

# The Self-Manager

CILT • Centre for Independent Living in Toronto

Spring 2017

## Retaining good attendants

### What I have learned

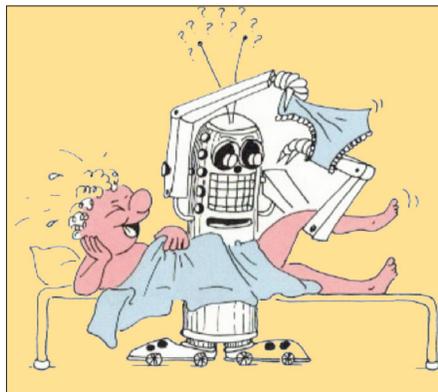
AUDREY KING  
SELF-MANAGER

ROBOTS ARE replacing attendants in Japan. This is the way of the future, according to ongoing research and articles in prominent publications, such as the *New York Times*.

#### Is it a good idea?

On difficult days the fantasy seems a great solution. Even Judy Heumann, prominent disability rights activist and Special Advisor for International Disability Rights in the U.S. Department of State, has uttered the thought. "Fantastic idea" she once whispered to me at a Munich conference when her attendant was having a "non-compliant" day.

When you become a Self-Manager plenty of information is provided about employment standards and business practices. Such information and advice



"... just give me an attendant who won't get bored, or tired, or frustrated, or impatient or want more money..."

Illustration by Audrey King

regarding personal employer — employee relationships is harder to come by.

#### Why is this?

Human nature. Every person has a unique personality, variable behaviours and expectations. Sometimes you and your attendant mesh and get along well. Sometimes you don't. How you relate

to each other can vary from day to day depending on mood and circumstance. Typically, it's up to you and your attendant to work it out — or not.

I vote to keep the robots in the factories making car parts or turning cans of paint on a scheduled programmed basis. Persons with disabilities are not "work objects". Neither are our attendants robots or slaves.

The Direct Funding Program enables a direct employer/employee accountability, a relationship and responsibility between worker and Self-Manager that facilitates quality lives that wouldn't be possible with robots or agency delivered services.

"Human nature" makes every attendant/consumer relationship unique. The choice and control of Direct Funding enables opportunities for learning, growing and resolving the interpersonal challenges that sometimes arise.

Please see **ATTENDANTS**, p. 8

## Welcome our new family member

Parsha Haque is the newest member of the Direct Funding family; she was born in December to AKM Shafiqul Haque,

who became a Self-Manager in February, and his wife, Nishat Sharmin.

Please see **WELCOME**, p.2





## Keep in touch

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# In the hospital...now what?

SOMETIMES, UNFORTUNATELY, Self-Managers do wind up in the hospital. Here are a few tips to keep in mind if this happens to you.

- Have a plan in place ahead of time. Try to set up someone you trust who can contact all of your attendants and bookkeeper in the event of an emergency. Ensure that you have a procedure in place with your attendants so they know who to call once they have called 911.
- Have copies of your WSIB and insurance information handy to take with you. The hospital may request this information to allow your attendants to work for you in the hospital.
- Please contact your ILRC or reporting center if you are in hospital. We need to know how to reach you, and we may have some helpful suggestions.
- Let your bookkeeper know. You will still need to keep track of your hours while in hospital, and your attendants will still need to be paid.
- 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 for some hours while you're in hospital, but remember: hours that you don't use in hospital (since, for example, you will not need meal preparation or housekeeping hours) can be helpful later while you're recovering. Under most circumstances, you shouldn't need to use your full budgeted hours until you get home.
- Remember when speaking with CCAC discharge planners 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.
- As always, you can still use any professional services from CCAC such as nursing, physiotherapy, occupational therapy and social work.



## Welcome

Continued from p. 1



AKM, left, and his wife, Nishat, recently welcomed baby Parsha.



# Bright Lights, Big City

Eric Molendyk, above, who launched TetraGear lights for wheelchairs and other mobility devices, and Matt Pregent (inset). Photos supplied by TetraGear Inc.

