JESSICA’S STORY

“It’s very stressful…If you have to deal with two companies, it’s not worth it.”

We’ve all felt at times that there aren’t enough hours in a day. This feeling is common among those who have to arrange personal care services—something 27 year-old Jessica Chan knows all too well.

Jessica has Spina bifida and uses a wheelchair. From Monday to Friday, she has a personal support worker come to her home to help her shower. She accesses this service through a Community Care Access Centre (CCAC) that contracts her caregiver from a private company.
The rules in place leave her very little control over her own care. She does not choose her own caregiver, and it is decided for her which services her caregiver provides. If Jessica’s care needs change, she has to go through a lengthy consultation process to access more services. Usually, any additional services are provided by a totally different caregiver altogether. Jessica is solely responsible for advocating for her own needs and coordinating the separate services.

“If you need a homecare nurse to help with your shower, and you also need someone who does wound care, you have to figure out for yourself what time the wound care person will come, what time the personal support worker is gonna come…how are you going to place them together?” said an exasperated Jessica.

To make matters even more complex, the private company who hires Jessica’s caregiver prohibits caregivers and care receivers from exchanging contact information. This means that any rescheduling has to be done through the company itself, rather than directly. Jessica finds this rule particularly frustrating: “Why go through the trouble of calling the office if you’re seeing the person every day? What’s the point? You may as well get their phone number!”

While Jessica is frustrated with the fragmentation of her care services, she feels that she has no other options. She simply can’t afford to pay out of pocket for her own caregiver.

Most of us can just jump into the shower when we need to, without a second thought. For Jessica, taking a shower is an ordeal, sometimes involving hours of scheduling and rescheduling every week.

How does Jessica summarize her experience of trying to arrange for her own care?

“Honestly, it’s just really, really difficult.”

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**1 in 7**
Canadians aged 15 years or older has a disability (2012)

**50%**
Of people with severe disabilities do not receive enough help with household tasks

**3% LESS**
Government funding per CCAC client compared to 2002/03, while care needs have increased significantly