O.D.S.P. ACTION COALITION

Telling Our Stories:

Disability Should Not Equal Poverty

“In the shadows of the blue collar
A disabled man bows his head
His pocket contains four dollars
Which must stretch thirty days”

July 2010

In the Shadows

In the shadows of the blue collar
A disabled man bows his head
His pocket contains four dollars
Which must stretch thirty days

In a specific area of town he has been assigned
Where he rents a small place with a small dog
Each month the government issues a cheque
Which is said to be plentiful for basic living

He had not enough food
To eat a proper diet
But the bills have been paid
And thus his place is his own

He is allotted four transit trips per month
Which does not include errands
Multiple trips carrying loaded bags,
Weakens the back and continues fatigue

He pinches pennies for his luxuries
Cable TV, phone and internet.
Anything else requires the sale of personal belongings
Though he has nothing left to sell

To see a movie would mean skipping three meals
To which heavy medication would react accordingly
Doctors claim that the time is not right
To go back to his blue collar life

So friends call less often and family too
Yes, he assures them he is in good health
Because this is what you want to hear from him
It’s true finances are maintainable

He will tell you, so you need not offer
Food is plentiful you are assured
Because you would not understand
But if you asked and really wanted to know

He would suggest the sick are kept sick and the poor kept poor
And though countless studies have proven,
Health is directly related to quality of life
The poor are sick and the sick are poor

If you know this man and his small dog
You will know a good heart and great smile
They will treat you with respect and kindness
To which they are sometimes left without.

~ Kevin from the GTA

Contents

Acknowledgements

This project wouldn't have been possible if it weren't for the 236 people who shared their experiences of ODSP with us. The advocacy that the ODSP Action Coalition does to improve the Ontario Disability Support Program is bolstered by your generosity!

On behalf of the Steering Committee of the ODSP Action Coalition, thanks to all those who worked hard at collating and editing the document.

People who shared their stories also offered some thanks for the opportunity to vent, share their struggles with the ODSP system, and voice their opinions on how problems might be fixed. We also received some expressions of hope that together we can improve conditions for people on ODSP.

People on ODSP face much stereotyping and discrimination as they struggle to deal with physical and mental disabilities. Each person's situation is unique. What is shared is a life of poverty.

Telling Our Stories is a project of the Public Awareness and Advocacy Committee of the ODSP Action Coalition, a province-wide coalition of people with disabilities on ODSP, community disability agencies, provincial organizations, anti-poverty groups, and community legal clinics.

The purpose of the project is to give people on ODSP a chance to tell their own stories about trying to survive on ODSP. We believe that these stories, taken from the responses of 236 people around Ontario, are the best evidence of the urgent need to improve supports for Ontarian's with disabilities.

……

Over 370,000 people with disabilities and their families depend on the Ontario Disability Support Program (ODSP) as their primary source of income.[1]

They are the lucky ones who got through the complicated application process and didn't give up when they were initially rejected – as many are.

Yet, once on ODSP, people with disabilities discover more problems.

ODSP replaced the Family Benefits Allowance in 1998. The rates paid to people on ODSP have increased by only 11% since 1993. A single person on ODSP receives a maximum basic allowance of $1042 a month (less if rent is subsidized).

While people with disabilities are encouraged to work, many aren't able to because of their disability. If they can work and do get a job, 50% of their

The **ODSP Action Coalition** was formed in 2002 following province-wide community consultations that found serious problems with the Ontario Disability Support Program (ODSP), which many people with disabilities depend on for their survival.

The Coalition's 2009 **Disability Declaration** identifies what we believe government must do to respect and supports the rights of people with disabilities.

Our mission:
To push for improvements to ODSP so that people with disabilities can live with justice and dignity

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[1] Ministry of Community and Social Services, Ontario

earnings are clawed back despite the fact that ODSP rates are so low. Families can make a modest contribution to their adult children's support.

Other sources of income that could raise the standard of living for people on ODSP are clawed back making the inadequate ODSP rates a ceiling rather than a floor on which adequate support can be built.

On top of economic vulnerability, persons on ODSP are too frequently treated with disrespect by those administering the ODSP program. Program rules require that ODSP caseworkers spend most of their time "policing" compliance with program rules.

The rules governing ODSP are complex, and often bewildering to recipients. Some benefits are unevenly available. There is often little information about rules and benefits. This is reflected in some of the quotes; recipients may have entitlements they are unaware of, or they misunderstand program rules. We have not edited to correct misapprehensions about the program – because for them, this is their reality. A benefit they are not aware of may not be available to them.

People on ODSP are often isolated by their poverty because of stigma and lack of resources to participate in community life. Rules inhibit spousal relationships, leaving many feeling destined to live alone. Lack of opportunities in terms of employment, education, transportation and basic community activities leaves many people on ODSP excluded from society and frustrated at not being able to contribute what they are more than able to contribute.

Who participated

The response to the project was amazing. We want to acknowledge and thank the 236 courageous individuals who participated in this project by sharing their stories and their ideas for improvement. The ODSP Action Coalition gets its strength and credibility from members and supporters who are prepared to stand together and use their own life experience to show the rest of the community what needs to be changed.

We read and valued what each of the 236 people told us. Each person's voice and story is important and unique and is helpful to the Coalition's advocacy work beyond this report. The quotes that we have used in this report come from all parts of the province (see Appendix C for a full list of communities) and from people with all kinds of disabilities (See Appendix D for a full list of disabilities participants are living with). Some quotes are from family members who are supporting or caring for persons with disabilities.

How people's disabilities affect them

We asked people to tell us how their disabilities affected their lives. The effects of many disabilities are hidden from those who are not living with them. To fully understand how well or poorly the ODSP program meets the needs of the persons it is designed to help, it is important to understand the unique challenges faced by persons because of their disabilities. Appendix E contains a full list of comments grouped by disability.

Some of the effects people described were unique to a particular type of disability, but others ran across different disabilities. A commonly reported impact is isolation and social exclusion: **feeling isolated, depressed, alone, not having friends, and lacking support.** These are effects that can be addressed through good social policy, including through an improved disability benefit program.

How *Telling our Stories* is organized

This report is organized around six main themes:

- Adequacy: Living with Dignity
- Aspirations: Education & Employment
- Stress & Social Isolation
- Beyond the Basics
- Program "Service", and
- Program Design

Running throughout the six categories are some overlapping values and needs expressed: **independence, choice, health and dignity**.

In addition to sharing their experiences of living on ODSP, we also asked what changes people wanted to see happen. Some of these ideas are shared in this report, but many are not. Ideas for change will be summarized and passed on to the Coalition's Policy & Research Committee to analyse and build upon. We will use what we learn to bring forward the best proposals to the province's upcoming Social Assistance Review. For now, we will tell you people's stories…

Theme 1

Adequacy: Living with Dignity

…it's not enough to help you sustain your life

They do not give you enough money. By the time you pay your bills you are digging into your food money. Any times when you have extra bills, then your money is gone sooner and you have no money for the rest of the month. Whatever material possessions you have now has to last you forever because there is no money to buy anything new – like furniture, clothes, appliances, etc. I cannot go on a trip or buy any extras – there is no money for anything like that.

~ **M. K.**, Southwestern Ontario

More people wrote to us about the amount of money they receive on ODSP than about any other topic.

It is not enough to help you sustain your life and try to train and volunteer to get a job to get off ODSP. It keeps me on it.

~ **Michael**, Toronto Region

I can't afford decent food. I can't buy clothes. I can't afford a social life. It's not enough. It's a dehumanizing insult.

~ **Dee**, Ottawa Region

ODSP is extreme poverty, and it is awfully scary being treated this way. ODSP has no respect at all for people who are disabled.

~ **Linda**, Ottawa Region

Increase in benefits must be done…allowing a vulnerable part of society to live that far under the poverty line is unsafe.

~ **Paul**, Southwestern Ontario

We heard how hard it was to stretch the amount over a whole month, and how it was common to run out midway through a month.

"His pocket contains four dollars
Which must stretch thirty days"

> I have a detailed budget that proves, with no existing credit based bills, the suggested monthly ODSP payment is next to impossible to live by. Basic living does not include cable TV, internet, or cell phones. These are considered luxuries. And cell phones are a necessity for certain disabilities such as Epilepsy.
>
> ~ **Kevin**, Toronto Region

Lack of choice is a recurring theme. To one contributor, not having enough money means going without coffee at the end of the month.

> … [ODSP] Forces you to live in poverty; limits choices in where you live; forces you to give up "healthy" pursuits.
>
> ~ **Peer Support Group**, Southwestern Ontario

Lack of appropriate and reasonable funding. The incapability to live a remotely normal life, inability to repair, replace or obtain new items deemed as standards of living (such as bed, dresser, curtains, dishes, pots and pans, etc. etc.)

~ **Candace**, Southwestern Ontario

> [We need a] clothing allowance. Left with $200 – 300/month after rent does not allow recipients much to live on. Haircuts, clothes, an outing with friends are luxuries.
>
> ~ **J.J.R.**, Central Ontario

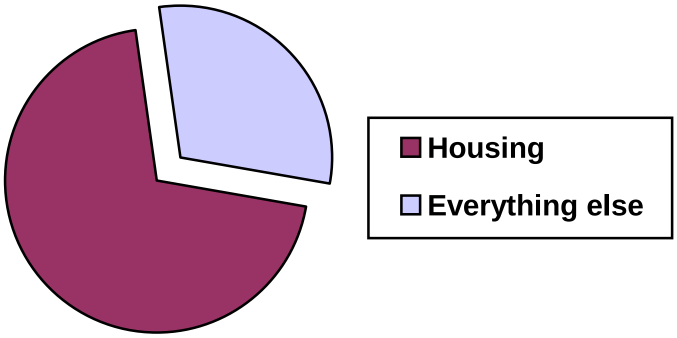
Many responses focused on how the lack of ODSP benefits result in a person having to depend on their family or friends, which erodes their independence.

