



LIVING WITHIN THE SYSTEM

THE STORY OF TWO WOMEN BATTLING TO OVERCOME THE COMPLEXITIES OF SOCIAL ASSISTANCE.

FEATURE STORY

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For many people with disabilities, life is a constant battle for survival to make ends meet. The same things that many Canadians take for granted, a heated home, a vehicle, food in the fridge, a telephone and a computer, are often out of reach for many Canadians with a disability.

According to a recent report by the Council of Canadians with Disabilities, more than 16% of adults with disabilities lives in poverty. It's an issue that's often overlooked for a variety of reasons, mainly due to a lack of knowledge or understanding about the issue.

In late spring, I sat down with two persons with disabilities, Gayle Dixon and Jana Friel, both of whom have struggled to live a quality life within a system that tends to perpetuate poverty. I was also joined by Judy Hannah, SACL Project

Coordinator for the Grassroot Alliance, and one of the key individuals behind the Disability Income Support Coalition (DISC):

Gayle's Story:

Now in her early 50s, Gayle has a warm disposition, her eyes bright and cheerful. From Gayle's laugh and smile, one would have little idea that in reality, life for Gayle has been a constant battle of making ends meet while struggling with her emotional disability including chronic depression.

It's a disability that Gayle has endured for most of her life.

Gayle thinks back to the years following her mother's death, which happened in the mid-90s. "I had a fear of leaving my house by myself, and friends had to take me shopping and to appointments, and my nerves were really bad," said Gayle. "I was really depressed, and I just wasn't coping with life very well."

A salvation of sorts came about for

Gayle 11 years ago by happenstance when she watched a television show featuring service dogs. The dogs are highly trained to provide support to persons with disabilities such as visual and hearing. Service dogs also guard diabetic owners, and have known to have saved numerous lives of diabetics who go into diabetic shock.

"After I saw the show, I went to my doctor and asked if maybe a service dog might help me, and she said why not?" said Gayle. After a long search for a suitable dog and a huge community effort where more than \$5,000 was raised to pay for service dog training, Gayle got Murphy, a young Black Labrador. Murphy, as it turned out, would be the first service dog in Saskatchewan to provide support for an emotional disability.

Gayle's situation is slightly more unique than others who are on social assistance. She owns her own small house – an inheritance from her mom. She also owns her own car, albeit very old and used, which helps her make frequent trips to the leash-free park to exercise her service

dog. Gayle's fortune of having a house, however, is offset by the system which has penalized her for having property. It's an issue that Judy has been working for years to change.

"Because Gayle has her own house, Social Assistance covers the taxes and utilities, but reduces her allowance so that she receives only \$473 a month to live on." "After her basic housing expenses are paid for, Gayle has \$58 a week to use to pay for everything. Her food, clothing, entertainment, car repair ... everything" says Judy.

The bond between Judy and Gayle has grown over the years. Gayle's experience with the system has given Judy a disturbing glimpse into living life on the bare edge of existence.

"I remember one time last winter you had a cold," said Judy as she turned to Gayle and smiled. "You had a few colds last winter and you called me and said you wanted to buy a box of Kleenex because you had a cold. I told her 'well, go buy a box of Kleenex then!'"

"Do you remember what you said? You said it would cost \$1.29 to buy a box of Kleenex and when you're living on so little money you have to always think twice if you're going to buy a box of Kleenex, you know?"

Gayle nods her head. "I'm barely surviving. Barely surviving. The price of food has gone up and I mean, you go grocery shopping and it doesn't go as far as it used to. And you can't buy really healthy food, and so you buy a lot of Kraft Dinner and macaroni because that's cheaper."

As Gayle can testify, being on social assistance means not only a question of living on the edge of existence; it's also a question of dignity. Every main expenditure must be tracked and explained to a social assistance worker in the Ministry. Failure to account for how money received is spent can mean a reduction of benefits, or loss of the assistance altogether.

Gayle is still haunted by a harrowing



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experience she had with her furnace, which had unexpectedly broken down. "I phoned Sask Energy and told them my furnace wasn't working. I had to explain that I owned my house but was on social assistance."

Because the furnace breakdown was an unforeseen expense, Gayle required special permission from her social assistance worker to approve a visit from Sask Energy. However, her frantic attempts to contact her worker before the end of the day were unsuccessful. "I had to spend that night without heat. It was very cold but I didn't have any choice, I couldn't get help."

Judy nods. "You have to ask for everything from your social assistance worker. If you need anything special or extra you have to ask."