**JOHN TAM**

AUDIT AND INFORMATION CO-ORDINATOR

A FORGOTTEN SANDWICH left in a lab becomes penicillin — a fluke. There was no such aha moment with TetraGear lights: they were born from the loins of necessity. While commuting to work one dark winter morning, Eric Molendyk was hit by a motorist who didn't see his power wheelchair decked out with reflective gear. Eric even had the right-of-way. After months in recovery, Eric collaborated with his team of engineers at the Tetra Society, an organization that uses skilled volunteers to create customized assistive devices for people with disabilities. They developed the high visibility TetraGear lights ([www.tetragear.com](http://www.tetragear.com)). After years of testing and refinement, they are now available in four configurations, from the basic "Strips Duo" (two strips for \$200)

to the deluxe "Aerial Plus" (two strips and one aerial for \$300).

Waterproof connectors were integral to the extremely weather-resistant design. The controller with two large feather-touch buttons helms every configuration. Press and hold the power button to turn on and off, and tap it to scroll through the five pre-set flashing modes. Tap the "colour mode" button to scroll through the five pre-set colours (red, white, blue, green and rainbow), and hold it to scroll through the infinite spectrum of colours, release to select, and power off to save as the default colour.

When first powered on, each strip momentarily indicates the battery level; more lights mean higher battery level — red indicates very low battery

levels. A full charge provides 4 hours of solid white light use, while coloured flashing lights can last up to 10 hours. The internal rechargeable battery lasts 3 to 5 years.

The aerial will pretzel into any pose and its universal bracket will attach it to almost anything. The LED strips are easily attached with industrial Velcro straps. The system allows you to be as imposing as a Las Vegas neon sign or as subtle as a low rider with ground effects lighting.

Whether you choose an integrated system like TetraGear lights or multiple bike lights, please embrace my mother's wisdom "we are meant to be seen and not hurt." At least, that's how I remember it now, cycling in the big city with my bright lights.

# Employment program turns out successful workers for Self-Managers

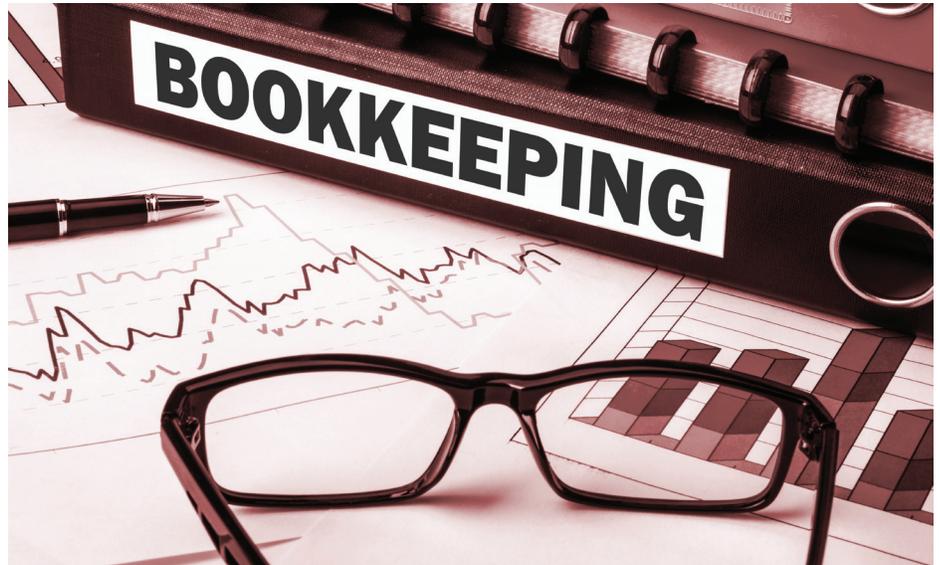
By ANNE MARIE COVELLO-BAXTER  
DIRECT FUNDING COMMUNITY FACILITATOR,  
NIAGARA CENTRE FOR INDEPENDENT LIVING

A GREAT BOOKKEEPER is usually a key part of being a successful Self-Manager on the Direct Funding (DF) program. Your bookkeeper helps with payroll and the quarterly reporting, but many do so much more: they will remind you of what are allowable expenses (and those that are not) and may even mention or recommend attendants they may know of who are working for other Self-Managers.