> Enough to survive but not live on, not enough to be able to save for anything or even buy healthy food, have to rely on parents.
>
> ~ **Kathryn**, Toronto Region

The ODSP shelter allowance is not enough to pay for safe, decent housing …

> Finding decent housing on the allowance provided for that is impossible. I need to use a scooter or wheelchair. The tiny, dangerous, damaged, smoke- and insect-filled apartments which are all that I could possibly afford are not accessible! My present building is so bad that I'd rather live on the street. I am so desperate that suicide enters my mind often.
>
> ~ R.G., Ottawa Region

People on ODSP are using far too much of their total income to cover the cost of their housing (some use 70%, 90%, 2/3 of their income or 'most' of their income).



> My son pays $700 for a modest heated apartment, hydro extra. This represents about 2/3 of his monthly income, leaving less than $100/week for groceries, utilities, clothes, etc.
>
> ~ On behalf of Kyle (written by his mom), Ottawa Region

My rent has been increased to $200 more per month over the past ten years. I can assure you that my Benefits have not increased at this rate. In my experience, every (oh so modest) increase in benefits has been chewed up by the mysteriously arbitrary “Allowable Increase” the landlords benefit from………

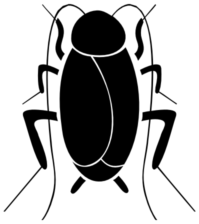
………**I want a dwelling allowance that is commensurate with my actual rent** or I want to have my rent reduced to the allowable amount. I would greatly appreciate it if the decision makers took a look around and came to the realization that the ODSP benefit is inadequate. Disabled persons live difficult lives; the added stress of trying to live on this allowance is a daily burden. We are disabled. We are sick. And now you have made us poor. **I would like for someone at the Ministry to live on ODSP for six months. I cannot see another way to reach these people….**

~ **Dee**, Ottawa Region

Rent in a safe building is expensive ~ Reg, Southwestern Ontario

I have had seriously hard times not only finding landlords willing to accept those on assistance, but also finding appropriate housing in a reasonable area under the low amount allotted for housing costs. Every time I would try to find affordable housing it would always be within an area that was not only inappropriate, but dangerous. A place I would never raise my daughter in.

~ Candace, Southwestern Ontario



Forced to live in sub-standard housing

~ Carla, Toronto Region

How can anyone start to feel better if you are living some place where people do not care and do not take care of their place or themselves because there is no hope. I heard someone speak about poverty and this sums it up nicely:

> *If you have money your elevator always goes up and if you work a bit you can go ever higher. If you live in poverty your elevator goes down and if you are able to work a bit to get out you never get anywhere. This is how people feel on ODSP – they will never get anywhere, everything is a struggle. For people with Mental Illness this makes them suffer even more.*

~ Earla, Toronto Region

My experience with acceptable housing is grim. ODSP recipients are at the mercy of subsidized housing or living in market rent substandard conditions

~ J.C., Southcentral Ontario

Because I am not able to afford market rent. I am forced to live in a room with subsidized housing.

~ John, Toronto Region

Before today I was struggling with a place to live and was out on the street for two weeks until I found a place but the place isn't up to code.

~ Yvonne, Toronto Region

Not many people on ODSP are homeowners, but for those who are (for example those living in rural areas with no rental housing options), challenges include:

- Unable to keep up with necessary repairs
- Unable to keep up with rising cost of hydro and heat
- Property taxes and condo fees increase much faster than the 1% or 2% annual increase in the ODSP

Why are we expected to eat poor food? Wouldn't we be healthier if we had enough money for a nutritious diet?

With food money needed to pay the rent, food insecurity and poor nutrition is the norm for many people on ODSP. Contributors described the feeling of needing to turn to food banks as one akin to begging. The reality of choices came up again here, this time in terms of food versus rent, taxes and bills: described as impossible choices.

> Budgeting is a fact we all face but in the case of ODSP amounts, it is IMPOSSIBLE for anyone to manage to meet the dietary needs of a child with the money allocated for that purpose. There is also many health related expenses that are NEEDED as prescribed by a doctor, but are not covered by OHIP or ODSP benefits.
>
> ~ Elisa, Toronto Region

> I need good nutrition because I am overweight and have medical problems because of it. It is very expensive to buy good nutritional food to lose more weight and be healthy.
>
> ~ Raymond, Northeastern Ontario

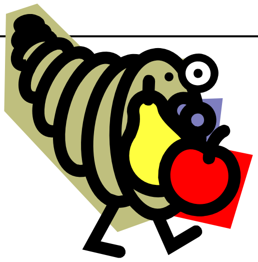
> I need special food and I got cut off special diet after they cut me from $250 to $40/month and to $0 for almost one year before I got back on. My family doctor is really mad about this stuff and he says that because of this stuff my health has really deteriorated. I have known this doctor for 7 years.
>
> ~ Brian, Toronto Region

> Food on ODSP is low quality and buying good food weekly is not possible. Why are we expected to eat poor food, which does not help with our health, moods and quality of living?
>
> ~ **Barb**, Ottawa Region

In March 2010 the Ontario government announced that it will eliminate the current Special Diet program, replacing it with a Nutritional Supplement that will leave many without additional support.

We heard from many people about how important the SDA is for people who have special dietary needs.

The **Special Diet Allowance** program is a long-standing part of Ontario's social assistance system.
It is intended to relieve the disadvantage faced by people who have extra dietary costs related to therapeutic diets prescribed by their health care professionals.



Parenting on ODSP: It hurts to see my kids left out

Not having enough money to raise a family, to me, is our social policy created disability.

~ D.S., Northeastern Ontario

I can barely feed my children. Often times I go without so that they may eat and have clothing (used clothing at that).

~ Nancy, Southcentral Ontario

I am a disabled 37 year old on ODSP with an 18 year old and a 16 year old. I was struggling with housing, food etc, then when my son turned 18 years old he graduated high school, but decided to stay one more year to get credit in physics and science and the government took of my baby bonus and now you can just imagine how much its hurting us financially ………

……..they are both in sports, so they need money when they go out of town to tournaments and its very hard for me to keep them in sports. But they have to because I don't want them to go bad, I want them active and contributing to the community. But if policies are not changed and I don't get back the 300 hundred I lost when he turn 18, I will have to take them out of sports and take my son out of school and there goes two lives down the drain.

They don't stand a chance of getting out of this cycle of not enough money…and its sad, all the work they have done and me to be good, hard working on education will be for nothing, why can't you guys see that the cycle will keep on going like that, until government really understand the way policies affect Canadian families. If I would have extra money in a month there would be a chance for my children, but there is not one policy that is working for us.

~ Sylvie, Northeastern Ontario

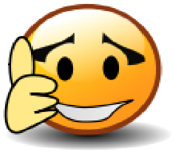
For this mom, trying to shield her child from poverty is the focus:

> There is so much the kids have to contend with, they've seen so much aggression in their neighbourhoods and they're not protected in their own buildings because of the housing conditions and the barriers to access adequate education, medical services, recreation, etc. **In the best of cases, the kids are not disabled, the parents are but the kids pay the price and this is a shame having kids living at risk with parents unable to provide for them and the ODSP not providing for their basic needs** (medicine, food, clothing, educational supports, transportation, etc). …I used to think of my child as being very resilient but now that he has endured so much hardship, I can see resentment building up and it hurts. …**I've done my best to keep my child as uninformed about my economical woes as possible but after a certain age, I knew he knew more than I wished and he showed awareness of the constraint and unfortunately the worry. It devastated me.**
>
> Once, the topic of poverty arose in his Art class at school. The first thing my child asked was what was poverty, some kids laughed and the teacher though he was kidding, but my son insisted on getting the definition because the teacher had photos of children from Africa with flies in their faces and was trying to get the students to think of the wonderful things Canadian children have without realizing that most kids in the classroom did not have any of the things she was talking about.…The kids were given the assignment of writing a poem titled poverty. My son wrote:
>
> *Poverty is despicable.*
> *Malnutrition is abominable.*
> *Poverty is the bitter fruit of a dictator's labour.*
> *Peace is no longer our watercolour.*
> *Why is it still here? Now that is questionable…*
>
> …**The phrase 'poverty is despicable' may have very little meaning to many but for most children living in poverty it describes their very own complex and devastating situations.**
>
> ~ Elisa, Toronto Region

> **We had to give our child up for adoption.**
>
> ~ **Pierre**, Ottawa Region

> ODSP should adequately support parents who are doing their best to keep their children/young adults at home.
>
> ~ Patty, Southwestern Ontario

Parents struggle to give their children the supports they need as they move into adulthood.



> [My] Daughter is in [her] 20s now and lives on [her] own but [I] had to help her financially while she was in school and university. I had to pay a lot of money for her to get to and from school everyday. [There] should be a transportation allowance for school kids or the spouse (separated) should be able to pay it without penalizing the mother when on ODSP – couldn't get subsidy from the school.
>
> ~ J.E., Toronto Region

Keeping us as poor as possible: Clawbacks take away the chance to improve our standard of living

Other disability benefits are deducted $$ for $$:

Because my daughter once worked and paid CPP, she qualifies for a small monthly disability allowance from CPP. ODSP rules deduct it from her ODSP allowance, even though it is my daughter's money. It appears that they want to keep clients as poor as possible.

~ E.F., Southwestern Ontario

Employment earnings are deducted at 50%:

[The 50% claw back] …does not make sense considering the amount of support is very basic. This rule does not encourage ODSP recipients to work.

