Deserving Dignity

People with HIV/AIDS Issues Relating to Ontario Disability Support Program

A Policy Paper for the Ontario HIV Treatment Network

Final - December 08, 2003

Joan Anderson & Glen Brown, Consultants

Deserving Dignity
People with HIV/AIDS Issues Relating to Ontario Disability Support Program
A Policy Paper for the Ontario HIV Treatment Network

Table of Contents

Section One: Highlights....3

Background....3
Context....3
Introduction to ODSP....4
The Current Environment....5
Key Findings: Issues and Impacts of ODSP on People Living with HIV/AIDS....5
Action Recommendations....6

Section Two: Specific Issues and Recommendations for ODSP....8

Issue 1 – Getting On ODSP....8
1a) The Definition of Disability....8
1b) Completing and Verifying Forms....9
1c) Income & Asset Levels....9
1d) "Grand fathering"....10
1e) Application Process – Complexity....10
1f) Length of Time to Process Applications....11
1g) Disability Adjudication Unit (DAU) Reviews....12
1h) Lack of Supports....13
1i) Role of community agencies....14
1j) Consistency of Rules & Process....14
1k) 90-day Limit to Application....14
1l) Knowledge Level of Doctors....15

Issue 2 – Staying on ODSP....16
2a) Reassessments....16
2b) Client Service....16
2c) "Team" Approach to Client Service....18
2d) Computer Generated Letters....18
2e) Complication of STEP Rules....18
2f) Appeals....19
2g) Role of Community Agencies....20

Issue 3 – Benefits On ODSP....21
3a) Level of Basic Benefit....21
3b) Transportation....21
3c) Special Diet....21

3d) Dental Coverage 22
3e) Complementary Therapies 22
3f) Speed of Processing Benefit Claims 23
3e) Lack of Information about Entitlements 23
3f) Paperwork 23

Issue 4 – Getting Off ODSP (And Returning to ODSP) 24
4a) Training/Education 24
4b) Drug Card 24
4c) Return to Part-time Work (levels of income allowed) 24
4d) Returning to ODSP 25
4e) Barriers to Employment Supports 25
4f) Inconsistency of Decisions 26
4g) Role of Community Agencies 26

Deserving Dignity
People with HIV/AIDS Issues Relating to Ontario Disability Support Program
A Policy Paper for the Ontario HIV Treatment Network

Section One: Highlights

Background

This paper was commissioned by the Ontario HIV Treatment Network, as advised by the Active Living, Work and Health Working Group. The Group had identified access to income supports as a key determinant of health for people living with HIV/AIDS (PHAs) and wanted to identify issues of policy and procedure within the Ontario Disability Support Program (ODSP) that would impact access to income.

Consultants Joan Anderson and Glen Brown were engaged to research the issues and produce this report. They reviewed a wide range of background documents from the ODSP, from disability advocacy groups and poverty advocacy groups, from government and opposition critics, AIDS organizations, researchers and other sources. They also interviewed a number of front-line advocates and service providers to gather their experience of how ODSP policies and procedures impacted PHAs. Further input and advice was offered by three technical advisors and by the full Working Group. (See appendix A for a bibliography and list of informants and advisors).

Context

There is substantial research evidence and wide-spread agreement among health policy analysts that income is a key determinant of health. People with low incomes are more likely to become ill, and are likely to suffer more adverse effects from illness, than people with higher incomes.

It is not surprising, therefore, that the impacts of poverty on the health of people living with HIV are also severe. Inadequate nutrition, poor housing, stress, inadequate access to medications and complementary therapies, and limited social support networks can all have an adverse effect on the health of someone with a compromised immune system.