So, with the DF program growing again, program staff across the province are continually on the lookout for good bookkeepers to support participants. One happy collaboration is the result in the Niagara / Waterloo region.

Mary Jane Waszynski, a case manager with the Work Link program at the Niagara Centre for Independent Living, recently recommended one of her program participants Dustin Schofield, to her colleague, Anne Marie Covello-Baxter, Direct Funding Community Facilitator.

Dustin, a one-time engineer, had recently retrained as a bookkeeper; could he work for some Self-Managers, wondered Mary Jane?



Dustin took payroll courses and worked with DF program staff and administrators to fine tune his skills and is now the bookkeeper for eight Self-Managers, with more program participants likely to hire him in the near future. He has also created a DF bookkeeping memo, which explains the duties and responsibilities of both the bookkeeper and the Self-Manager; this memo is available on the [www.dfontario.ca](http://www.dfontario.ca) website if you have a Self-Manager log-in account

(if not, please visit the site and request a log-in account).

In another program crossover, a second Work Link graduate, Amy Gillis, retrained as a personal support worker and has become an attendant for two Self-Managers living in St. Catharines, Cindy Fegan and Joan McRae. Amy, who has a hearing impairment, has been teaching sign language to Joan, who had always wanted to learn the skill.



## Did you know...

### Bookkeepers

The Direct Funding program is always looking for good bookkeepers across the province. If you would recommend your bookkeeper and if the reporting centre where you send your quarterly reports typically finds them problem-free, please ask your bookkeeper

if he/she would be interested in taking on more clients who are on the Direct Funding program, before passing along their name to your local Independent Living Resource Centre or your reporting centre.

# Dozens of graduates emerged from Self-Manager's 'academy'

By LEANNE LARMONDIN

PROVINCIAL PROGRAM CO-ORDINATOR



John MacDonald

WHILE EVERY Self-Manager has her or his own training regimen and schedule for new attendants, one recently-deceased Direct Funding participant developed his own training "academy", in which "graduates" — attendants who eventually moved on to other jobs — even received certificates.

John MacDonald, a Self-Manager living with multiple sclerosis in Peterborough (he passed away in October, 2016), hired dozens of attendants while he was on Direct Funding for 16 years. Some lasted only a couple of weeks, while others stayed for several years at a time; most were students from nearby Trent University.

The students either picked up on his routines and stayed with him or they didn't and they left; those whom he retained would typically become close to him and his wife. He came up with a name for both his attendants and the "academy," which was the training they went through: the Daphne Academy of Peterborough, with his attendants affectionately called his "Daphnes".

In an essay he wrote in 2009, John explained that the name for his attendants and the academy came from the television comedy show *Frasier*, which featured a character, Daphne, who was a live-in physiotherapist and housekeeper.

"It seemed to suit the type of position of my attendants," wrote John, adding that one attendant, upon graduation from Trent University, said she also felt she was graduating from working with him, as she was moving out of town. "So the concept of the Daphne Academy was born."

And, what would an academy be without a diploma? Dorothy, John's wife (pictured on the left, with a "graduate" of the Daphne Academy), said each attendant received a certificate when they left his employment.

"John created a graduation certificate, signed by the Dean (himself) and Chancellor (also himself)," said Dorothy. "Each certificate had an official seal. The seal was from his father's grain business."

"One 'Daphne' told us she framed the certificate and it hangs beside her Trent graduation certificate."



