

The Self-Manager

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

Winter/Spring 2020

Morning snuggles with my twin sons: *priceless*

By GREG MOORE, WATERLOO REGION

At the age of 18 I had a motorcycle accident, resulting in a C4-C5 spinal cord injury and have used an electric wheelchair for mobility ever since. For 29 years I used an agency for attendant service. In August 2017 I became a Direct Funding client and a year later, I became a father of twin boys. Earlier that year I had learned of a DF program called Nurturing Assistance. Without that assistance, I don't know where my wife and I would be.

Nurturing Assistance has allowed me to father my kids in a way I never thought possible. Being able to have someone pick up my kids for me, allow me to prepare them meals and supervise them while they eat are just a few of the things that benefit my family. It makes me feel good about being a parent with a disability.

When I get up at 6 a.m., being able to have someone there to go into the nursery with me when the boys wake up so that they can lift them up and put

Please see **NURTURING**, p.8



Dad Greg Moore tows twins Dylan, in front, and Jesse in the caboose



Our Deepest Sympathy

The Centre for Independent Living in Toronto (CILT) and the Direct Funding Program are mourning the loss of Sandra Carpenter, who died January 23, 2020, after a brief illness. Sandra, a Self-Manager since 1999, retired as Executive Director of CILT in early 2019.

For reflections on Sandra's legacy, please see page 3.

Service dog provides 'extra set of hands'



By LEANNE LARMONDIN
PROVINCIAL PROGRAM COORDINATOR
CENTRE FOR INDEPENDENT LIVING IN TORONTO

Morgan Smith now has an "extra set of hands" after her recent match up with her new service dog, Crockett. A Self-Manager in the Niagara area since 2017, Morgan recently attended the Lions Foundation of Canada Dog Guides national training school in Oakville, Ont. For 18 days, she lived in residence (with the help of her attendants) and learned the commands and procedures to direct Crockett.

Now living back at her family home, Morgan says she considers Crockett an "extension" of herself. He can pick things up, put items on the counter, open and close doors, push buttons like door openers, bark for help and follow commands like, "Go get Mom," to alert her mother to come to her. Having



Crockett by her side has also had the added benefit of boosting Morgan's confidence, particularly when she is home alone.

"I'm the primary handler for Crockett," explains Morgan, explaining

she is the only person who directs the service dog. Her attendants, who helped her with her activities of daily living during the training, only assist with putting on Crockett's equipment.

A marketing graduate from Mohawk College, Morgan is still bonding with Crockett and expects to look for work in her field soon.

The Lions Foundation of Canada provides dog guides to individuals with various disabilities, including cerebral palsy, vision and hearing loss, seizures, autism and diabetes. The average cost of raising and training each dog guide is approximately \$25,000, however they are provided at no cost to qualified applicants through donations and fundraising.

For more information, please see www.dogguides.com



Please note:
all staff email addresses
have changed to a first
and last name format.
Please update your
contact list accordingly.

Keep in touch CILT Direct Funding staff can be reached by
telephone: **416-599-2458/1-800-354-9950**, fax: **416-599-3555** or by e-mail.

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Remembering

Sandra Carpenter

March 19, 1954 – January 23, 2020

This isn't just a loss for us, Sandra's colleagues and friends. It's also a great loss for the Independent Living community as a whole. In Canada, the fight for choice in and control over our own lives has been a long one, spanning decades, and Sandra was one of the true pioneers.

At an early age, Sandra experienced the significant limitations that are associated with living in a "Home for Incurable Children" (as inscribed over the institution's front door). She turned this negative experience into an enduring positive throughout the rest of her life. It fuelled and sustained her drive. Sandra long dreamed of receiving her day-to-day support services in such a way that allowed her to be as independent as possible. When the notion of an Independent Living philosophy began to spread internationally, it resonated deeply. No matter where Sandra worked and what she involved herself in, she consistently believed in IL, advanced IL and, most of all, lived IL.

Sandra played an enormous role in developing and administering the Direct Funding Program. She was dedicated to this model, and her leadership and strong support have helped to ensure that people with disabilities for years to come will have the independence and freedom they deserve. I'll dearly miss Sandra's kind friendship and dry wit.