"For those of us who don't depend on

assistance, we never do that. If we need the furnace fixed, we just get it done." Gayle's experience is hardly uncommon for those who have long-term disabilities and have little option other than social assistance to survive. One of the major drawbacks for persons with disabilities who are on social assistance is they are severely restricted by any attempts to plan or save money for the future.

Constantly managing every precious penny, Gayle once decided to set aside her GST tax credit for savings and investment, if only to plan for her future and give herself a cushion for unexpected expenses, like maintaining her old car.

"I was saving my tax credits so I could keep it for things like repairs for my car," says Gayle. "Went I went to report to my social assistance worker, they saw that I was setting aside money for savings." "It wasn't a lot of money, but when they found out, it was a big problem. I came really close to getting kicked off of social assistance and if that had happened, I'd have no options left to survive."

Gayle's harrowing experience from her attempts to save money has played a big role in motivating her to become involved in reforming the system. She was one of the first people involved in the now-established Disability Income Support Coalition (DISC), and she has helped to lobby for Saskatchewan Assured Income for Disability, or SAID program.

"I started coming to meetings and getting interested in trying to make a difference," said Gayle. "I've been on Social Assistance for over 10 years, so I know what it's like and I know how the system can be very difficult for people who depend on support."

"I like coming to the DISC meetings, because we're all of one mind. We're all working for the same thing which is to get people onto the SAID program." The SAID program, which following years of planning, meetings and lobbying, was established in 2008. The program is unique in that it provides assistance for people with significant and enduring



Gayle Dixon with her newest service dog, Angel.

disabilities, and gives individuals who receive the assistance greater control over how the money is spent.

"SAID's reporting structure will be much less restrictive," says Judy. "It gives recipients greater control over their lives, and it won't force them to report every single expenditure for approval."

Also unlike social assistance, SAID doesn't punish its recipients for saving money says Judy.

"Here Gayle was, being responsible by trying to put her tax credit money aside and the system wouldn't let her do that." "When it's fully developed, SAID would allow for money to be set aside and nobody would question her about it."

"If you're on welfare you're not allowed to save for the future. On SAID, Gale can set money aside for home maintenance, and if she does, nobody will threaten to cut her off."

"SAID is gonna be great because there's

so many people with disabilities that are just barely surviving," says Gayle. "We need the government to really listen to us and to be able to meet with DISC to understand why we need the SAID program."

Judy quickly interjects. "What Gayle is asking for is just to be able to live, really. And social assistance doesn't allow that, plus the lack of dignity from being on welfare, and she has to go every year for intake where people with disabilities are asked 'do you still have a disability?'"

"That's something that will change when they go on to SAID. They will have to report in every three years. But these disabilities never disappear – if anything your condition often deteriorates over time, so it will give more dignity to their lives, and even the people who are on it already have said it feels different."

Judy remains very positive that the SAID program will soon be expanded to include more persons with disabilities.

"Kudos to the government," says Judy. "They launched SAID and they got people in residential care on the program."

Ironically, even with her long-term debilitating disability, Gayle has yet to be approved for the SAID program, due largely to backlogs and red tape. Still, she holds out hope that within a year or two, she'll finally be approved.

"They got people in residential housing on SAID 18 months ago," says Judy. "Since that time, nobody else has gotten on. Right now the government is testing an assessment tool, and the hope is that they'll finish testing by the end of this summer and start getting more people like Gayle on SAID this fall and winter."

Gayle is adamant that not being on social assistance will provide her with a precious feeling of dignity and control. "If I get on SAID I'll feel like I have respect for myself. I'll feel like I'm not just existing and that I'm actually able to live."

"I'll feel like I'm worth something."

Jana's Story:

Jana Friel is a 29 year old woman with an intellectual disability. Born and currently residing in Regina, Jenna has lived independently for the past 8 years at an independent living apartment in the city.

I met Jana recently at an SACL Self-Advocacy forum. Warm and engaging, Jana immediately directs us to a meeting place. She does not lack independence and assertiveness. Indeed, Jana has lived a great portion of her life independently, extending all the way back to when she entered the work force at a tender 16 years of age.

"I started working while I was still going to school. I was at home and I like to go out but I was also bored. So I asked my mom if I could work and she took me in to talk to the manager, and they hired me on the spot."

Because of Jana's disability, she depends on social assistance to help cover her basic living expenses. The system, however, has very strict rules for the amount of money people can earn while working. Up until February of this year, the Ministry penalized individuals who earned more than \$150 a month. 75% of any monthly earnings over the \$150 amount were deducted off of her assistance check.