~ V.F.B. & H.M.B., Toronto Region

Removing 50% of money earned if you find work on ODSP seems to defeat the process of helping people save money and get back on their feet. After all being on such a low income system does nothing but ensure debt and increase the health decline, poverty and quality of life in an individual or family.

~ Candace, Southwestern Ontario

Stupid is the right word. Again, there is not much chance in getting ahead, with the extra money you earn you need transit, clothes, lunch money and so on. It is demoralizing – people are blamed for their disability. They do not get respect.

~ Earla, Toronto Region

50% earnings claw back makes it so there is no way to get ahead, no way to get out of the bottom line of civilization because the starter jobs don't pay enough and ODSP is removed.

~ Kathryn, Toronto Region

Child Support is deducted $$ for $$

If my ex pays child support in any form it is removed from my ODSP. Absolutely nothing goes to benefit the child. I am in no way capable of putting money towards a college fund, putting my child into extracurricular activities or simply taking my daughter to a movie once in a blue moon. What kind of society have we become when we steal from the mouths of our future? We are doing nothing but instilling the same circumstance that has befallen us onto our offspring. Shouldn't we be trying to better their future?

~ Candace, Southwestern Ontario

Deducting child support payments from monthly benefit cheques..... That money is supposed to be for the children, to help feed and clothe them. It just isn't worth the trouble of trying to make dead beat dads pay.

~ Nancy, Southcentral Ontario

Parents receiving the federal Child Tax Benefit and the Ontario Child Benefit had their ODSP benefits reduced so their children get less out of these programs than other children

Those benefits are there to help children. I find it disgusting if such a monetary benefit is being removed from children’s mouths. How exactly does such a benefit help children if half of it is being removed?

~ Candace, Southwestern Ontario

Let people keep extra sources of income:

Relax on the deductions. I mean we are actually disabled and should be allowed to collect child support, work one or two days a week and accept monetary gifts or allow a friend or relative to give us food without being penalized for it through repaying it back.

~ Nancy, Southcentral Ontario

If ODSP would take only 25% of earnings after a set amount, such as $250, it would give some recipients the support to get back on their feet. This isn’t the case and it’s a shame. Why would anyone work when ODSP won’t allow them to keep most of their wages? Would the officials and administrators of ODSP work for $4.00 an hour?

~ M.A., Southwestern Ontario

Theme 2
Aspirations: Employment & Education

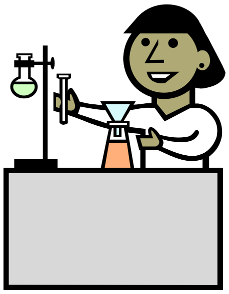
Opportunities to participate in employment and educational pursuits are integral to feeling connected and included in community. They enhance the choices people have, and in turn, how independent we can be. The 50% deduction of earnings is only one barrier towards moving into employment.

The work and earning program is not helpful and very complicated. No initiatives to help become independent.

~ **Jordan**, Toronto Region

Since the support agencies failed at getting my son even part-time employment because they did not understand their client's disability nor tried hard enough, ODSP gave up on him and seem happy just writing cheques. He can do more but the support is not there. They leave it up to his parents. We may not be there for him tomorrow.

~ **Dezman**, Lake Ontario East Region



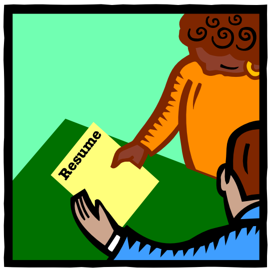
I cannot describe what I would give to not live off such low costs, to be able to afford university instead of settling for a private college or to have the support to rid myself of many of my medical problems. …Given the chance it could be one of us to be the next Prime Minister, the next scientist that cures cancer or the next engineer, MP or Doctor. …when a system removes those opportunities by putting you into debt, poverty or into a mode of simply struggling for life, it makes success seem like a distant star in a far off galaxy.

~ **Candace**, Southwestern Ontario

Many people have worked part-time or occasionally, but face significant barriers in maintaining work steadily or over long periods of time. Persons with recurring, episodic medical conditions may be able to work consistently during some parts of the year and be entirely unable to work at other times.

Even though our Human Rights Code prohibits discrimination on the basis of disability, the job market is not a welcoming or friendly place for persons with disabilities. More effective supports are needed both inside ODSP and outside in the labour market to increase access to employment opportunities.

> **We didn't choose to be disabled (for everyone life can change in instant), we are willing to work but unfortunately rare are companies whose hiring people with disabilities.**
>
> ~ Musswac, Toronto Region



> **There is also much more community education that needs to happen so that employers will give opportunities to persons with disabilities. The challenge still remains accessibility for many. The government should offer more in terms of wage subsidy to entice businesses to give all people a chance.**
>
> ~ Rhonda, Central Ontario

For those trying to enter the workforce, the employment supports that exist within the ODSP have not been helpful.

> **...there's no real incentives to work because of the 50% claw back. Also – employment supports were no help. They sent me to McDonalds, and I knew I wouldn't be able to do it, as it was too fast for me. I got really critical feedback at McDonald's, and it was hard for me and sapped my self-esteem. I got the same criticisms I'd been hearing all my life. It was like telling someone with a physical disability to run faster. Every time I try and work I run into the same problem.**
>
> ~ Debbie, Toronto Region

Depending on how far from a major city a person lives in

Ontario (and how accessible their transit system is), not having a vehicle restricts their employment prospects:

> I have a college diploma and I have been unsuccessful at finding employment for my apprenticeship. I even struggle getting the money to copy my resume and get around to the places I need to apply. I require a vehicle to travel to and from work – if I get a job – and I can't afford a vehicle or the insurance.
>
> ~ Andrew, Toronto Region

People who shared their stories agreed that not only should the 50% earnings deduction be reduced or eliminated, but that there needs to be an increase in employment opportunities (for everyone who wants them) in terms of helping people get jobs, incentives to employers, and so on. Employment supports and training is one key way to improve access to employment.

> I would like respect to be given to people on ODSP and greater incentives to employers who will hire people with disabilities – all types of disabilities. If people were allowed to work as to their ability there would be a greater self esteem for the person with a disability and the employer would receive a benefit for hiring this person and the person with a disability would be able to help themselves get a little ahead by having the ODSP and benefits as well as the income whether a minimum wage or better or a job sharing or part time or even a few hours a day or a few days a week. More flexibility and more respect for people of all abilities and capabilities.
>
> ~ Kathryn, Toronto Region

Education

Education, in addition to being a key self-development tool and building self-esteem, is also a way that people broaden their employment opportunities. The stories here, rather than being tales of opportunity, describe frustration and barriers.

I would like to go back to school but I would need special accommodations which would cost money, like having a note taker.

~ Debbie, Toronto Region

I won an award worth $17,500 from the Social Sciences and Humanities Research Council. I worked hard during my undergraduate studies and now I earned the award to do research as a graduate student. I assumed the award was mine to keep. After all, if I earned the money from employment and I am a full time student, I get to keep the money. So, I spent the money on things and I didn't keep the receipts.

Months later, ODSP wanted me to provide evidence that I bought things for educational purposes. To me, what is for educational purposes is not clear. For example, is high speed internet for educational purposes given that I require that to do my school work? But one could argue that it is not for educational purposes because I got it to watch movies online……….. Anyway, because of my failure to provide detailed receipts as evidence that I used the money for educational purposes, **ODSP stopped giving me any income and said I owe them money because I was given income while I had the award. I see it as discrimination. A student without a disability and who has a steady income from his/her parents will enjoy the extra $17,500 while I don't because I am disabled.**

~ Rosina

As a mother of a child with Autism, a Respite Home Provider, a Transition Worker, front line staff, a Trustee, as well as an Adult Case Manager for many years I have encountered many flaws with this system both personally and for the people I support. …Some [people want] to continue with their education after high school and the few elite programs that are available remain at regular tuition fees, making the likelihood of attending college impossible.

~ **Rhonda**, Central Ontario

…make funds available for individuals to got to school to further their education or enhance job training making more jobs to those who wish to remove themselves from the system …Wouldn't it be easier to help those with medical problems overcome them and be able to find meaningful work in the work force instead of them being stuck on ODSP for life?

In theory $20,000 for school seems like a better option than $200,000 over the course of many years on the system. **This would improve the quality of life for many individuals, create a greater educated community base, further the economy, create more jobs and further the work force.** I fail to see how this doesn't benefit Canada when a lot of people with disabilities can make a difference just anyone else can.

~ Candace, Southwestern Ontario

Theme 3
Stress and Social Isolation

Stigma & discrimination

> Biggest challenge on ODSP? For me it is the stigma. I look normal, can walk normally sometimes and act 'normal'. Some taxpayers view individuals like me with suspicion.
>
> ~ J.J.R., Central Ontario

People have experienced discrimination and stigma from family, landlords, peers, shelter, employment and social situations. Several people characterized their experience as being treated as a non-person or sub-human.

> We are routinely vilified in the media simply for being poor; where social assistance is usually portrayed as a wasteful 'lifestyle choice' or a 'drain on the system', rather than a necessity. ...I have been frequently viewed with scorn and indifference by my neighbours when it is discovered that I require social assistance, even though I have contributed hundreds of volunteer hours every year to make this town better for all residents.
>
> ~ Anne, Southcentral Ontario

> My children don't deserve to be treated like 2nd class citizens
>
> ~ B.J.R., Southwestern Ontario

> ODSP dooms recipients to live in a degree of poverty that is soul destroying and health destroying.
>
> ~ Maureen, Guardian of daughter Peggy, Toronto Region

Many wrote about stigma and discrimination and described the impact as very stressful. Two people went further and said “the stress is making us sick!” Others said discrimination affected their health, listing depression as a common effect. People described being made to feel that that they were begging or that they have to justify their need. Another wrote about feeling that they would never get ahead.