Ian Parker, Self-Manager since 1995



The first time I met Sandra Carpenter was at a steering committee for the Direct Funding Program, around September 1994. The steering committee consisted of CILT and government folks who pulled together to make decisions about how this

innovative and unique new program would be run. Sandra was the only person who checked both boxes since she was a consumer of attendant services who also worked for the Ministry of Labour at the time. Sitting around that

table I quickly learned Sandra was an intelligent woman who was not scared to share her views.

Sandra fully understood the flexibility of the Direct Funding Program but was also keenly aware of the risks – this was perhaps where Sandra was most insightful. She believed risk was an important part of Independent Living; she encouraged others to make their own choices and accept the consequences and she never assumed she knew what was best for someone else. She imparted that wisdom as Executive Director of CILT as well, impressing upon her staff (me included) that we could provide information, but that final decisions had to come from the consumer.

Leisa DeBono, Direct Funding Program Manager

Please see more about Sandra Carpenter at
www.cilt.ca/2020/01/sandra-carpenter-dedicated-advocate-and-il-visionary/



By **MARISA FALZONE**
SENIOR REPORT COORDINATOR & ADVISOR
CENTRE FOR INDEPENDENT LIVING IN TORONTO

Mobile cheque deposit – depositing a cheque remotely by taking a photo with a smartphone app – is growing in popularity. The Direct Funding Program wants Self-Managers and their attendants to have all the benefits and convenience that comes with the newest financial technology. As this becomes more popular as a banking method, please be sure to keep an eye on these key DOs and DON'Ts to depositing funds. We encourage you to share this information with your staff.



Use the original version of the cheque only, not a photocopy, PDF or printout and ensure the cheque hasn't already been deposited.



Endorse your cheques before using mobile cheque deposit.



After completing the mobile cheque deposit process, keep the cheque in a safe place until you have confirmed it has successfully been deposited; then, write "VOID" in large letters on it or shred the cheque.



Sign someone else's name on the back of a cheque destined for your account.



Deposit same cheque twice. If you mistakenly deposit a cheque more than once, contact your financial institution immediately.

There's an app for that!

Use your phone to find accessible locations, get fit, shop and get out of town



By Samantha Walsh
Intake and Resource Facilitator
Centre for Independent Living in Toronto

Technology has changed the way we do both big and small tasks. As a wheelchair user, I am delighted to have found many conveniences using my smartphone. These services may have a fee involved and it is worth checking to see what services are available in your area. As a wheelchair user who lives in a large urban centre, I have had success with many of these apps. I find they can often fill the gaps or solve small but nagging issues in my life.

Access Now is an app

Developed by a Self-Manager, AccessNow is like Yelp, a crowd-sourced business directory service and review forum but focused on accessibility. To use the app, you input your location and the type of service you are seeking. The app shows a list of locations rated by other people with disabilities and their experience. In my experience this app can help a person with a disability be more spontaneous and gives reliable reviews from the perspective of another person in a similar situation. **Free / available throughout Canada**

Runkeeper

This app, which I think should be renamed "Wheelkeeper", acts as a pedometer tracking the route of the run, walk or wheelchair ride you take. If you are a wheelchair user, it will track the distance you've wheeled and is compatible with other fitness apps and programs. **Free / available throughout Canada**

Grocery Delivery Services

App-based grocery pick-up and delivery services vary. These services employ a third party to shop for you and then drop it off to your home. The app usually allows for same day or even grocery delivery within the hour. Search the various services, including Instacart, Instabuggy and Cornershop to see if they service your area; many are available in small cities. **Approx. \$5-\$10 fee for delivery; not all services are available in all areas. The customer assumes some risk as the individual making the delivery is a third party.**

Click and collect or store-based delivery services

If you live near a Loblaws, Walmart or other grocery chain, check to see if they offer a click and collect service or

grocery delivery. Click and collect allows you to select your groceries online, someone at the store gathers all the shopping and bags it. Then you simply go and pick it up (or, ask an attendant, friend or family member to do so). You can even pay online. **Availability based on local stores.**