## In Memoriam



**Etta Ginsberg McEwan**, a Self-Manager living in Toronto, died in February at the age of 90; at the time of her death, she was the oldest participant on the Direct Funding program. Etta, who had polio as a 5-year-old child, also recently participated in the Project Value initiative. She was one of 20 people

with disabilities who gave a video testimonial on the Facebook group that was created to "share stories and experiences that contradict the narrative that disability is a fate worse than death." Her video and those of some other Self-Managers can be viewed at [www.facebook.com/projectmyvalue/](http://www.facebook.com/projectmyvalue/)

# Direct Funding program growing again



LEANNE LARMONDIN

FOR THE THIRD time in as many years, the Self-Managed Attendant Services – Direct Funding program has received additional funds to expand the number of people who can benefit from it. This latest \$5 million is the final instalment of a planned \$15-million expansion of the program; the funding comes from the Ministry of Health and Long-Term Care. It will allow 120 new people to participate in the innovative program, which provides monthly funding to adults with permanent physical disabilities across the province to recruit, hire and manage their own attendants to assist with their activities of daily living.

By spring of 2017, the expanded program will provide funding directly to more than 1,000 Ontarians with physical disabilities to help them self-manage their care. Last year's funding expansion allowed about 60 new people to participate in the program. More than

1,400 people have participated in the program since its inception 22 years ago.

Program manager Leisa DeBono said the funding increase shows that the province sees the value of the self-managed program. She added that an operational review carried out by an external consulting company was overwhelmingly positive, which likely made the funding increase possible. That review looked at every facet of the program and interviewed both new and veteran program participants.

"The reviewers were blown away with the responses from new and long-time participants," said Ms. DeBono, who added the consultants received even more contributions than they were seeking. "These Self-Managers were just so eager to share their experiences on the program."

The program manager added that the provincial government has shown

its confidence in the philosophy of the program – namely, choice, flexibility and control – and the Independent Living movement in general.

"I think the government has seen that our program can reach more people faster and with less red tape than with almost any other program," said Ms. DeBono. "Putting funds directly into the hands of participants means it goes so much farther than it could through an agency."

Administered by the Centre for Independent Living in Toronto (CILT) through the Toronto Central Local Health Integration Network (TCLHIN), the Direct Funding Program ([www.dfontario.ca](http://www.dfontario.ca)) provides monthly funding to about 850 people across the province to manage their own attendants; participants determine how and when their attendant services are provided.



## Did you know...

### Employing family members

It can be cause for termination from the Direct Funding program to be employing and paying an immediate family member as an attendant. The Direct Funding Agreement defines an "immediate family member" as *"any parent, child, sibling, person to whom the Participant is married, or person, other than a blood relative, with whom the Participant has lived for at least 1 year, and with whom the Participant has a personal relationship of primary importance."* Some applicants and Self-Managers occasionally ask if they can employ family members who would fall

somewhat outside this definition (for example, nieces, sons/daughters-in-law, romantic partners who maintain a separate residence), but we always advise strongly against this. When the program was first designed, the Ministry of Health was emphatic that participants not employ family members. Additionally, mixing family with employer/employee relationships is fraught: just imagine having to dismiss a family member. There is also the potential of a conflict of interest, since there would be a financial benefit to the family.

It can also damage the reputation of the program if participants

are found to be employing family members. To that end, Direct Funding program manager Leisa DeBono notes that Self-Managers will soon be asked to sign a code of conduct that is being drafted; that code is intended to remind program participants that they are being entrusted with public funds and they should not be seen to be doing anything that would jeopardize the program.

Lastly, one common refrain we hear from Self-Managers is that Direct Funding allowed their family members to become just family again — not caregivers.

# Meet the new Direct Funding staff . . .



## Jennifer Grooms

Direct Funding Co-ordinator  
Independent Living Sudbury Manitoulin

Jennifer Grooms has lived her whole life in Northeastern Ontario. With a passion for working with the public, she studied at Cambrian College as well as Laurentian University. Following her many years of study, Jennifer went on to start her career in hospice palliative care.

After a short break, Jennifer felt the need to work with individuals who want a better quality of life. The Direct Funding Program was a perfect fit for her.