Being on ODSP is stressful, and stress is making us sick!

> Since my induction to the system, my health has deteriorated in many ways. Mostly everything is stress related. After my SCI [spinal chord injury], I was house bound for about a year as I ‘recovered’ and in January 1989, I was hit by a truck. That’s when the brain injury happened and went undiagnosed and untreated until 2003. **It doesn’t help that I am alone…and have no support anymore from my family out of town. …I have not been able to sustain many healthy relationships anymore because I have no money to get involved in anything or do anything. I no longer have anything in common with the class of people I used to socialize with. I’m also not as positive, cheery and pleasant as I was pre-SCI. So I don’t get included anymore.** Even volunteering costs money for transportation, clothing, grooming and then they all want donations of some sort. Of course, money is not the sole reason, but it’s a close runner up.
>
> ~ **Janice**, Northwestern Ontario

> **I will tell you that worrying about money every month for the last ten years has created a constant anxiety. This anxiety is reflected in my overall health. Multiple Sclerosis patients are supposed to avoid stress. Stress makes us sick.**
>
> ~ Dee, Ottawa Region

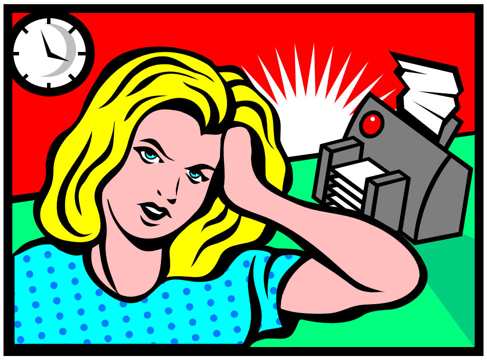
> **I don’t have the money so I just suffer, and society loses out on my contributions**
>
> ~ B.J.R., Southwestern Ontario

I would like the phone to be considered an essential/necessary expense like heat and hydro because it is my life line since I am not able to get out much

~ J.M., Ottawa Region

Health has proven directly related to quality of life. Persons with disabilities are forced into poverty, and most of those people live in areas of poverty and crime. I use the word poverty because the poverty line in Ontario is between $14,000 and $18,000. I personally make $10,466/year. We cannot afford even simple things like seeing a movie at a theatre once a month. If sick people are constantly stressed and unhappy, and/or depressed, they will only become more sick.

~ Kevin, Toronto Region



I do not have enough money to do anything. I have enough for food, rent and phone. I am not able to save for anything, go anywhere, or do anything interesting. The lack of stimulation drives me crazy. Sometimes I just want to visit my brother but I can't get there!

~ Andrew, Toronto Region

Spousal Rules: Destined to be alone?

ODSP leaves people living in isolation because of its rules – some of which discourage relationships.

> To be able to live common law or married and still receive my disability benefits without having to depend on partner for support, and, for instance if I were to meet someone and ODSP threatens to cut off income and benefits because new partner makes good income they be responsible to support me who would take that on what chance do I have for a relationship?
>
> ~ Jeff, Lake Ontario East Region

The rules say that after 3 months of living together, people are treated as a couple and the partner (not on ODSP) must support the person on ODSP. For everyone else, Ontario Family Law says it's after 3 years. This rule is a significant barrier for becoming a couple, leaving most people to live alone. People expressed a desire for independence, and in terms of spouses, the freedom to live with a spouse, but not forced to be dependent on that spouse.

> **Without a spouse for love and companionship and help, I'm lonely and depressed and without a means to elevate my standard of living.**
>
> ~ Christian, Ottawa Region

> **If you live with someone, you lose money.**
>
> ~ Kathryn, Southwestern Ontario

Theme 4

Beyond the “Basics”

Transportation - No money to get around

Transportation was identified as a big issue. We received responses around general transportation, and also around medical transport. Many people told us how isolation and loneliness was caused or made worse by unavailable or unaffordable transportation. We also heard that where ODSP does provide support for transportation, the rules and the bureaucracy can be very frustrating.

> I cannot afford to drive, yet the major part of my disability is the lack of ability to walk
>
> ~ Paul, Southwestern Ontario

> Transportation is a huge cost for daily living let alone for recreation. I saved enough money to take a dance class yet I have to walk to and from (1 hour each way) as I cannot afford a taxi
>
> ~ M.P., Southwestern Ontario

> I need to be driven to my activities and appointments. My sister-in-law who drives me everywhere needs to buy the gas and pay for car repairs. That is expensive.
>
> ~ Raymond, Northeastern Ontario

Because of my daughter's problems and the town in which we live, my daughter frequently needs to go to see doctors in other cities. The…ODSP office has spent most of 2009 questioning why she doesn't see local doctors, and, in a couple of cases refusing to pay the travel allowance because "she could see local doctors". The fact that there are none locally doesn't seem to matter to them. It is just a constant struggle with them. I now have to do bookkeeping that they should be doing because of their non system for reimbursing us for medical travel expenses.

~ E.F., Southwestern Ontario

Have bus passes covered

~ Randy, Southwestern Ontario

I have extra travel costs because I have to travel to see a specialist, but when they cover my travel costs, they take it out of my volunteer money. Yet I have to take a GO-bus to Hamilton, so really it doesn't cover the costs.

~ Debbie, Toronto Region

Special Needs: “If I get summer shoes, I can’t get winter boots”

> ...many medical and/or dental procedures and expensive prescription drugs are not covered by ODSP, so I have sometimes had no choice but to reluctantly leave a medical clinic, dentist office or pharmacy empty-handed because I could not afford the products or services I needed.
>
> ~ Anne, Southcentral Ontario

> At this moment I need new shoes. My feet are deformed because I was born with club feet so normal shoes don’t fit. I have to order special shoes. The muscular dystrophy association will pay only $750 and this leaves me and my mom to pay the rest, around $200. Needless to say we don’t have the money. We will have to go to other associations to help us. If I get summer shoes, I can’t get winter boots. They need to increase the ODSP so we can afford some of the necessities.
>
> ~ J.B. & C.B., Northeastern Ontario

Assistive devices and products were one of the most frequently mentioned extra costs, and particularly the difficulty getting repairs covered by ODSP. Several contributors take issue with the decisions made within the program about what devices are covered versus what people want and need as supports.

> I can’t afford things that would help me out, like assistive products, taxis, more nutritional supplement shakes, Meals on Wheels (including purees), etc.
>
> ~ Maria, Toronto Region

> I recently had surgery.... This surgical procedure requires a new bandage be applied every two days, as well as gauze packing the wound. I have been approved for surgical supplies which adds $3.10 per month. But, one box of gauze is $25.00, not to mention tape, Alcohol, etc.
>
> ~ Kevin, Toronto Region

I have suffered with Migraines for years. ODSP will not pay for any pills for migraine even with a request from a neurologist. I think cost for Imitrex is about $18-20 per pill. However, the health plan will pay for as many visits to ER as I make. 1st – the nurse assesses me, next I'm taken usually right away to an examination room. The whole process takes 2 ½ to 4 hours. The doctor sees me. Orders shot and gravol and IV because I'm dehydrated. The nurse gives the shot. The doctor comes in again to see how it's working. I tie up an exam room for all this time, our hospital only has 3 rooms!! The doctor signs me out, I don't know what this costs, but I'm positive it costs a lot more than a few migraine pills. If I'm really bad I get into a bed in the ER.

~ Patricia, Southcentral Ontario

In addition to every day expenses, people on ODSP often have expenses related to their disabilities. While some special needs are covered by ODSP, many essential are not:

- Some medications
- non-Western or natural remedies
- vitamin and mineral supplements
- orthotic inserts
- trauma therapy
- physiotherapy
- chiropractic treatment
- orthopaedic mattresses for severe back problems
- adequate vision and dental care

Even where it seems that ODSP has some discretion, people described making the case to their ODSP worker only to be told later the program simply doesn't cover.

I would change the cost to medical benefits. Many much needed health/life changing prescriptions are not covered and the cost incurred by those who already have nothing to live off of. Most of the time we are given the cheapest possible medication as it is the only one covered by our medical drug plans.

~ Candace, Southwestern Ontario

Theme 5

Program “Service”

Where’s the “support” in the Disability Support Program?

> This is potentially one of the most serious problems. Not only are persons with disabilities not respected by some of the general public, but they are not respected by people working within the ODSP program. I have called many times to the Wilson Ave location. During one call, I was told to call my worker directly. When I dialled his number he answered. He asked who I was. When I told him, he became extremely angry, telling me never to call him directly again. He said he does not deal directly with clients and that only his co-worker handles clients. So consequently I filed a complaint and was directed to only call his co-worker.
>
> She is fairly nice to deal with. But after having been assigned to that office for over a year, I have never met her or received any help that was not directly asked for. There are no support programs for persons on ODSP. No one checks up on these people to see how they are doing or if they need help with anything. They are left to fend for themselves. No one knows what their options are, or how to get help. So if you don’t teach yourself the system, no one is there to help you. I think it is unfair to allow ODSP to include the words “Disability support” in the name of their program. There is no support, just a monthly payment that a lot of people cannot manage.
>
> ~ Kevin, Toronto Region

Over the years, the Coalition has advocated for improvements in the way people applying for and receiving ODSP are treated by the staff who administer the benefits. ODSP workers have a lot of power over the lives of people on ODSP. The result of some of these ‘service’ issues is very stressful, and can result in not receiving any income at all (i.e., lost paperwork can mean a suspension of benefits with no advance notice).

