of the utmost importance. It left me thinking that I wasn't very worthy as an individual, [as well as]... not meeting my daily needs. It felt as if frustration and being worthless were quietly becoming my constant companions.

This new program provided me with the opportunity to have unrestricted care of my daily needs as for the times of day and types of work being provided to me.

I heard from workers that they were more relaxed and able to get to know their employer (me) and feel that they could really help me in a relaxing atmosphere for both of us.

As a disabled man: I really enjoy the thought that I can make my own decisions, whether they are the right or wrong ones. I am learning about myself and learning to deal with people (my attendants). If, I am having company coming, I can call and change the attendant's time to come in for work. On the Direct Funding Program I don't have to feel like I am giving up my personal time, for the system. I am more able to enjoy life. Also, I am more assertive in my daily life. I am in charge of my own life.

I feel this is the very best program out there now, and it has been a "God-send" to me. I feel fortunate to be on this program.

Freedom to Choose

Fern Desjardins

Before the program came in place for me, I was a client of an outreach program and hours for directing my care were very restricted and not so flexible as this program allows me to be and was not in control of who came in and out of my home.

Since I have been on direct funding for the past 2 years my life has changed in many ways, such as the freedom to choose my staff and when they come in and out of my home, giving me total control over my own life. I really enjoy the whole process of being a self manager.

Because of the flexibility of direct funding and being able to direct my own care, I can have staff at more convenient times for me, therefore making it easier to manage my life and needs.

I am very appreciative for this program and thank all who were involved in developing this program. I hope it will continue on for others to experience.