A literature review on HIV/AIDS and income security published by the Canadian AIDS Society in 1995 highlighted the following:

> *"Recent descriptive studies substantiate an intuitive relationship between socio-economic status and the health states of people living with HIV/AIDS. Martin Schecter et al. have demonstrated a positive relationship*

between higher socio-economic status prior to seroconversion or enrolment in the study and the probability of being a non-progressor through the spectrum of HIV-related disease (Schecter, 1994). Supporting this finding, further study of the same cohort has demonstrated a significant relationship between low-baseline income and shorter survival time (Hogg, 1994). A comparison of the baseline socio-economic values of 122 patients in a Montreal study reinforce the credibility of these findings (Grover, 1992). A comparison of patients who had died by the end of the study (n=36) versus those who remained alive (n=86) yielded the following results: of those patients remaining alive, 19% had incomes of less than $11,000/year; whereas, of those who had died, 36% had incomes of less than $11,000/year (Grover, 1992). A positive association between socio-economic status and survival time has also been established among cancer patients (Ansell, 1993; Cella, 1991).”[1]

Another important context of the relationship between poverty and HIV is that HIV infection can often lead to poverty. The disabling effects of the disease – or of the side effects of HIV medications – can affect employment opportunities; the cost of treatments and related therapies can also lead to poverty.

Introduction to ODSP

The Ontario Disability Support Program came into effect in 1998 as part of the Ontario government’s overhaul of social assistance programs. Along with Ontario Works, ODSP replaced the former Family Benefits, General Welfare and Vocational Rehabilitation assistance programs.

ODSP is intended to provide income and employment supports for people with physical, intellectual and mental health disabilities. The program provides higher benefit levels and more flexibility than Ontario Works; the latter program has been a high profile target for government cutbacks and restrictions over the past number of years.

Just over 1% of the nearly 200,000 ODSP cases in 2003 are people living with HIV/AIDS. These 2,000 PHAs are approximately one in ten people estimated to be living with HIV/AIDS in Ontario.

ODSP has valuable components but it has serious flaws which have been subject to criticism since its inception. Disability advocates have decried the level of benefits – benefits remain frozen at 1993 levels while the cost of living has increased by 18%. Critics also argue that the program is inaccessible, inflexible

[1] G. Williams. *HIV/AIDS and Income Security*. Literature Review and Annotated Bibliography, produced for the Canadian AIDS Society, 1995.

and unwelcoming to many people with disabilities. We explore the specific areas of concern later in this report.

The Current Environment

The ODSP has been subject to considerable political and public scrutiny in recent years. Two private member bills (both defeated) in the Ontario Legislature highlighted the inadequacy of benefit levels. The ODSP Action Coalition, formed in 2002 as a coalition of lawyers, community workers and consumers, has led a well organized campaign to document and publicize problems with the Program, and has engaged in lobbying and advocacy to encourage solutions to the problems. After much pressure, the Action Coalition gained an audience with Ontario Minister of Community, Family and Children's Services in January of 2003 and secured commitments to address some of the procedural problems with the Program (though the Minister offered no commitment to increase benefit levels). The Action Coalition has since had a number of meetings with senior bureaucrats, and a number of joint working groups are attempting to make progress on procedural issues. Many issues remain unresolved, however.

The advocacy efforts have had a higher profile in the summer and fall of 2003 with elections at both the municipal and provincial government levels. The ODSP Action Coalition and many of its allies have attempted to highlight problems with the ODSP during the elections. The Ontario AIDS Network has also highlighted ODSP issues in its election materials.

At the provincial level, all three leading parties made commitments related to ODSP. However, none made income support for people needing ODSP or OW a focus of their campaign. The new Liberal government presents opportunities and challenges for advocates.

Key Findings: Issues and Impacts of ODSP on People Living with HIV/AIDS

The second section of this report describes a wide array of policies and procedures of ODSP that have an impact on PHAs and other people living with disabilities, and outlines specific recommendations for improvement. In this section we wish to highlight those issues that our research identified as key issues for PHAs.

- Basic Benefit Levels: Income supports frozen for ten years while the cost of living has increased by 18% have an immediate, urgent impact on PHA health. People cannot afford the basic ingredients for health: nutrition, housing, medications, transportation, clothing, etc.
- Other Benefits: Allowances for transportation, medical devices, special diet needs, and dental care are inadequate to meet anyone's health. They are especially inadequate for PHAs with complex medical, dietary, transportation and dental needs.