Some of these issues are about communication, but others centre on attitudes and how people are treated. These issues are compounded by the stress many experience already in contending with sometimes very complex and challenging disabilities.

ODSP recipients need social workers who volunteer all resources available to us and no longer have an adversarial relationship with us.

~ **Christian,** Ottawa Region

All I can say is that from my initial intake meeting with ODSP back in 2003, I have been treated like a non-person.

~ Andrew, Southwestern Ontario

No person should ever be treated as a piece of garbage, which is how many ODSP workers view their clients. Many on ODSP are on it through no fault of their own, such as myself. Others are mentally ill. We deserve to be treated with respect and dignity. The people who make the rules and who work within ODSP and OW systems should have to go through the process before they are hired. **They should have to live for two months on the funds provided for people on ODSP and see how they get by.**

~ **M.A.**, Southwestern Ontario

As the financial trustee, I had received some very alarming correspondence from the Ministry of Community Services that was stressful until I could quickly resolve the issues. The majority of this correspondence was not even signed. Other times, the staff conducted themselves in a very intimidating and disrespectful manner. I have heard similar concerns from many individuals who have had to deal with ODSP.

~ **Lynda**, Northern Ontario

Having no support via the ODSP offices without being made to feel like a pauper/beggar/less than human etc.

~ Teri-Lee, Southwestern Ontario

> **It is unfortunate that the entire relationship between ODSP and its clients appears to be financial. In other words, once you get on, the money comes in regularly and every once in a while they verify your financial eligibility. No one works with the person to see if they need help achieving goals, or even in dealing with the ODSP bureaucracy.**
>
> ~ On behalf of **Kyle** (written by his mom), Ottawa Region

There seems to be a lot of miscommunication and missed-communication, with workers:

- Not listening, not trying to understanding
- Being unclear
- Not being available, or returning phone calls
- Some people have never met their worker

> **I don't even know who my worker is much less what benefits I can have.**
>
> ~ **Andrew**, Toronto Region

Many people described how they experienced the attitudes of workers:

- being treated like a child
- feeling criminalized
- treated like a liar
- mistrusted
- "oppressive", "hostile" attitudes

> **The lack of accountability. I had a worker…who said if I'd been homeless for years there was no urgency for me to get housing anytime soon.**
>
> ~ A.J., Toronto Region

Others described the issues as poor customer service with little ‘customer care’ skills; unfriendly, rude and disrespectful behaviour; losing important documents; and a lack of clarity around who the ‘right’ person is to speak to.

> **Being ordered to go to the ODSP office every time someone thinks that something isn’t right – this takes time, money, is physically exhausting and very stressful.**
>
> ~ Anne & Peter, Southwestern Ontario

ODSP workers aren’t given information about the type of disability their client has, so it’s not that surprising that several people feel their worker doesn’t understand their disability.

> **Improve the quality of customer service ODSP clients receive. Address accessibility issues: forms in alternative formats for blind users, office staff taking long time to help clients who need help, info not being easily available to clients (extra benefits available, eg.)**
>
> ~ Maria, Toronto Region

Not only are people frustrated at how they’re being treated, several went further to speak about how intimidating it is to ask for what they need; being scared to complain; afraid to be scrutinized or draw attention to themselves; and the not uncommon occurrence of being threatened with being cut off assistance or receiving letters that threaten loss of benefits and often contradict the letter received the day before.

Some people framed these issues in terms of accommodation of their disability: Home visits are possible within the program as an accommodation, but don’t happen. One contributor pointed out their view that the service by ODSP staff doesn’t comply with the Accessibility for Ontarians with Disabilities Act (AODA) standards.

Access to Information

> **ODSP recipients should be informed, in writing, of all the special benefits they may be entitled to.**
>
> ~ Dee, Ottawa Region

Many contributors expressed frustration with how little information they receive on the benefits available to them while on ODSP. When we asked the question about access to special benefits or services, several people wrote that they aren't aware of any. Others said they don't find out about such benefits unless they ask directly.

Bureaucracy

> **Their [eligibility] "reviews" are anxiety-provoking, demoralizing, and rob you of your privacy and dignity.**
>
> ~ Peer Support Group, Southwestern Ontario

Lots of people remarked on issues that can be described as "bureaucracy", but relate at times to both systemic issues (like policy) and also implementation of policy (by workers). The more systemic/design issues will be described in the Program Design theme, which comes next. In terms of bureaucratic issues around program administration, the most common issue was **timelines and response time issues** (including waiting once applied, waiting for decisions around extra benefits, etc)

Theme 6

Program Design

“Jumping through hoops”: Eligibility and Access

> Initial process of applying for ODSP was difficult in the extreme, and complicated beyond belief (with far too many rules and stumbling blocks). It often felt as though ODSP had forced me to jump through more hoops than the proverbial trained seal. Dealing with bureaucratic red tape continues to be probably the most frustrating and stressful experience of my life. **I have sometimes been scolded like an ungrateful child, or treated like a criminal by suspicious ODSP workers who automatically assume (not matter what I say or do to prove otherwise) that I am trying to defraud the system, when the opposite is true.** Inevitably, whenever their decisions are questioned, their automatic response is to intimidate us into submission by threatening to cut off our benefits, regardless of the validity of our concerns. I once had an ODSP worker tell me ‘not to take it personally’ when I protested her intention to suspend my benefits for some unspecified reason. Strangely enough, she didn’t have an answer for me when I asked her how personally she would take it, if her employer had arbitrarily frozen her salary without just cause.
>
> ~ Anne, Southcentral Ontario

For most of the people who talked about access (to the program and/or other benefits while on the program), it was a challenging and difficult process that confused them and took far too long.

> **Streamline the application process and make the program work for the disabled instead of making the disabled have to fight in order to get what they need in order to live a normal life.**
>
> ~ Raymond, Northeastern Ontario

Lots of contributors told us how long it took them to get accepted onto ODSP, sometimes only after multiple rejections and reapplication, “forever”, or 2-4 years.

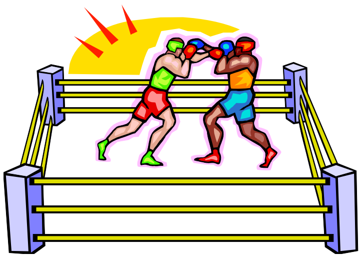
Some people described how hard it is to get back onto ODSP after being suspended, returning to Ontario, working full-time temporarily, or changing their marital status.

> People on disability in other provinces should be able to transfer when moving.
>
> ~ **Dennis**, Lake Ontario East Region

Eligibility criteria for being accepted to ODSP can be complicated, especially for those receiving other sources of income, like Canada Pension Plan – Disability (CPP-D):

> I think there ought to be some leeway for people so close to the cut-off amount (it would be nice to have access to eye glasses and dental and drugs). Perhaps now that I'm having my income tax taken off my CPP-D cheque I would qualify...
>
> ~ **Susan**, Southcentral Ontario

Navigating the system: Have to fight for everything!



The most common experience in this category was the need for getting some support (usually a legal clinic, an advocate, an MPP, etc) to intervene in order to successfully gain the support requested. Many people also described the need to fight in order to get anything. People gave examples of getting support from their MPP, from social service agencies, and from family or parents. One contributor asked the question: **what is the cost of this**?

> Special benefits difficult to get and not always "advertised"
>
> ~ Peer Support Group, Southwestern Ontario

Several people talked about the challenges in navigating the ODSP system with a disability (for example, a developmental disability).

> I have been helped by having support workers from a community living being patient, understanding and taking the time to process what they were saying to me when they were explaining something to me and when I was doing someone. I need help when filling out applications but it depends on if

I can understand what I am filling out. Sometimes they are not put into plain language and I wish they are.

~ Yvonne, Toronto Region

My son would have a lot of difficulty navigating the system if he did not have parents who are well-informed, have financial resources and have the ability to advocate on his behalf and deal with the bureaucracy. How could a person with these disabilities, on his own, respond to the legal requirements of dealing with ODSP?

~ On behalf of Kyle (written by his mom), Ottawa Region

Access to medical care

In order to gain access to the ODSP, applicants need the help of a medical professional for the application process, and again in their efforts to secure funds for such things as special diets. For some who wrote in, not being able to find a doctor or get access to such medical support was a challenge. Specifically, for others, resistance from doctors prevented them from getting the application or related forms completed.

[Make it] easier access to medical care. Northerners rely on travel grants which are restricted to nearest medical provider. Allow ODSP recipients to see the specialist of their choice or attend the specialty clinic of their choice. Many have developed long term relationships with their specialists. It does not make sense to force them to change.

~ J.J.R., Central Ontario

A means of connecting people on ODSP, or trying to get on ODSP, with doctors who have proven to be willing to honestly evaluate their claims would be nice. …My back pain is the biggest reason for my not being able to work, and if there is any chance an operation could fix the problem then maybe I could get off ODSP or at least work some hours without becoming incapable of moving due to massive pain.

~ Joseph, Southcentral Ontario

Surveillance: Intrusion into people's daily lives

As mentioned above in the Program "service" theme, many people wrote of their frustrations with bureaucracy, but the way people are treated goes well beyond that.

- the amount of paperwork (for the application and continued benefits)
- financial reviews (demoralizing & invasive)
- red tape
- the need to report exempt income
- how confusing the reporting requirements are
- how strict and unbending rules are
- must get paperwork in on time or get cut off
- the need to get multiple estimates for repairs (even toilets)
- the forms are hard to fill out, and
- people get shuffled between Ontario Works and ODSP for some benefits

These experiences in isolation may resemble some of the frustrations many people experience in terms of accessing programs beyond ODSP. But for people on ODSP, the consequences of not complying or mistakes in complying is the loss or reduction of their income, which is often followed by loss of their home.