Uber

Uber is a fee-for-service ride share program that works like a taxi. However, in some areas they have programs such as UberWAV (Wheelchair-Accessible Vehicle) and UberASSIST. UberWAV provides wheelchair-accessible vans on demand. However, it is mostly available in large urban areas such as Toronto; it may be worth checking if it is in your city. If it is not available, you might consider tweeting at Uber that you would appreciate this transit option. UberASSIST is a group of drivers with typical private vehicles who have agreed to support passengers with disabilities and mobility devices. They can take folding walkers and wheelchairs. This service is largely available in large urban centres, but also some mid-size cities. **This app is fee based and location specific. The user also assumes risk as it is a third-party provider.**



Two Self-Managers returned to Ontario with medals after the recent Canadian Boccia Championships, held in Victoria, B.C. Taking home the competition's bronze medal, the Ontario team included Lance Cryderman (far left), a Sudbury Self-Manager since 1999, and Jim Davis (far right), a Self-Manager from the Niagara area since 2002.

I'm in hospital ... now what?

Sometimes, unfortunately, Self-Managers wind up in the hospital.

Listed below are a few tips to keep in mind if this happens to you.

- **Please contact (or ask someone to do this for you) your Independent Living Resource Centre or reporting centre.** We need to know how long you expect to be hospitalized, how to reach you, and we may have some helpful suggestions. You will still need to keep track of your hours while in hospital, and your attendants will still need to be paid.
- **Have an emergency plan in place ahead of time.** Set up someone you trust who can contact all of your attendants and bookkeeper in the event of an emergency. Ensure you have a procedure in place with your attendants, so they know who to call once they have called 911.
- **Have copies of your Workplace Safety and Insurance Board and liability insurance information handy to take with you.** The hospital may request this information to allow your attendants to work for you in the hospital.
- **Save some attendant hours for later.** We understand hospital staff are stretched and may not be able to provide the additional or specialized assistance you may need due to your disability. You may use your attendants while you're in hospital but remember: any hours you don't use in hospital (since, for example, you will not need meal preparation or housekeeping hours) can be helpful later when you're home recovering.
- **Tell the hospital you're on Direct Funding.** Remember when speaking with discharge planners from the Local Health Integration Network (LHIN) or hospital staff, you are on the Direct Funding program, which is funded by the provincial Ministry of Health and Long-Term Care; *your attendants do not work for you "privately"*. Hospital staff who do not understand Direct Funding may try to discharge you with extra assistance from Personal Support Workers (PSWs) from LHIN agencies – remember, your Direct Funding Agreement prohibits you from using LHIN-funded PSW services while participating on the Direct Funding program. Since both are funded by the province, this is considered "double dipping".
- As always, you can still use professional services from the LHIN such as nursing, physiotherapy, occupational therapy and social work.



Submitting your remittance information to WSIB

Many Self-Managers are submitting their payments to the Workplace Safety and Insurance Board (WSIB) online. WSIB is one of the few payments that the Direct Funding Program permits to be made via online banking. This is great news, and it's made it much easier for Self-Managers to make those payments. Remember when making your WSIB payment online, you still need to provide remittance information to WSIB. Please visit the WSIB website at www.wsib.ca and go to Online Services (top right-hand corner of the screen). You will need to create an online account with WSIB.

Please note: WSIB's online service may not work on all internet browsers. If you have questions please contact eServicesSupport@wsib.on.ca

Ministry of Labour hotline

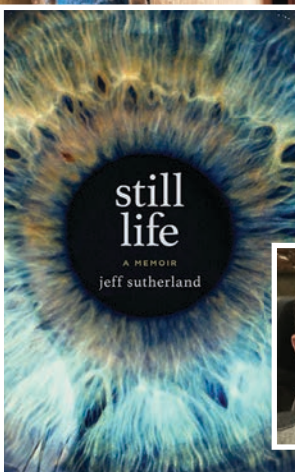
If you have an employment-related question and would like to speak to one of the Ministry of Labour's experts, call the Employment Standards Information Centre at: **416-326-7160** (Greater Toronto Area) / **1-800-531-5551** (Toll-free) / **1-866-567-8893** (TTY for the hearing impaired). Information is available in multiple languages. You can also find answers to your questions online: www.labour.gov.on.ca/english/es/pubs/fs_compliance.php

Self-Managers' writings



Melissa Graham, a Toronto Self-Manager since 2014, has had a chapter published in *The Routledge Handbook of Disability Activism*, which was released in early 2020. The chapter is the culmination of a few years of effort, reports Melissa, who is a community activist and one of the founders and organizers of the Toronto Disability Pride March. She is also the Community Facilitator for the Direct Funding Program at the Centre for Independent Living in Toronto.