- Customer Service: It is bad enough that people have to struggle to survive on inadequate benefits; they do not deserve disrespectful and poor quality service by an unwelcoming, inflexible delivery system. Although some PHAs have access to ASO advocates to negotiate their way through the system, many do not.
- Delays and Interruptions: There still appear to be many instances where entitlements are delayed or interrupted to PHAs through no fault of their own, through unnecessarily complex procedures or due to minor mistakes in paperwork.
- Complexity: The rules, regulations and paperwork facing PHAs can be daunting, and can create significant barriers to getting on ODSP and maintaining access to benefits.
- Limits on Employment Benefits: there are strict limits on how much employment income PHAs can earn before ODSP benefits are clawed back. This presents a disincentive to pursue employment. Limits on maintaining access to drug benefits while exploring employment, and the complexity of re-entry to the ODSP program are also barriers to many PHAs considering employment. Lack of trust is also an issue – stepping forward to explore employment is seen as a huge risk by PHAs who fear losing benefits if they find they can't manage.

Action Recommendations

The second section of this report identifies a number of specific recommendations to the Ontario government to improve the ODSP program. Some of the recommendations are policy while others are procedural. In both cases a political commitment for change from the government will be crucial for forward movement.

Here we highlight some strategic action recommendations for the OHTN and other AIDS organizations to consider:

- Build and nurture alliances with other disability advocates in pressing for change in the ODSP program. Most of the policy and procedure problems with the program affect all disabled people. The impact of working together is sure to be greater than working apart, and there is already a well-organized movement to press for systemic change. The ODSP Action Coalition has expressed a strong desire to welcome further involvement from the HIV/AIDS community. (Involvement has already increased, partly as a result of this research project).

- Consider a provincial advocate/ombudsperson position to help PHAs and support workers negotiate the complexities of accessing ODSP. The position could also serve as a systemic advocate to urge policy and

procedure changes within ODSP. (A follow-up feasibility study is currently underway to examine potential funding sources, host agencies, etc.)

- Provide ongoing education and support to ASO workers and/or health care providers on how best to negotiate the ODSP system for their clients.

- Consider a provincially coordinated project to provide local training of ODSP workers by ASO support workers and PHAs

- Consider a small provincial strategy conference for HIV stakeholders to review this report, consider options, and develop strategies for change.

Deserving Dignity
People with HIV/AIDS Issues Relating to Ontario Disability Support Program
A Policy Paper for the Ontario HIV Treatment Network

Section Two: Specific Issues and Recommendations for ODSP

In this section we review a number of specific issues relating to ODSP policies and procedures, the impacts of those policies and procedures on PHAs, and offer recommendations for improvement. Much of the information in this section has been provided by the ODSP Action Coalition and by the Income Security Advocacy Centre.

Issue 1 – Getting On ODSP

1a) The Definition of Disability

The definition of disability from the Ontario Disability Support Program Act, 1997 is as follows:

"A person is a person with a disability….if,

(a) the person has a substantial physical or mental impairment that is continuous or recurrent and expected to last one year or more;
(b) the direct and cumulative effect of the impairment on the person's ability to attend to his or her personal care, function in the community and function in a workplace, results in a substantial restriction in one or more of these activities of daily living; and
(c) the impairment and its likely duration and the restriction in the person's activities of daily living have been verified by a person with the prescribed qualifications. 1997"

***The Issues*:** The definition of disability is too restrictive, especially in relation to mental health illnesses. The definition may not accommodate the pattern of mental illnesses that entail “good” and “bad” periods. Addiction is not recognized as a disability: "A person is not eligible for income support if, the person is dependent on or addicted to alcohol, a drug or some other chemically active substance. 1997".

The Impact on PHAs: Eligibility is not a major barrier for PHAs. Policy effective April 2003 states clearly that anyone diagnosed with HIV shall be considered to have a substantial impairment. The diagnosis must be confirmed by an HIV/AIDS test confirmed by ELISA and Western Blot. If these test results are not available, due to the passage of time, then a consult from an HIV/ infectious disease specialist or HIV clinic, or blood work consistent with the CDC 1993 revised classification may be used. The policy also states that no medical review date should be assigned when approving an application for HIV positive persons. Some PHAs and doctors are not aware of this policy, or are familiar with earlier

policy with linked eligibility for ODSP to active use of antiretroviral medications, and therefore do not apply if they are not on medication. In the past, HIV positive applicants have had applications rejected if ‘recommended for medication’ was not cited on their forms.