> **Make the system workable. It should not be so hard to deal with the miles of paperwork, and being treated like a child by everyone you deal with. I had no "people" contact at all until my tribunal. It was a soulless procedure, with nameless people just saying "no". We are not animals, we are people with feelings and hardships, and when you are dealing with "no one", the frustration, anger and pain only increases.**
>
> ~ I.N., Southwestern Ontario

Assets, Savings & Gifts

My son had an unfortunate experience in regard to a First Nation Specific Claims Settlement. **As a member of an Ontario First Nation which lost a portion of its reserve due to unlawful acts of the federal and provincial Crown, my son received a cheque for $20,000.** This action by government…was arguably a factor contributing to the social situation and family dysfunction at the root of his disability. Advice provided by the First Nation indicated the money was not to be considered "income" for purposes of social benefits. At our suggestion, he placed $15,000 of this money in GICs in order to safeguard it for the future when he might be in a position to purchase a car or a home.

> **Unfortunately, the money…immediately became an "asset" for the purposes of ODSP. So his benefits were cut off until such time as ¾ of this money was used up. He was not allowed to give the money away or have it put into a trust.** In other words, the money he received to compensate him for the loss of his homeland could have been used up for daily living expenses over a period of about 18 months with no lasting benefit, if action were not taken immediately to reduce his "assets" to below $5,000.
>
> **To deal with this situation, I purchased his GICs (borrowing money to do so), to avoid penalties for cashing them in early, and we proceeded to look for ways to spend $15,000.** He does not have a driving licence, and in any case could not afford to maintain a car, nor was there enough money to purchase a home. We therefore spent a few weeks going shopping for furniture, a television, clothes, etc. Even Christmas gifts were not considered to be appropriate use of the funds. The effort of making all these purchasing decisions and going shopping was very stressful for him. We had to provide $15,000 worth of receipts (ranging from items such as a television, to a bath mat, a frying pan, etc.)….
>
> **In the end, he was cut off benefits for only a couple of months, and he lost an appeal on that. …As an Aboriginal person myself, I feel very bitter that land claim settlement payments are not protected to enable ODSP recipients to gain lasting benefit from them.**

~ On behalf of Kyle (written by his mom), Ottawa Region

Many people wrote about difficulties with the rules on savings, assets, gifts and special payments. They puzzled over why they have to shed their assets and make themselves destitute to qualify for ODSP. And they wonder why a program with such low benefits would limit how much people can have as savings (though most people have no money to save come the end of the month).

Over and over we heard of people being forced to spend retroactive payments or inheritance quickly to avoid being disqualified, rather than prudently saving it for unexpected expenses. Although, ODSP allows parents to leave inheritances in a trust for the future benefit of a child, the children of parents who don't have the resources to make those legal arrangements can be out of luck: One ODSP recipient told of how his father took a reduced pension in order to leave his son a survivor's benefit – not realizing that when the time came for his son to use that benefit to top-up his ODSP income, it would be deducted dollar for dollar.

People find the rules around gifts confusing. ODSP policies now allow gifts from all sources of up to $6000 annually, but they must be reported to ODSP. People continue to worry that accepting gifts for themselves or members of their family could result in reduction of benefits.

Independence / Trustees

> **Clients must be provided with means to remain self sufficient**
>
> ~ Paul, Southwestern Ontario

Independence is a recurring theme in the stories: people's desire to be independent, their wish for support in gaining that, and how inadequate rates and supports lead some people to rely on family support.

People related their frustration about the lack of autonomy on ODSP – even the ability to handle an inheritance which should provide some independence is restricted – while others are asking why ODSP does not do more to empower and encourage independence.

> I'd like to be able to leave my son an inheritance that won't affect his ODSP, without having a discretionary trust.
>
> ~ Sandy, Ottawa Region

Another set of comments relate to issues around trustees and guardians, with people having questions about their rights, responsibilities and level of influence over decisions. One person expressed frustration that the trustee they have to rely on sometimes doesn't get them the money they need on time. Another contributor doesn't have a trustee but feels they need one.

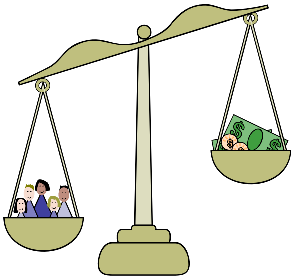
Overpayments: We'll cut you off if you don't pay back the 10 cents we overpaid you…

> Due to a clerical error on their part, I was accidentally overpaid by a few pennies a while ago. If someone had used common sense at that point, I would probably never have noticed such a small anomaly. But, rather than being reasonable and decreasing the next month's cheque by the same amount to correct their mistake, they immediately over-reacted by sending me a letter which threatened to cut off all future payments (with no chance for appeal) unless I reimbursed them for the entire 'overpayment' (less than 10 cents)!
>
> ~ Anne, Southcentral Ontario

Several people wrote about the particular ways in which overpayments and back payments are treated by ODSP. Part of the issue is that the rules, in some contributors' experience, change without notice to them, resulting in overpayments. Most of the overpayment issues related to employment income, and the slow processing (or losing) of information they provided which ended up threatening receipt of ODSP benefits.

A few people wrote about back payments – some related to CPP-D (which people had to pay back to ODSP once they were accepted).

System Overhaul: We want to be at the table!



For many of the people who contributed to this project, there is an awareness of the bigger picture, the systemic issues like poverty. Some described being on ODSP as a life sentence of poverty, while others feel the system is keeping them in poverty. One person characterized ODSP as extreme poverty.

> **You feel that you will never get ahead on anything. Most people feel this way – 'Under a thumb' living**
>
> ~ R.C., Toronto Region

People characterized the ODSP system in a number of ways:

- Harmful
- Focused on reaction not prevention

And that it leads to deprivation, in terms of resources, means, choices and power, and many find navigating the system to be demoralizing. For some, there's a feeling of having no rights, either human or civil. While for others, ODSP results in taking on debt simply in the course of providing the necessities of life for themselves and their families.

> **[I]t is my fervent hope that there will soon be a system in place for everyone in this country where each and every person is entitled to receive an adequate amount of money to meet their individual needs without having to rely on food banks, soup kitchens, homeless shelters or a plethora of other charitable organizations simply to survive each month. …I only hope that common sense will soon prevail, and that the Powers-that-be will finally demonstrate the courage and foresight necessary to correct the inadequacies of not only ODSP, but the entire income security system without further delay. We cannot allow such shameful discrepancies between rich and poor in this country to grow at such an alarming rate.**
>
> ~ Anne, Southcentral Ontario

Given all that people have identified as in need of change, there is also a call for involvement of people with lived experience in determining what reforms are best:

> I would LOVE the government to LISTEN TO US and ASK US what we need instead of the government deciding for us. ...Bottom line is we cannot afford to be in poverty. ...If Canada is so great then why is there such a poverty problem? When exactly is the government going to take it seriously? We are human just like they are so why are we treated with less than respect and dignity? It is NOT (always) our fault that we're in the situation we find ourselves to be in. We NEED more money on our checks, more dignity, less government interference and more humanity. We NEED it NOW.
>
> ~ Teri-Lee, Southwestern Ontario

> The ODSP needs to consider the human element and the impact their decisions have on clients.
>
> ~ Norman, Central Ontario

> These agencies need to connect with the humans that they are helping. We are not nuisances, numbers, greedy people always looking for more. The paradigm has to change. Living costs go up, not our benefits. To be motivated we need better food to increase health, mood, motivation. If your food is not good you can not sustain working, or volunteering. At the end of the month with little food you can not focus on anything else but getting your next meal. ...I am grateful for ODSP but please make it more human, caring. I do not want to be here so do I have to be demeaned, stressed out, treated as a problem person.
>
> ~ **Barb**, Ottawa Region

And awareness of who might pay for the necessary reforms:

> More provincial and federal funding should be available so ODSP could rectify the inadequacies of their support program.
>
> ~ Patty, Southwestern Ontario

Some positives & gratitude for ODSP…

Thank you for your financial assistance. Without it I would surely die as money is a necessity of life in our society and I don't have what it takes to earn an honest living, and I'm really glad I don't need to earn a dishonest one. I tried my best, and it wasn't good enough, or when it was good enough they raised the bar.

~ B.J.R., Southwestern Ontario

Amidst the many voices of outrage, depression, and demands for change to the program, there were also a few people who shared that they didn't have many challenges with the program, or that they're grateful for the monetary assistance they do receive from ODSP, and that sometimes the amount they receive is enough for them. And in contrast to some pretty disturbing reports about how people feel they were treated by the staff at ODSP, there were exceptions to that, namely the helpful staff in Cornwall and Sault Ste Marie, as well as a general comment about positive experiences with specific ODSP staff.

Not everything is negative. I'm thankful for the help I get, but more would be helpful.

~ Badger, Southwestern Ontario

We do appreciate the money we do get, because it's better than nothing. Thank you for your understanding.

~ Raymond, Northeastern Ontario

Conclusion

236 stories from 61 places across the province. Diverse types of disabilities. Depressingly common experiences of social exclusion, deprivation, and frustration with a system all too often lacking in support.

The stories and experiences we read are not unlike those we've heard around the table and from our partners across the province since the ODSP Action Coalition began. In fact, these stories reinforce how vital it is that we continue to advocate for improvements to ODSP. Those we heard from in this project have been receiving ODSP for different lengths of time, but the **toll that inadequate rates and supports are taking on people cannot continue**.

Throughout this report is a call for independence, choice, health and dignity; **Values and needs shared widely by Ontarians**. ODSP is not meeting these needs for people with disabilities. People are forced to depend on family to find money for basic needs or food banks when money's not available; make impossible choices between eating and paying the rent; experience worsening health due to poor nutrition; and often leave ODSP offices with their dignity in tatters.