Jana wasn't generally affected by the penalty – working reduced part-time hours, Jana's earnings were under the cap. However, with her employer issuing paychecks every other week, there are two months out of every calendar year where three pay stubs are issued. The combined total of the stubs exceeded the earnings cap, and as a result, Jana's social assistance benefits were penalized.

"I felt sad when they took money away," says Jana. "I worked hard for my money but I had no more in my bank account. I have to have enough money for rent, the phone bill, groceries and other things to live on. I didn't have any money to do other things like go to a movie or go out with friends."



"I worked hard for my money but I had no more in my bank account."

Jana wasn't only sad. She was angry.

With the help of Judy and the DISC, Jana managed to meet Social Services Minister June Draude face-to-face about the penalty.

"I met with Minister Draude last summer and I talked to her about how I once got three pay stubs in a month, and asked her what do I have to do to keep my money?"

"She said that wasn't right." Indeed, following that meeting, Minister Draude enacted an adjustment a few months later which raised the earnings cap by \$125 to \$275 a month.

For Jana, her big wish right now is to work more hours, perhaps even getting a second job. "I would like to work on the days I don't have anything to do, like three or four days a week and work 16 or 20 hours a week."

"The problem is," says Judy "if she were to work more hours, she would still

lose money, because the earnings exemption isn't very high."

"We're working on raising that further. Jana deserves to keep the money she's earning."

For Jana's parents, Shirley and Mark Friel, the concerns they share for Jana go beyond making ends meet month-to-month (which often, she can't). They think about Jana's long-term future, and what supports will be there to ensure she will be taken care of after they're gone.

"Every month we have to subsidize Jana for things like clothes, and some groceries and cleaning supplies," says Shirley. "It really doesn't take very long for her money to be used up."

"Exactly," says Mark. "I've talked face to face with people from Social Assistance who issues these checks and they know that all the parents are providing some help to their children. The big question is how would Jana survive if Shirley and I weren't here?"

Right now the Friel's are putting money away through the Registered Disability Savings Program (RDSP), where money can be put away until the recipient reaches the age of 59.

Still, Shirley and Mark don't stop worrying about Jana's future.

"Prior to the RDSP, which I think is phenomenal, the long-term is helped a little, but Jana needs to look at the pure long-term," says Mark. "If I last until I'm 80 years old, and I can keep putting money in yearly into a RDSP, and look after any shortfall, then that's okay."

"But what if I don't live until I'm 80? It's on my mind every day."

"We know that while we're alive we make sure that she's got things she needs in her apartment," says Shirley. "But we know if we were to be gone

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suddenly from the picture that the system would probably take over, and Jana might not be able to retain that independence and live on her own."

While advances like the RDSP have been made in helping to provide greater security for the future of individuals with disabilities, Shirley and Mark are still haunted by pessimism.

"Are things moving fast enough? No. Hell no," admits Shirley.

"But are they moving forward? Yes. And hopefully for those who come after as we look back on the days of integration and mainstream integration that we fought so hard for with Jana to stay and remain in her neighborhood schools."

"What has happened in the years to follow has been to benefit parents bringing very young children into

schools, and finding programs in place, and supports in place that weren't there when we enrolled Jana."

Shirley's voice dims. "Things are moving forward, but there are still a lot of issues. Right now Jana can't earn much more than a couple hundred dollars of her own money before they start clawing back on what is already a very low income."

"Will we live long enough to see persons with disabilities have enough money to live a quality life? I'm not sure."

"I don't think we'll see it in our lifetime."

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A few weeks later, I happened to meet Gayle again, this time she's beaming with her new service dog, Angel. We sit down and talk about how things are coming along – matters are up and down. Her car is acting up, and she fears that she might have to get

expensive repairs done. With Angel at her side though, I sense that Gayle feels like things will turn out alright.

We talk about her future. I ask Gayle what her life dreams are.

Gayle pondered my question for a bit. "I'd like to be able to buy treats for my dog. She works so hard for me that I wish I could buy something for her in return."

"I'd love to be able to buy Christmas presents for my friends. I try every year to make things for my friends just to say thanks for all they do to help me."

"I'd like to go to a movie if I saw one that I thought was good. I have a friend that lives on the other side of the river and we don't see each other very often because it costs so much for transportation."

"I'd love to phone her up and say 'hey, can we meet for coffee or something?'"

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