

The Self-Manager

CIILT • Centre for Independent Living in Toronto • A publication for Direct Funding Program participants

Winter/Spring 2022

Self-Managers' skill and support makes all the difference

LEISA DeBONO
DIRECT FUNDING PROGRAM MANAGER

All of us are living in the COVID time warp where time seems to speed up and slow down all at the same time, but throughout this process we've seen the resilience and pure will of Self-Managers on the Direct Funding program who have kept employing and recruiting staff through this difficult time. For starters, everyone else in the province has learned what Self-Managers have known all along, and that is the importance of a strong



“Loyal attendants continued to show up through the scariest days of the pandemic.”

relationship between attendants and their employers. We heard about a lot of challenges since March 2020, but we also heard stories from Self-Managers about their valued and loyal attendants who continued to show up through the scariest days of the pandemic, and the gratitude those Self-Managers felt for their staff. (Please see the story of Toronto Self-Manager Oliver Pace and his quarantine experience on page 2.) We heard, too, about the challenges of recruiting and fears that no one would show up, but once again so many participants kept repeating those ads and through perseverance, not to mention pure necessity, found a way to recruit new staff, even with case counts rising and vaccines in short supply. Everyone



Kathryn Bloomfield, a Self-Manager in Collingwood, rolled up her sleeve for an early COVID vaccination in 2021.

hopes we are done with all the waves of this pandemic, and that the movement of time will soon return to a normal pace, but I remain impressed at the management and people skills of the Self-Managers who continued to employ the same staff, and the resourcefulness and sheer will of those participants who recruited new staff during the pandemic (in particular, we were inspired by a group of North Bay Self-Managers who connected recently and are now all benefiting even more from the program by sharing attendants; please read about their experience on page 5).

The program would also like to acknowledge the important role

Self-Managers played in keeping the program running (almost) seamlessly by embracing the online quarterly reporting system. Prior to launching the online reporting portal in 2019 participants used to send in paper

Please see **SKILL AND SUPPORT**, p.8



Ian Parker 1947-2021
The former Direct Funding Program manager “left an indelible mark and will be remembered forever ...”
For full story, please see p 3

Under one roof

Self-Manager's attendants move in during quarantine

Oliver Pace, a Toronto Self-Manager, saw up close the benefits of the special relationship Direct Funding participants can have with their attendants.

In early 2021, Oliver learned that one of his regular attendants, although asymptomatic, had tested positive for COVID. Oliver then tested positive as well and was subsequently required to quarantine for 14 days. Two of his attendants chose to move in with him temporarily for his quarantine period, covering both their own regular shifts and those that his other attendants could not work. The two attendants worked with Oliver and his sister, Mary, through the quarantine period, using extra personal protective equipment to keep each other safe.

Oliver wrote to the program recently: "My sister forwarded these two photos of one of the attendants who

stayed with me while I had COVID last year. Her name is Thao Vo. The other attendant was reluctant to consent to having her photo or name on a public website for privacy reasons. That's too bad, as she was indispensable and did

all the overnights while we were all quarantined.

"I'm glad to have helped show how beneficial this program is. I am truly fortunate to have such wonderful attendants."



Quarantined together last year, Oliver and attendant Thao Vo passed the time by playing cards.



Oliver and attendant Thao Vo, shown recently.

Keep in touch



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memory

Ian Parker 1947 – 2021



LEISA DeBONO
MANAGER, DIRECT FUNDING PROGRAM

If you mention the name Ian Parker to almost any advocate of Independent Living in Toronto, they are sure to have either met him or know of him. Seriously. He'd been around the community for that long, working to improve the lives of people with disabilities.

Ian died on April 15, 2021, but he left an indelible mark and will be remembered forever for his efforts to improve the lives of people with disabilities, including most readers of *The Self-Manager* newsletter.

Ian was among the first people to come out of Lyndhurst (Toronto Rehabilitation Centre) and live in supportive housing around 1975 – but it wasn't really supportive housing back then, it was a pilot that would later become supportive housing, where he lived until he moved into his own home 20 years later. In between earning his Bachelor's degree in music, consulting with multiple government ministries and working with the Ontario government on the International Year of Persons with Disabilities in 1981, Ian used to teach piano to children! Although Ian was involved in many worthwhile causes over the 40+ years he was a quadriplegic, he channeled most of his time and energy into bringing a unique idea to fruition that has increased autonomy for more than 1,800 disabled Ontarians over the past 26 years.