People who shared their experiences of life on ODSP also shared ideas on how to improve the program to better meet their needs. The Coalition will be carefully looking at these ideas in the coming months, to help shape the policy suggestions that guide our advocacy work – including our submission to the Social Assistance Review that the Ontario government has committed to begin in fall 2010. Our advocacy work in the Review and beyond will build on the work already done by the Coalition, in particular our **Disability Declaration**, which is based on the UN Convention on the Rights of People with Disabilities, which Canada ratified in March, 2010.

At the same time, we hope the government hears the **urgency** in the voices on these pages and responds with badly needed improvements before the Review begins. Our Coalition has already suggested a number of such changes that should be made to ODSP and OW regulations (see "Stupid Rules Create Dire Consequences" at www.odspaction.ca).

The experiences, stories and ideas of the 236 people who contributed to this project will guide the Coalition in our ongoing work to improve the lives of people with disabilities on social assistance. We hope that our efforts in the coming months will honor the trust they placed in us by sharing their struggles and dreams in such an honest way.

Appendix A:
“Telling Our Stories” Project Letter and Questionnaire

Dear Friend,

The ODSP Action Coalition is a province-wide coalition of community agencies, provincial groups, anti-poverty groups, legal clinics and people with disabilities on ODSP.

The coalition’s mission is to advocate for improvements to ODSP so that people with disabilities can live adequately and with dignity.

The ODSP Action Coalition is collecting personal stories from people on ODSP. We want to know what the challenges of living on ODSP are. We will use these stories to:

a) Lobby elected officials in government to improve the ODSP system and make it a more humane, accessible and generous one;

b) Get media attention about issues around ODSP;

c) Educate the general public around the issues and challenges faced by people on ODSP.

Please complete the questionnaire (feel free to use extra paper) by January 15 2010, and return to:

ODSP Action Coalition
c/o Income Security Advocacy Centre
425 Adelaide Street West, 5th Floor
Toronto, Ontario   M5V 3C1
Fax: 416-597-5821
e-mail: odspstories@gmail.com

For more information about the ODSP Action Coalition, or to find this document online go to: www.odspaction.ca

If you have any questions about this project, you can contact Naomi at: 416 539-0690 ext 258 or naomibe@houselink.on.ca.

ODSP Action Coalition
"Telling Our Stories" Project
Questionnaire

Page One: Your Basic Information

Your name: ____

(A nickname or initials are fine)

City or town where you live: _________________________________

(This helps us to show that we talked to people all over Ontario)

Your postal code (if you prefer, just give first 3 digits): ________________

(We will be able to find out who your Member of Provincial Parliament is)

Would you be willing to have your story shared with the media?

(Stories help people understand what it is like to be on ODSP) __________

Would you be willing to be interviewed by the media about your story?

(Please write Yes or No) __________

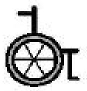
If yes, how can you be reached? Phone number, address, e-mail

(this could be a friend, family member or worker)

____

ODSP Action Coalition
“Telling Our Stories” Project
Questionnaire

Page Two: Questions About Your Story



1) What kind of disability do you have, and how does it affect your life?

2) What are some of the **biggest challenges** you have being on ODSP or applying to ODSP?

3) Do any of these issues affect you, and how?
(Put an X by the ones that affect you, and write how they affect you underneath)
(Answering these questions helps us show the challenges that people face on ODSP)

a) The amount of money you get on ODSP ___
- is it enough?

b) Acceptable housing ___

c) Being a youth or parent on ODSP ___

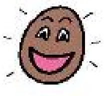
d) The extra costs of having a disability ___

e) "Stupid" ODSP rules ___

(e.g., working when on ODSP but having to give 50% of money earned back)

f) Problems getting ODSP ___

(including getting on ODSP, and once on, knowing about and getting special benefits and other services)



4) What would you most like to change about ODSP and why?

5) Do you have any more comments?

(feel free to use another piece of paper)

Appendix B: What is ODSP?

The Ontario Disability Support Program (ODSP) is part of Ontario's social assistance system. ODSP provides an income for people with serious health issues and/or disabilities who are unable to work or who are only able to work part-time.

Approximately 370,000 Ontarians with disabilities and their families depend on ODSP as their primary source of income.

ODSP rates have only been raised 11% since 1993. The maximum amount of mandatory benefits a single person on ODSP can receive is $1042 per month, which amounts to $12,504 a year.

People on ODSP face stereotyping and discrimination as they struggle to deal with physical and mental disabilities, while at the same time facing all the challenges of living in poverty.

How much money do people on ODSP get to live on for a month?

People on ODSP get mandatory benefits for Shelter[1] and Basic Needs. If they have children, they also get the Ontario Child Benefit and two child benefits from the federal government. Small tax credit amounts[2] are also received from both the provincial and federal governments.

	Maximum Shelter[1]	**+ Basic Needs**	**+ Ontario Child Benefit**	**+ Federal Child Benefits**	**+ Tax Credits[2]**	**= Total**
Single person	$464	$578	$0	$0	$46	$1,088
Parent + child	$721	$729	$92	$286	$78	$1,906
Parent + two children	$739	$791	$184	$553	$91	$2,358

1. The Shelter allowance is capped at the maximums listed here for the various family sizes. If a person or family's actual rent is more than the maximum allowable, no additional funds are provided.
2. The amounts shown here are estimates based on calculations for a 2008 income. People receive tax credits in quarterly installments, so counting them as monthly income here is done only for purposes of illustration

Appendix C: Where did we hear from across the province?

We received responses from **61 different places** across the province of Ontario. Sometimes, we received several responses from a small place, like Sharbot Lake, and thank our partners in community agencies and groups across the province for promoting the project and encouraging people to contribute their experiences!

We heard from people in:

Toronto (81 people), including North York, Etobicoke, Scarborough
Ottawa (22)
London (14)
Essex (11)
Sault Ste Marie (6), Sharbot Lake (6)
Sudbury (5), Tecumseh (5), Windsor (5)
Belleville (4), McGregor (4), Timmins (4)
Barrie (3), Belle River (3), Thunder Bay (3)
Brantford (2), Kingsville (2), Kitchener (2), Leamington (2), Peterborough (2), Woodstock (2)

And the following places where one person contributed from each:

Alexandria
Alliston
Amherstberg
Arden
Aurora
Aylmer
Bellrock
Blenheim
Brampton
Cambridge
Caledon
Carleton Place
Chalk River
Chatham-Kent
Cornwall
Deep River
Dryden
Englehart
Hamilton
Huntsville
Kenora
Killaloe
Kingston
Kirkland Lake
Lion’s Head
Madoc
Milton
Mount Forest
Nepean
North Bay
Oakville
Renfrew
Seaforth
Smith Falls
St Catharines
St Thomas
Thornhill
Tillsonburg
Walkerton
Wiarton

Appendix D: What kinds of disabilities did people have who shared their experiences?

Most of the people who shared their experiences with us, told us some information about the type of disability they have. Many people reported having multiple disabilities, conditions, illnesses, symptoms or challenges, so the information that follows does not ‘add up’ to 236, rather is indicative of the variety of disabilities people reported. We didn’t ask contributors to indicate which was their primary or secondary disability (for the purposes of ODSP application), so the lists that follow don’t let us know the condition(s) that qualified someone for the program. In addition, it was hard to know when people mentioned depression, diabetes, and so on, whether the condition(s) have resulted from the inadequate nutrition and living in poverty, or whether they were pre-existing before being granted ODSP. These causal links are mentioned anecdotally by some contributors, but we have no way of knowing this conclusively. This information is to give readers a sense of the variety of disabilities people have, so their experiences of ODSP remain in context.

We’ve organized the lists of types of disabilities people have under the same general categories used in the Disability Adjudication Handbook, prepared by the Government of Ontario. That being said, people named and described their disabilities in their own language, so there were some disabilities that were hard to categorize. This is meant to display the breadth of types of disabilities had by people who wrote in to share their experiences. In brackets following each condition is the number of people who reported having the same). We’ve tried to include as much of the language people used to identify their own disability as possible.

Mental & Behavioural Disorders (217)

Mental Illness, not specified (including ‘serious & persistent’, mental health issues, mental disease & “invisible” disability) (25)
Depression, including major depressive disorder (19)
Learning Disability, including dyslexic (19)
Developmental Disability, including ‘global’/developmental delay (18)
Schizophrenia (17)
Bi-polar Disorder (14)
ADD/ADHD (13)
Intellectual Disability (13)
Anxiety Disorders, including panic disorders (10)
Brain injury or damage (7)
Post Traumatic Stress Disorder (PTSD) (7)
Social Phobia(s), including agoraphobia (6)
Autism (5)
Fetal Alcohol Syndrome, including FAS, FASD, Fetal Alcohol Neurological Disorder (5)
Addiction, including duo diagnosis (4)

Down Syndrome (3)
Psychiatric diagnosis or disorder, not specified (3)
Asberger's (2)
Borderline Personality Disorder (2)
Hydrocephalus (2)
Memory Loss (2)
Mood related (swings, disorder) (2)
Obsessive Compulsive Disorder (2)
Paranoia (2)
Schizo-Affective Disorder (2)
Suicidal Tendencies (2)

And the following were identified by one person each:

Alzheimer's
Cerebral Atrophy
Dementia
Eating Disorders
Intruding thoughts
Manic depression
Multiple personality disorder/Dissociative Identity Disorder
Oliver McFarlane Syndrome
Stress Disorder, not specified
William's Syndrome

Cardiovascular System (8)