PHAs who have addictions need not be rejected due to ineligibility based upon addiction. The regulation provides for exceptions: "Subsection (2) does not apply with respect to a person who, in addition to being dependent on or addicted to alcohol, a drug or some other chemically active substance, has a substantial physical or mental impairment, whether or not that impairment is caused by the use of alcohol, a drug or some other chemically active substance. 1997"

Recommendations for ODSP Reform

- Review the definitions of disability, especially in relation to mental illness as a cyclical condition or as a concurrent condition with other health concerns.
- Substance addiction should be recognized as a disease and the statutory bar on eligibility in addiction cases should be eliminated.

1b) Completing and Verifying Forms

The Issues: The list of referees may be too restrictive; for example social workers, medical health workers, and teachers are not allowed to complete the forms despite the fact that they may have intimate knowledge of the applicants’ abilities or encumbrances.

The Impact on PHAs: This is not seen to be a big issue, although access to knowledgeable doctors is key. This could be a significant issue for clients who are not on medications, but whose social worker/support worker at an ASO or hospital-based HIV clinic knows about their day-to-day restrictions. Currently, they are not permitted to complete the application form.

Recommendations for ODSP Reform

- The categories of people who are legally qualified to complete the ODSP application forms should be expanded to include accredited social workers and mental health workers.
- HIV positive prisoners should be offered assistance with paperwork and referrals to knowledgeable physicians as part of their pre-release planning.

1c) Income & Asset Levels

The Issues: The asset level that applicants can have before losing eligibility is currently $5,000. Applicants are also ineligible if he/she is a single person without dependents and in receipt of a student loan exceeding the ODSP monthly

entitlement. Many people applying for ODSP need money urgently and therefore apply to OW first. Asset levels are much lower for OW (equal to one month's assistance -- $520 in the case of a single person). The person needs to clarify that they are also applying for ODSP so they are not rejected for OW because of assets. A person with the larger amount of assets can only be on OW while awaiting an ODSP decision (and appeal time) once in a lifetime. If the person misses their ODSP application deadline they will be without OW support while waiting for ODSP and will have to rely on their assets.

The Impact on PHAs: This is not seen as a big issue for PHAs. However, clients should be advised that:

- RRSP's need to be cashed in and used first (unless they are 'locked-in') and there are limits to insurance benefits that can be received
- If they are eligible for student loans or if they have an outstanding loan, this will impact the Employment Supports Program once they are on ODSP

1d) "Grand fathering"

The Issues: Clients who were on FBA prior to the introduction of ODSP in 1998 do not need to demonstrate their medical eligibility. However, the criteria can be confusing. The key problem may be for those who 'exit' ODSP (employment, incarceration, or leaving the province). Only those grand fathered recipients who leave ODSP because of income from employment and return within one year can be rapidly reinstated. Some recipients who lose their ODSP because of incarceration are able to get back on as grand fathered, but it depends on the length of their incarceration. If they go off because they left the province, then they have to re-apply.

Recommendations:

- All "grand fathered" clients who leave the ODSP system should not have to demonstrate their medical eligibility upon re-entry, and should be eligible for rapid reinstatement. This should include people who exit ODSP due to incarceration.

1e) Application Process – Complexity

The Issues: The forms do not contain the statutory definition of disability, nor the criteria required for doctors. Applicants sometimes have difficulty accessing the forms required, and difficulty contacting personnel at ODSP. The forms are difficult to interpret. There are many steps to complete that require an endurance that some applicants are not physically and mentally capable of. Clients are expected to be 'self reliant' in getting all the paperwork and processes completed.

There are reports that some OW offices make clients complete a Medical Deferral form from OW participation requirements before they will give them a Disability Determination Package, but it is not supposed to be up to an OW worker to determine whether or not a client should or can apply.

The DDP forms say that the intellectual and emotional wellness section is 'not necessary' to fill it out if the principal diagnosis(es) are not mental health; this sometimes means that doctors filling out the form neglect that section, even though some ancillary mental health issues are often key to eligibility.