The Self-Managed Attendant Services - Direct Funding Program epitomizes the Independent Living philosophy of choice, flexibility and control by providing funds to adults with physical disabilities, allowing them to recruit, hire, train and schedule their own attendants. The program provided a much different model of attendant services for assistance with activities of daily living, since it put control in the hands of the person with the disability. Participants themselves could decide who would come into their home and when; this control had previously rested with agencies.

Getting a project like Direct Funding off the ground was not fast or easy. Starting in 1989, Ian worked with other individuals with disabilities who used attendant services, along with government representatives, to develop policy and legislation that would pave the way for the program, including an important exemption under the Regulated Health Professions Act. A staunch advocate of the concept of self-management and author of the original policy guidelines, once funding was secured in 1994, Ian took on managing the pilot project while also being one of the first participants on the program. He led Direct Funding through the all-important formative years including the original program evaluation in 1997, which was so overwhelmingly positive that the "pilot project" received ongoing "program" status, and the ability to take on hundreds more Self-Managers, as program participants are called.

Ian served as the manager of the Direct Funding Program from 1994 until 2011, when he became the Senior Policy Advisor. He helped navigate Direct Funding through its critical

formative years; his analytical mind saw the program through all the legal issues it faced in the early days and his compassion and humanity helped shape the program to where it is today, meeting the needs of individuals outside the boundaries of what was originally anticipated.

Even after his retirement in late 2018, Ian was generous with his time and would answer any questions put to him. Over the years he was seldom stumped for an answer about why we did — and why we do — things the way we do on the program. The Independent Living philosophy and his years of lived experience of his own disability informed everything that underpins the program to this day.

There are few programs that embody the Independent Living philosophy better than the Direct Funding Program, so it feels fitting that Ian recently posthumously received the David C. Onley Award for Leadership in Accessibility for his work within the community: <https://news.ontario.ca/en/release/1000222/ontario-recognizes-exceptional-individuals-and-champions-of-accessibility>

It is comforting to know that his many contributions, including the Direct Funding Program, have earned him a place in the history books and that future generations will always know and benefit from his legacy.





PDN Vibrant Songs and Discussion for Parents with Disabilities

CILT's Parenting with a Disability Network (PDN) in partnership with Vibrant Healthcare Alliance welcomes disabled parents of children from newborns up to four years old to join our monthly songs and discussion group.

The group meets over Zoom on the third Tuesday of the month at 11:30 a.m. and begins with a half hour of songs and stories, followed by peer support discussion. This is a chance to learn new songs, promote bonding with your child and connect with a cross-disability group of parents.

If you would like to join for the discussion/peer support portion of this program only, please let us know when you register. Please also inform us about any accommodations or Zoom support you may need. Automatic closed captions will be turned on. Participants can join by phone, if necessary.

To register: email Parenting with a Disability Coordinator Rebecca at rebecca.wood@cilt.ca

DID YOU KNOW?

Your attendants may be eligible for up to three days of paid infectious disease emergency leave for COVID-related absences — up to \$200 per day. Please visit the page titled "Ontario COVID-19 Worker Income Protection Benefit" in the COVID-19 section of the Ontario.ca website for more details, including how to apply for reimbursement through WSIB.

www.ontario.ca/page/covid-19-worker-income-protection-benefit

Ellie's in the kitchen with Dinah

DINAH COTTER
SELF-MANAGER, KINGSTON

In 2019, Chase, my service dog began slowing down and was tiring easily. I knew it was time for him to hang up his working harness. Due to the COVID lockdowns Chase continued to work but only when a human wasn't available. With the flexibility of the Direct Funding Program, I was able to continue going to appointments and such by shuffling my hours.

I fully retired Chase (my second service dog) November 5, 2021, as he was more than ready to live out his final years at his forever home relaxing and not working.