For more information, please see www.routledge.com



Jeff Sutherland was a family physician and hospital administrator who was diagnosed with ALS at the age of 41; he is the father of three sons. His book, *Still Life*, examines his life pre- and post-diagnosis, including his preparations for the progression of his ALS. The loss of his 21-year-old son and his son's girlfriend brought new challenges for Jeff. "It dropped his father into an abyss that his own disease had never plumbed, shattering his soul and bringing him to the realization that even with ALS, he had lived a relatively unexamined life. It left him questioning his religious beliefs, the nature of the human spirit, the meaning of death, his scientific worldview, his closest relationships, his desire to go on living," writes his publisher. Jeff wrote the book using eye-gaze technology and it is also available in audio format. A Self-Manager since 2016, Jeff and his wife live in Terra Cotta, Ont

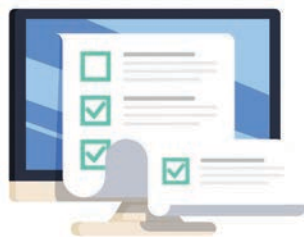
For more information, please see www.sutherlandhousebooks.com or www.audible.ca



When **Lisa Jones** was a baby, experts told her parents she should be put in an institution. Her parents refused. That moment, according to Jones' recently published motivational life story, *What My Wheelchair Taught Me*, kick-started a life spent exceeding the expectations of others. Lisa, who lives in Mississauga, Ont., has been a Self-Manager since 1996. She is a mother of two adult daughters and formerly worked as Assistant Executive Director of the Peel District Health Council and transportation planner for the Region of Peel and Metrolinx.

For more information, please see www.lisajonesauthor.com

Benefits of Online Reporting



- More efficient process – it's now easier to get your quarterly Self-Manager report in on time.
- Less hand dexterity needed, because there's less paper to flip through
- No need to purchase and mail Xpress-post envelopes
- Reports can be downloaded to your computer as one document that is easier to review and store.

Testimonials

**Richard
Andi**

The online report verification & approval is a great tool as it is easy to use and timely fashion. I do appreciate the fact that it was made available it makes life easier for the community.

**Patrick
Prior**

As a Self-Manager who does my own bookkeeping, I always appreciate when methods are developed which help to streamline and improve the process of managing my care. The new online reporting system saves me hours per quarterly report, and the report verification and approval process is quick and effortless. The wonderful support and guidance provided by the Direct Funding staff was instrumental in setting up my account and has made the entire process a pleasure.

**Louis
Sigouin**

I support the online reporting system. I am a Self-Manager as well as a bookkeeper. It was high time that this simplified reporting came into effect. It minimizes mistakes and paperwork and saves time. Good for all of you to make it available.

I very much appreciate the efficiency of the online report. It means less paper, no more postage expenses and it's quicker to review and submit. Definitely a step in the right direction.

**Fernande
Hadley**

**Audrey
King**

I have been a Self-Manager since the program began in 1995. I have used the online quarterly report submission twice now. Patrick at CILT helped me through it until I became familiar with the process. One of the great advantages of this online reporting is that the process guides you through a review of each section and reminds you of what you need to be looking at before you sign off.

I find the online report verification & approval very convenient and easy to use.

**Edward
Belkiewicz**

**Heejee
Jang**

The online report verification has made it easy and convenient for me. I don't have to send by mail each time, so it is also very cost effective. With your help, I was able to understand how to verify and approve the report and make corrections if needed.

Using the online reporting system is far superior to the previous format. It is immediate and easy to read. If necessary, any changes can be addressed and corrected with no delay. Direct Funding also receives the report as soon as it is approved. I am glad this online report verification and approval is now available. Kudos to CILT and DF.