“My goal is to make applicants feel comfortable with the process,” says Jennifer. “I am regularly out in the community looking for people who would benefit from a program such as this that will allow them to be independent in their own home.”



## Courtney Mina

Direct Funding Resource Facilitator  
Independent Living Resource Centre Thunder Bay

Born and raised by elders in beautiful Thunder Bay, Courtney recently completed her Bachelor of Arts degree in gerontology and is most proud of her published contribution to an assessment tool in elder abuse, which exemplifies her dedication to her community and her passion for learning. Working with Direct Funding since May, 2016, Courtney is working to help grow the program well beyond its current reach and foster an ongoing rapport with current and future Self-Managers in the Northwestern Ontario region.



## Samantha Walsh

Intake and Resource Facilitator, Direct Funding  
Centre for Independent Living in Toronto (CILT)

Samantha Walsh proudly identifies as disabled. She is a scholar and a disability rights activist. She is currently a doctoral candidate at the University of Toronto-OISE in the department of Humanities, Social Sciences, and Social Justice Education, formerly Sociology and Equity Studies. Her doctoral research is in interpretive sociology with a focus on disability and social inclusion. She holds a master's degree in Critical Disability Studies from York University (Toronto). The focus of her master's research was disability and beauty (body image). Samantha completed her undergraduate degree in Sociology at the University of Guelph. She is passionate about inclusion and access for all. She is excited to join the team at CILT.



## Did you know...

### Outside the province

Sometimes, you just need to hit the road ... And, when you do, Direct Funding is available to fund your attendant to accompany you outside the province for up to 21 days in a calendar year. Of course, it is your right to be out of province beyond that period. DF cannot fund attendant support beyond that 21-day window. We encourage you to speak with your local Independent Living Resource Centre if you expect to be away or have a special request. When you know you will be away at any time please let us know (per your service agreement) in case we do need to get in touch for any reason.



Rowan Marchand, son of Jennifer Marchand, executive director of the Disability Resource Centre for Independent Living in Kapuskasing, was put to work in preparing the Centre's newly-purchased building. Centre staff plan to move into their new offices in early April.

## Attendants

Continued from p. 1

I have been a Self-Manager since the Pilot Program began in 1994. My first attendant stayed until she retired — 18 years in total. Another has been with me for 16 years. I've hired difficult-to-deal-with disasters as well as "saints" who've solidly supported me through crises situations.

I've learned many a lesson along the way ... which may be helpful to others:

- The standard three-month probationary period may not be enough to really know a person, particularly if they only work an hour or so a week.
- Be clear about pay expectations, pay schedule and benefits. Review the details of your job contract with your attendant(s) periodically and at least once a year.
- When you hire someone, be very clear about your requirements, job expectations and the attendant's role. For example, you are not looking for a companion.
- Never "pay-it-forward" by giving hours you expect the attendant to work later.
- A job is neither a "right" nor a "religious duty". It is a job and YOU are the employer. Dependence on another person, sometimes for intimate tasks, can evoke assumptions about vulnerability and issues related to dominance, respect and power.
- Many years of employing an attendant who meets your needs well and with whom you share interests in common may lead to friendship. You need to be very clear about roles and pay — which of course — can inevitably compromise friendship.
- Different attendants have different skills and interests. (e.g. cooking, organizing, fixing things). Take advantage of this and assign jobs accordingly.
- Consider how you might respect the attendant and their needs. For example, if you do not physically manage the kitchen, and have the same attendant every day for these tasks, you might let that worker organize the dishes/fridge/cupboards etc according to how they like to work.
- Periodically show appreciation. Acknowledge a birthday, or when out shopping buy your attendant coffee and a muffin — or even lunch.
- Decide how "flexible" and tolerant you can be and/or how much you want to accommodate and adjust to what annoys you.
- Consider investing a little time in your attendant's future. Helping fill out a government form, correcting English, giving a leg up to other careers are just a few examples.



## Direct Funding Program

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