I applied for a successor service dog and eventually I received "the call". I was invited to come train for a new dog guide.

In early November, I started online Zoom training for my new dog guide. We learned things over Zoom that we didn't need to have the dog present for; then, on Nov. 7 I left Kingston to go to the Lions Foundation for Dog Guides Canada training facility in Oakville, Ont. There I began my hands-on training with my third service dog.

As a Self-Manager, I was able to bring one of my own attendants to the training school. This enabled me to have my care run smoothly, making my stay in a new environment less stressful and easier on me, even though we were using different equipment.

On Day 2, I was introduced to the dog that the training facility had matched to me for my needs. Ellie is a yellow Labrador born Dec 9, 2018. Some of her tasks are opening automatic door buttons, opening the fridge, opening and shutting doors and drawers, barking

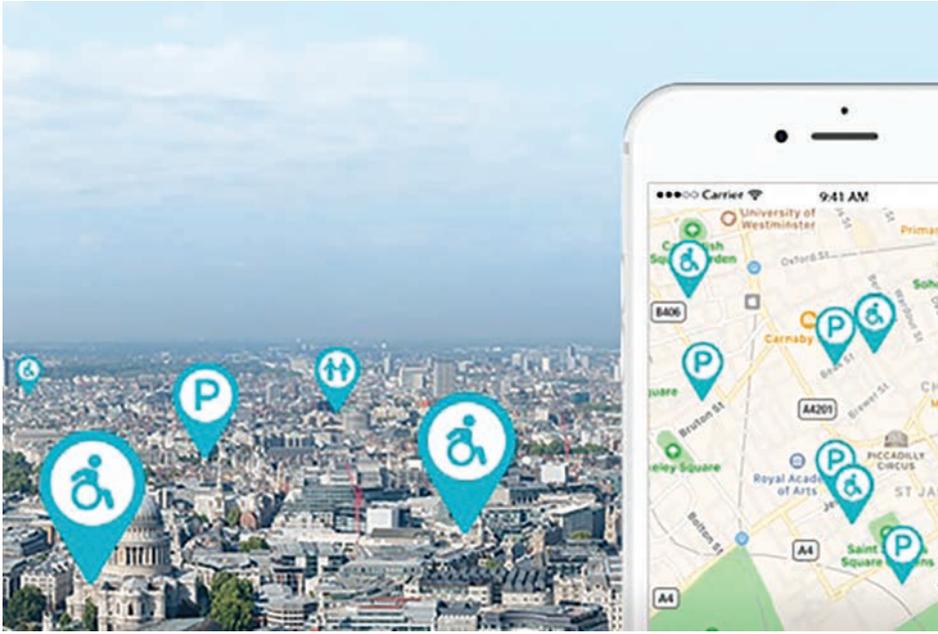


"Ellie makes my life easier and I feel so much safer."

for help, and operating my lifeline in emergencies.

Ellie makes my life easier and I feel so much safer. There are many things that would be impossible to do without Ellie. She also does other tailored tasks such as pushing a button on my wheelchair to shut it off if I have an epileptic seizure.

Even with COVID ever so present, rapid tests twice a week and all the extra precautions my experience at the Lions Foundation Dog Guide school was a great one! I cannot imagine it working out so smoothly without my employee through the Direct Funding Program.



From WheelMate app

WheelMate App Review

MARLENE BENEDICTO
DIRECT FUNDING PROGRAM STAFF

As a wheelchair user living in downtown Toronto, one of the main obstacles I face while navigating the city is accessibility. I often find it difficult to determine which businesses are wheelchair accessible because everyone's interpretation of what is and is not accessible is always up for debate. To a non-disabled person, accessible parking or wheelchair-accessible washrooms may not sound important, but it's crucial for many disabled folks. Locating accessible parking and washrooms can determine whether a person with a disability can go to a doctor's appointment or meet up with a friend for dinner.