PHA Impacts: This is especially difficult for PHAs with mental health issues, or without access to an experienced advocate.

Recommendations

- Change the call center (ISU) process so ODSP applicants applying through OW can easily by-pass telephone screening and have their application taken in person.
- Simplify and shorten DDP forms. Make the revised forms public and allow for community consultation.
- Provide clear language information and training on the application process for applicants, community agencies and health practitioners.
- Pamphlets on self-help and where to get assistance with an application should be available at all ODSP offices and should be given to all applicants
- The application forms should be revised and simplified to make them more "user-friendly", with clearer plain-language explanations of the information required and the tests to be met - they should also be made available in different languages.
- Individuals should have access to an effective doctor-referral service
- The fees paid to doctors for ODSP applications should be sufficient to cover both completion of the application forms and attachment of consultation reports
- The mental health section of the form should be mandatory, even if mental health is not the primary diagnosis.

1f) Length of Time to Process Applications

The Issues: The processing of ODSP applications is too slow and too complicated. It can take up to 5 months to move the file from Ontario Works

(OW) to ODSP. This is despite the fact that OW and ODSP now share computer systems. Also, OW sometimes either does not make referrals, or submits late referrals to ODSP, resulting in lost benefits. Meanwhile, OW benefits are so low people may not be able to pay rent. If there is an initial denial, an appeal can take an additional 8 months to a year, or longer.

PHA Impacts: Health impacts of living on below-poverty OW rates can be devastating.

Recommendations

- Shorten the time it takes for applicants found eligible to begin receiving benefits.
- The transition between OW and ODSP should be streamlined to avoid unnecessary delays, OW referrals to ODSP should be confirmed in writing to the applicant, and communication between OW and ODSP should generally be improved

1g) Disability Adjudication Unit (DAU) Reviews

The Issues: The criteria for the DAU are not made available to applicants. The DAU is not easily accessible. Many users report administrative errors such as lost-documents, miscommunication between related agencies, as well as between applicant and DAU. The DAU has refused to recognize various medical conditions (physical and mental) without adequate justification. The DAU will reject applications because of missing information, rather than just ask for the information – this results in further delays. The high rate of successful appeals to the Social Benefits Tribunal (SBT) of DAU rejections demonstrates a problem with the DAU. The Tribunal applies a broader definition of disability from relevant court decisions, that is, takes into consideration the context of the individual. This approach needs to be integrated at the DAU. On a more positive note, there are reports that the DAU review process has improved in recent months.

PHA Impacts: Any delays can be damaging to health.

Recommendations

- The DAU decision-making process must be made more transparent and accountable. This would include:
    - Explaining the rating system used by adjudicators
    - Giving more weight to the opinions of applicants' health practitioners
    - Guaranteeing that decisions are made within 60 days of submitting complete applications

- The DAU should apply the ODSP disability test in accordance with the principles established by the courts and the SBT, and should consider the individual's whole picture, including the cumulative effect of all impairments and the compounding effects of socio-economic barriers
- DAU adjudicators should be required to have certain minimum qualifications
- The DAU should be more pro-active in obtaining necessary documents and clarification
- The DAU should provide fuller reasons for its denial at first instance - including attaching a copy of its adjudication summary to the denial letter
- Resources and funding should be made available so that an ODSP applicant can obtain a psychological or functional assessment in appropriate circumstances

1h) Lack of Supports

The Issues: OW staff are not allowed to coach disabled people on filling out their ODSP application. There is a lack of support for non-English speaking persons in regards to the application. Additional resources for marginalized groups, such as the homeless, mentally ill or cognitively impaired, are not currently available from ODSP. This leads to a substantial number of applicants falling through the cracks, or simply giving up.

PHA Impacts: This is especially important for marginalized PHAs or those without access to experienced advocates.