Heart Problems, including arteriovenous malformation, heart disease, high blood pressure (7)
High Cholesterol

Pulmonary System (11)

Asthma (6)
COPD (2)
Cardiopulmonary problems
Bronchitis
Pulmonary Emboli

The Nervous System (63)

Spinal injuries, disorders, incl. stenosis, pain, degenerative disks, scoliosis, osteomyelitis (21) [2]
Seizure (Disorders), including grand mal, atonic (7)
Sleep Disorders, including apnea, insomnia (6)
Epilepsy (5)
Migraines, including chronic episodes, arterial hemiplegic (5)
Cerebral Palsy (4)

---

[2] Spinal injuries and disorders cross over and we don't have enough information to be more specific, so this listing appears in both the category of the Nervous System as well as the Musculoskeletal System

Multiple Sclerosis (MS) and MS-like symptoms (3)
Stroke (3)

And the following were identified by one person each:

Tourette’s syndrome
Shaking of the hand
Benign, extended tremors
Balance Disorders
Sciatica
Spasticity
Cauda Equina Syndrome
Autonomic Dysreflexia
Neuropathy

Musculoskeletal System (38)

Spinal injuries, disorders, incl. stenosis, pain, degenerative disks, scoliosis, osteomyelitis (21)
Physical Disabilities due to injuries, including leg, skull, spinal, hip, neck, back, knees, feet (10)
Fibromyalgia, including trauma-related (7)
Chronic Fatigue (Syndrome) (6)
Arthritis, including severe & osteoarthritis (5)
Quadraplegia, including spastic (2)

And the following were identified by one person each:

Muscular Dystrophy
Congenital Birth Defect (Spina Bifida)
Paget’s disease
Rupturing tendons
Skeletal fractures
Toes, fingers amputation
Rotator cuff problems
Chronic Bursitis

Rheumatology (3)

Rheumatoid arthritis, including Reiter’s syndrome (3)

HIV, AIDS & Related Disorders (8)

HIV + (8)

Hematology (1)

Blood Disorder

Endocrine System (11)

Diabetes (9)
Hypoglycemia
Thyroid/adrenal exhaustion

Gastro-Intestinal Disorder (8)

Irritable Bowel Syndrome & Digestive Disorders, including chronic indigestion (4)
Chrone’s Disease
Ulcerative Colitis
Atrophic Gastritis
Celiac Disease

Liver & Biliary Tract (4)

Hepatitis C (3)
Liver problems

Renal System (1)

Renal Failure

Visual System (3)

Glaucoma (3)

Ear, Nose, Throat & Related Structures (5)

Hearing Loss (3)
Spasmodic Dysphonia
Dental Issues

Conditions, disabilities and symptoms not categorized with the above (22):

Physical Disability, not specified (8)
Allergies, including food (4)
Rhinitis
Acne Rosacia
Thrush
Oral Herpes
Low level of B12
Ankylosing Dysphonia
Albinism
Cancer
Morbid Obesity
Tendonitis

Appendix E: How Disability affects people's lives

Learning/Intellectual/Developmental Disabilities (Including ADD/ADHD)

- require full time/constant care
- prevents me from getting promotions
- affects all aspects of life
- affects my relationships and schooling is hard
- can't get a job (not a good one), don't understand numbers/money
- language concerns
- constant support in everyday activities (reading, keeping appointments, medication)
- trouble following directions, can't handle pressure
- get confused, nervous
- frustrating that people don't get what I'm trying to say
- makes me sad
- isolated for at least half of every year
- I need to do things slowly
- trouble reading signs
- trouble interacting with others/reliance on help communicating
- make poor decisions
- hard to concentrate
- poor memory, easily distracted
- wasn't able to get regular high school diploma
- need assistance in understanding written materials
- others sometimes try to take advantage of me

> **When I was younger everyone called me retarded and I had speech problems. It has made it hard to get a job because employers say that I am too slow.**
> ~ **Cathy**, Toronto Region

Mental Health Issues (Schizophrenia, Bi - Polar Disorder, etc.)

- lost interest in things I used to do, very low energy
- lack of supports
- effects relationships and schooling
- lost life coping with alcohol and drugs
- affects my life in every possible way
- hard to deal with people at work
- tired from so many medications (hard to work early mornings)
- can't work due to stress, reduced ability to cope with stress
- need a quiet life, extra time to do things
- can't hold full time employment

- impaired ability to be independent
- exposes us to stigma, discrimination
- lack of housing
- diminishes self worth
- can’t handle change/spontaneity
- can no longer drive
- was in prison
- need stability, structure and routine
- problems with impotence (side effect of medication)
- makes me uncomfortable
- interferes with forming and keeping relationships
- colours everything and I live in constant fear
- require lifelong medication, monitoring, therapy and support
- leads to other debilitating conditions, i.e., addiction
- restricts safe and affordable housing
- 12 years of life taken away through coping with drugs and alcohol
- makes it hard to keep active
- ended up on the street
- medication sedated me for 15 years

“Invisible” Disability

> **I have an invisible disability. It affects every aspect of my life. I know what I’ve lost by becoming disabled but I don’t remember what being normal is like. The relationship I have with my body has changed as my health deteriorates but I’ve managed to adapt and overcome my own barriers. I believe that I have a positive contribution to make to this world but many aspects of my life have been on hold for quite some time. For now, I am struggling to survive, rather than living. The hope for a better future for my child is the only thing that keeps me fighting with all my might to overcome my own limitations. I keep repeating to myself: This is not who we are, it’s just something we’re going through. It’ll be over one day and I have to be not just alive but well to enjoy it when the day comes to do more living than surviving. I just need to move along and get through another day in the most dignified way possible. It keeps me going despite the challenges we may be facing.**
>
> **It’s not the disability itself that limits what my contribution to this world is.**
>
> **There have been too many barriers to overcome besides disability, like poverty. I think my disadvantage is not my disability itself but being stuck in this situation, unable to improve my circumstances because of lack of supports.**
>
> **I know I have the capability and motivation to do better than this, if only I could allocate my resources to activities that will change our future, sowing the seeds for a**

> **better tomorrow by working hard today. However, the thing with poverty is not merely having a low income but it comes with complex situations intertwined with lack of adequate housing, barriers to education and limited access to appropriate health services.**
>
> ~ Written by **Elisa**, Toronto Region

Autism and Autism Spectrum Disorders

- takes me longer to learn things or understand situations
- can't understand social cues (understanding what other people mean)
- require 24 hour support
- being labelled and can't make friends
- can't find employment
- have trouble taking care of daily necessities

Physical Injury causing disability (Physical)

- can't lift anything over 20 lbs, affects employment
- can't walk, bend, stand, or sit for prolonged periods of time
- gained weight since going on ODSP, resulting in problems with ankles, legs, diabetes
- household duties are difficult
- no strength

Physical Injury (including prenatal) causing disability (Brain Damage/Brain Injury)

- changed my life 180 degrees
- lots of things I can't do now
- have trouble with math now
- ten fingers and toes removed from frost bite, can't walk well
- depend on family for everything
- have no friends and makes my life very isolated

Musculoskeletal conditions

- can't work full-time, need to take rests during the day
- suffer from many things
- hard to keep up
- lots of hospitalizations
- unpredictable disease/condition
- limited mobility
- walking and balance problems, have to use a scooter
- can't exercise, feel mentally and physically feel unable to participate in recreation, which is isolating
- affects muscle control, strength, balance, coordination

- limited fine motor movement in hands and fingers (can’t do things requiring a lot of manual dexterity)
- unable to sit/stand for any length without pain
- unable to find suitable part-time work

Visual or Hearing Impaired

- (challenge) being fully employed, so not having adequate income for basic needs
- not having an adequate income
- can’t get a drivers license which restricts employment prospects
- has affected my life very negatively
- affects ability to access information, overall mobility – hard to work part-time

Arthritis and Joint Issues

- limited mobility
- ongoing surgeries
- limits daily function and affects work
- cooking and bathing are hard
- can’t go out alone
- can’t manage things myself
- lost ability to do repetitive work
- pain meds caused loss in concentration and make it hard to finish things
- can no longer walk any significant distances

Physical disability not specified

- in the winter sometimes I fall in the snow
- can’t drive
- can’t write
- can’t get a job
- mobility is sometimes very limited
- pain so bad sometimes I can’t function normally
- feel lonely, live alone
- can’t go wherever I want because some places not wheelchair accessible

HIV/AIDS & HEP C

- can’t do “normal” employment or volunteer work
- medication costs
- have a hard time with depression
- lack of family support
- lack of specialists
- complications on all fronts

- have a hard time getting to doctors' appointments
- daily on my mind
- constant pain
- no strength in arms and legs
- no longer drive (motor impairment)

Addictions and Substance use related disabilities (FAS, FASD, FAND)

- assisted living
- need paid companions to help shop, bank, pay bills, clean the home, and get to work
- never have any money
- at risk of ending up in jail
- can't handle part time job (though have many skills)
- son of one contributor died of a drug overdose
- impulsive, hard to follow instructions (therefore can't keep job)

Seizure Disorders/Epilepsy/Strokes

- paralyzed, can't walk, speak eat or drink
- confined to a wheel chair
- lead a quiet lifestyle
- things go blurry
- frustrated at things I haven't achieved that I could have
- very difficult to do basic daily activities (cooking, not allowed)
- speech affected, balance/walking affected
- can't go out alone

Chronic Pain/Fatigue

- can't exercise
- need a quiet life with lots of time off to do things
- hard time doing daily activities
- in constant pain
- relationship loss, depressed
- high levels of stress

Gastrointestinal Disorders

- severe weight loss
- constant pain
- don't absorb nutrients
- causes distress