WheelMate is a free app that uses an interactive mapping system to assist wheelchair users in finding the nearest wheelchair-friendly parking spots and washrooms. Users of the app also have

the ability to add new parking and washroom locations and rate existing locations. The best part? WheelMate is powered by wheelchair users and not by some bot that determines where the closest accessible parking spot is located. The app is simple to use, but the ratings are sparse. This issue can be easily fixed by encouraging users to rate every location they add. The other issue I encountered is that icons are not clearly labelled, which makes it difficult to understand what each icon means. Overall, WheelMate is a helpful tool for wheelchair users, especially if they are navigating their way in an unfamiliar city.



WheelMate currently has more than 35,000 locations registered across 45 countries with close to 17,000 downloads.

Sharing attendants

STUART KIDD
SELF-MANAGER, NORTH BAY

Hello from amid the winter cold and COVID. Last October, I almost passed on a CILT sponsored Zoom call for Self-Managers to talk about common issues and concerns. However, it turned out to be very positive.

A number of us on the call talked about staff shortages, perhaps aggravated by the pandemic. I asked if there were other people in my area who had similar problems and who had staff who might be interested in work with other Self-Managers. Two other managers in my area (Wilson Libita and Sally Harper) confirmed similar problems and that they had staff who might be willing and able to add more people in open parts of their schedules.

Within a month, three of us enjoyed the benefit of sharing staff to fulfill our support care needs. Personally, the changes also made improvements to the scheduling for each of the three people who work with me. Ashley M., our longest serving care worker, of about five years now, myself & Duncan are shown below.

The result of that one Zoom call has been a good win for all three Self-Managers and their staff as well.



REMINDERS

Check your bank statements!

Self-Managers are reminded it is your responsibility to review your bank statements and cheque images every month. While this has always been a program requirement, Direct Funding staff are seeing increasing instances of cheques that have been double-cashed (often, using mobile deposit, whereby individuals deposit cheques via online banking by taking photos with cellphones). If cheques are altered or double-cashed and you do not notice or correct this with your bank within 30 days, you are personally responsible for all missing funds. You and your bookkeeper should be doing a monthly bank reconciliation, in addition to the quarterly reconciliation you submit with your Self-Manager's Report.

Provide alternate contacts

Please provide the program with an alternate contact; if we can't reach you for some reason, having an alternate person we can contact will help us ensure no interruptions to your funding. Please contact your local program resource person or the individual who reviews your quarterly Self-Manager Reports to confirm we have the correct contact information. Thank you!



Gabriela and baby Giovanna

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Testimonial

Direct Funding gave me a fresh start. I am very grateful to the program. It allows me to stay in the comfort of my own home. That is huge.

Greg Maskwa, Self-Manager, Sudbury



The Direct Funding program enabled me to hire a hand-picked team. Under my direction, my brilliant staff give me the very best of care. They know my house, where things belong and what my preferences are. They know me. They brighten my day. They lift me up and inspire me on days when I feel disconnected from my muse. The difference is astonishing. I am a better person because of it. Every day, I look forward to seeing them, and I am ready for the day's routine. I have more control, and this empowers me. I am a proactive participant in my own healthcare. I am overwhelmed with amazement at all this program offers.

I am spoiled. I could never go back to the revolving door of healthcare workers that came from an outside service. There is simply no comparison. The continuity of having the same trusted attendants allows me to establish a deeper connection. My team has set up a program that is designed for my specific needs, maximizing my care.

As a result, I have more free time to

splash some paint on a canvas. I am convinced that without Direct Funding my creativity would be compromised. The freedom it gives me is awe-inspiring.



Greg Maskwa is a Self-Manager since 2016. He is also an artist who donated one of his award-winning paintings, *Things Could be Worse (Self-Portrait with Pain)* to the Integrated Chronic Pain clinic at his city's Health Sciences North hospital.

Parenthood

GABRIELA CARAFA
SELF-MANAGER, WOODBRIDGE

Becoming a single parent by choice was not a decision I took lightly. In September 2021, my daughter Giovanna McKenzie Carafa was born, and in that same month I moved and had to hire new staff. So many transitions happened very quickly! With the support of the



Direct Funding program, I am able to care for my baby exactly how I envisioned, and I'm empowered to be the best mother I can be every day. Like any new mother there are definitely challenging moments and days, but overall this transition has been rewarding and full of love (and baby cuteness).