Recommendations

- Provide support workers to assist applicants in getting through the process. This would include providing ODSP liaison workers in OW offices (in larger centres where offices are separate) and funding trained community workers to outreach to disabled individuals in the community, including those living on the street.
- Support workers should be assigned to help with the application process - ODSP offices should ensure that applicants who need special help are matched with appropriate support groups or advocates
- The number of local ODSP offices in each region should be increased, and both ODSP offices and the DAU should be given adequate resources so that applications can be processed in a timely fashion

1i) Role of community agencies

The Issues: Community agencies have in many cases taken over the role of guiding people through the system, but they are not funded, trained, or supported to do so.

PHA Impact: This is especially a problem for PHA clients who do not have access to ASO advocates/case workers with a focus on ODSP issues.

Recommendations

- Consideration should be given to the establishment of a funded advocacy office with a mandate to assist individuals and advise community workers with the ODSP application process and other ODSP issues.
- ODSP applications should be made available at community agencies and institutions.
- ODSP workers should be permitted to send forms and correspondence to applicants through designated agencies or individuals where applicants are homeless or transient, as can currently be done with ODSP cheque payments.

1j) Consistency of Rules & Process

The Issues: OW and ODSP staff apply the rules inconsistently.

PHA Impact: This results in uneven access to benefits, based on interpretation of rules (or based on skills of AIDS community advocate).

1k) 90-day Limit to Application

The Issues: Shortages of physicians and specialists make the application process difficult. Applicants often have to succumb to long wait-lists that do not fit within the 90-day limit especially if they require specialist reports. Another consequence is that letters that are written in time to meet the deadline are often rushed and may not accurately portray the applicant's circumstances. In addition, most clients and many community agencies cannot afford the reports the DAU insists upon to determine eligibility, further delaying the application process or resulting in substandard applications.

PHA Impact: Unknown; the problem is probably worse in areas with limited access to HIV-knowledgeable physicians.

Recommendation

- The 90-day deadline on the return of applications should be extended

- Community agencies should be provided with resources to gather the reports needed for the process (See also 1g DAU reviews).

1l) Knowledge Level of Doctors

The Issues: Doctors are not clearly advised as to the importance of submitting consultation reports and test findings, which can result in an incomplete application.

PHA Impact: Doctors may not be aware of the importance of recommending medications, of reporting additional complications for those not on medications, the need to include lab reports confirming HIV status and the vital importance of including information about all medical conditions.

Recommendations:

- Doctors should be given clearer instructions on the completion of the application forms - in particular, doctors should be told to attach relevant specialist reports and test results - and they should be provided additional space on the forms to include further information, especially with respect to the Intellectual and Emotional Wellness Scale.

- Link questions on the DDP forms to the legislated definition of disability.

- The OHTN should consider playing an education role with primary care physicians working with HIV patients.

Issue 2 – Staying on ODSP

2a) Reassessments

The Issues: The process can be cumbersome for some recipients because they must re-obtain information and documentation from doctors that is already on file. This is unnecessary if their health status has not changed.

PHA Impacts: HIV/AIDS is recognized as one of a group of diseases that is chronic; therefore reassessment dates are not set when someone is accepted onto ODSP. However, AIDS organizations need to be vigilant to any prospect of change or any inappropriate application of reassessment to PHAs in their community. Some PHAs have expressed fear that a reassessment will be made at some point and an improvement, such as lower viral load, will result in their benefits being taken away. Another source of anxiety is that the difference between a financial reassessment (which everyone receives) and a medical reassessment is not always made clear.

Recommendations

- Reviews of medical status should have simplified forms geared to whether there has been an improvement in the medical conditions, not a complete reassessment based on the submission of an entirely new DDP.
- Eligibility reassessment periods should be longer, and the reassessment process should be simplified - a recipient who is being reassessed should not have to provide as much information as on his or her original application.
- Reassessments should not be scheduled for persons with chronic, long-term illnesses or other disabilities of a clearly permanent nature. This information should be made clear to the individual when accepted onto ODSP. ODSP needs to affirm/communicate such a policy to the HIV community sector and other affected disability sectors.
- ODSP should clearly communicate the distinctions between financial reassessments and medical reassessments.