**Randi
Daniels**

ESA poster

As employers in the province of Ontario, all Direct Funding Program participants are obliged to follow the province's Employment Standards Act (ESA). As such, Self-Managers have traditionally been required to display an ESA poster in their homes (which are, of course, their attendants' place of work); however, that rule has changed recently. Now, all workplaces covered by the ESA must distribute an employment standards poster to all employees, but they are no longer required to post it in the workplace. This poster:

- describes important rights and requirements under the ESA;
- must be provided to employees who are covered by the ESA within 30 days of their date of hire;
- is available in 15 different languages.

Employers can order hard copies from ServiceOntario Publications (free) at www.publications.gov.on.ca or download and print the poster at www.ontario.ca/page/posters-required-workplace#employment-standards-poster



Nurturing

Continued from p. 1



them on my chest and we can have a morning snuggle is priceless. To be able to share parenting so that my wife Keri gets breaks: also, priceless.

Here's a good example of the freedom Nurturing Assistance provides: on a recent winter day, between the two boys, Keri, my attendant, and myself it took about 30 minutes to get ready. And as always, as we are ready to go, surprise! One of them needs a new diaper. All fixed and we were able to take the boys out for a walk (most of the way) around the block. We had a great time out and I got to see my boys' excitement for the first time playing in snow. Without Nurturing Assistance, we might have given up and stayed at home.

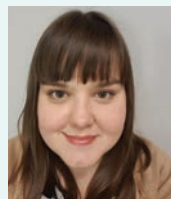
Not everything is easy. Finding the right people to be my attendant and nurturing assistant has proven difficult at times. Great attendants do not always make great nurturing assistants, and great nurturers do not always make great attendants. Also, there is an exchange of more assistance which often allows for less privacy.

Overall, I feel blessed to be able to take part in my kids' lives as their parent the way I can with the assistance of Nurturing Assistance. Without it my life experience would certainly be less, and my kids might not understand the love I have for them quite as well.

Welcome new staff

Kate Deacon

**Direct Funding Support Coordinator
Independent Living Centre Kingston**



I am very excited to join Independent Living Centre Kingston in the role of Direct Funding Support Coordinator. I have been working in the disability sector for many years now. My first job in the field was as an attendant for a Self-Manager in London and I am thrilled to have found my way back to Direct Funding. I moved to Kingston last summer from Ottawa, where I was a Program Coordinator at the Ottawa Independent Living Resource Centre. I am originally from Sudbury. I hold a degree in Social Work as well as a diploma in Developmental Services. My favourite pastime is visiting museums, my favourite indulgence is merino wool socks, and my favourite passion is social justice.

Chelsey Deman

**Direct Funding Program Assistant
Disability Resource Centre for Independent Living - Kapuskasing**



Chelsey, originally from London, Ont., comes to the Direct Funding Kapuskasing team with a wealth of knowledge and experience working with people with disabilities and seniors. A graduate from the Physiotherapy and Occupational

Therapy Assistant Program with a francophone diploma, Chelsey has spent the last 10 years providing physiotherapy and program supports to people with disabilities and seniors in various settings. Much of Chelsey's youth was spent volunteering during summers for a family-run summer camp for children with special needs, where Chelsey found her passion for volunteerism and working with persons with disabilities. In 2014, Chelsey relocated to Kapuskasing and started her family. A proud hockey mom with two children, Chelsey enjoys spending her free time enjoying the outdoors with family and friends.

Josephine Hui

**Bookkeeping Report Reviewer
Centre for Independent Living in Toronto**



I recently joined the Direct Funding Program as a Bookkeeping Report Reviewer. My main role is reviewing Toronto-area Self-Managers' reports. I graduated from the University of Toronto with a Bachelor of Arts in Economics and International Relations. In my spare time, I enjoy watching football (or soccer), and movies and reading novels. I also like travelling the world and my goal is to fill every page of my current passport with stamps before it expires. One of my greatest achievements would probably be winning March Madness Bracket two years in a row at my previous company. I won a \$50 gift card and, according to my former co-worker, lifelong bragging rights!



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