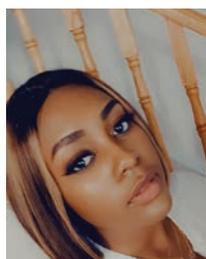
New Direct Funding Program staff



Dan Lajoie
Program Manager
Waterloo



Elizabeth Rodriguez
Bookkeeping
Report Reviewer
Toronto



Gold Olatifede
Intake Administrator
Toronto



Katherine Pohjolainen
Direct Funding
Resource Facilitator
Thunder Bay



Marlene Benedicto
Intake and
Resource Facilitator
Toronto



Martin Glassford
Direct Funding Report
Reviewer
Waterloo



Natalie Dupuis
Community
Resources Navigator
Kingston



Roberto Guardado
Direct Funding
Resource Coordinator
Ottawa



Robin Green
Interim Executive Director
Ottawa



Robyn Jackson
Direct Funding
Resource Coordinator
Waterloo



Sara Stonehouse
Agreement and
Resource Administrator
Toronto



Wedded bliss

Congratulations to Tammy Gould, Executive Director and Direct Funding Coordinator at RISE Resource Centre for Independent Living in Parry Sound, and George Shoebottom, who were married recently!

Skill and support

Continued from p. 1



reports, so the move to online reporting could not have been better timed in terms of COVID, since all program staff have now been working remotely for two

years. Program staff know the online report had many advantages (no more mail to send in!) but that it came with a learning curve for Self-Managers and especially their bookkeepers. And once the Temporary Pandemic Pay (TPP) got started in mid 2020, followed later by the Temporary Wage Enhancement (TWE), we then asked all Self-Managers to submit timesheets and pay stubs, effectively tripling the documentation submitted with each quarterly report; but once again, participants and their bookkeepers copied and submitted all the extra documents required. The support of so many participants and bookkeepers in using the online reporting portal has been a key component in our ability to function since the pandemic began.

We know the pandemic is not over, but I think all Self-Managers deserve a round of applause for your ingenuity, resourcefulness, excellent management skills, and for working with the program to move forward digitally. It is no wonder the Ministry of Health continues to invest in Direct Funding, including two sizeable investments totalling \$4.9M in 2020 and 2021, after seeing the way participants managed their staff and reports in these unprecedented times.

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Testimonial

As a Self-Manager, I have been able to access the support I need to live my life by design.

Kim Latour, Self-Manager, St. Catharines



I was diagnosed with Relapsing Remitting Multiple Sclerosis in 2006 before moving on to a progressive disease course. As my disability increased, I found tasks of daily living such as maintaining a tidy home, taking a shower, or cooking a meal difficult. Over time I felt less and less engaged in life. The Direct Funding Program has, from the start, been a game changer.

From the beginning, learning the responsibilities of being a Self-Manager has offered challenges that have lit me up! I enjoyed learning about the program and governing legislation as well as feeling connected with others and being responsible for managing my schedule and budget. The pandemic

resulted in increased isolation and coincided with a relapse that meant continuing to live without assistance was not possible.

As a Self-Manager, I have been able to access the support I need to live my life by design. Now, taking a shower, preparing a meal, and other tasks of daily living are safer, and I am able to preserve my energy. The assistance has resulted in my family being less worried about my wellbeing, and I feel more confident and dynamic showing up as my best self. The support has enabled me to participate in exercise, engage with my friends and family, and has resulted in improved quality of life.

Save the date

**March 22,
2022**

Workshop for Self-Managers and other consumers

The Centre for Independent Living in Toronto will be hosting an online workshop on Infection Prevention and Control (IPAC) on March 22 at 1 p.m. Topics to be discussed in this ever-changing landscape include:

- Mask requirements & proper use of personal protective equipment (PPE), particularly with new variants of COVID
- Isolation and incubation periods if you or your attendants test positive for COVID
- Where to access and how to use rapid antigen tests
- Sick benefits for COVID-related days off work

Please bring your questions. The program will be sending more information about this by email. Please register as soon as possible.

The Self-Manager Newsletter editorial team: Marlene Benedicto, Leanne Larmondin, Sara Stonehouse



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