2b) Client Service

The Issues: There appears to be a culture within ODSP that does not recognize that access to benefits is a *right* for disabled persons. Recipients and advocates find some ODSP staff impersonal, and their interactions with them have been characterized as "demoralizing, and dehumanizing". ODSP workers may need further training to understand what it's like to be living in poverty and with health problems at the same time. ODSP does not have enough support staff to respond to demands of their recipients. Information (i.e. change of address) is not processed in a timely manner. Relevant supplementary information is not

provided automatically such as other entitlements under ODSP. This makes it difficult for clients to manoeuvre the system without support/an advocate.

PHA impact: Unneeded stress is an additional health threat.

Recommendations

- Bring back the human element to ODSP delivery - each client should have a specific ODSP caseworker who is held accountable for actions and decisions taken on his or her file. They should see advocacy for their clients as part of their mandate.

- OW offices should designate specific workers to handle all ODSP application cases, and the telephone screening process should not apply to ODSP applicants

- Telephones in ODSP offices should be answered by human beings, not voice mail, and telephone staff should be trained to be able to accurately answer questions

- ODSP offices and communications should be fully accessible to clients with diverse disabilities

- Steps should be taken to ensure privacy and confidentiality at all ODSP offices

- Communication between offices should be improved so that individuals are not burdened with duplicate information requests

- The processes should be followed consistently in all offices and be transparent

- All clients should be given clear and accurate written information as to their ODSP entitlements and any other available benefits and programs, their responsibilities, relevant telephone and fax numbers, and their rights of appeal.

- Decision notices and all correspondence from ODSP should be clear and case-specific, and should include a contact name and number for any necessary follow-up including detailed information about the reasons for decisions, and the information required of clients to address the situation.

- ODSP workers should receive additional training and ongoing retraining on service standards, client relations, mental health issues and sensitivity (accommodating disabilities, anti-racism, cultural issues)

- ODSP should take steps to increase community presence and awareness by holding information workshops, sending representatives to employment

resource centres, and establishing liaison workers in community agencies, institutions, hostels and shelters

- ODSP should consider establishing a standing committee of ODSP clients to advise on client service issues as they arise.

2c) “Team” Approach to Client Service

The Issues: ODSP staff now function as teams – no single worker has responsibility for any single ODSP client. Recipients and advocates cite this approach as one of the contributing factors responsible for their discontent. Many recipients require consistent interaction with ODSP that is not possible with the “team” approach. This results in clients having to repeat their story/information/questions over and over, and in clients getting a variety of responses to their queries. ODSP does not disclose staff directory and contact information.

PHA Impact: Unneeded stress is an additional health threat.

Recommendations

- Bring back the human element to ODSP delivery - each client should have a specific ODSP caseworker who is held accountable for actions and decisions taken on his or her file.
- ODSP should provide an ODSP liaison worker for community partners - when client issues arise community workers have a contact to work with, someone with the capability to resolve the issue

2d) Computer Generated Letters

The Issues: Letters are often unclear, and leave no option for clear resolution of issues between recipient and ODSP. (There have been some improvements on this front lately).

2e) Complication of STEP Rules

The Issues: The rules and reporting requirements for extra earned income are confusing for clients. Clients make reporting errors and can be accused of fraud even though their efforts to report income were in good faith. ODSP payment adjustment calculations are made by computer, are not always right and often not timely. Subsequent 'explanations' to the client are also computer generated and confusing. Sometimes even when workers are asked to explain, they cannot. It is very frustrating for the clients and their advocates. Clients are sometimes not made aware of the Extended Health Benefit, which could alleviate some concerns about maintaining access to a drug card during a period of employment.

PHA Impact: Fear of loss of benefits, or of loss of drug card can be a major disincentive to work.

Recommendations

- The STEP program should be changed to provide true work incentives by increasing the earnings exemption limits
- Reporting processes for earned income should be simplified with any ODSP money adjustments made on a timely basis.
- Access to the Extended Health Benefit should be more routine and widely communicated.

2f) Appeals

The Issues: Time frames for internal reviews are too short, and the requirements are too rigid. Internal reviews of decisions by the local office are rarely completed within 10 days. Clients do not realize that if they do not get a response on an internal review after 10 days of filing, their appeal window starts running out. Clients risk losing their appeal rights. An appeal with SBT takes too long, usually one year.

Recommendations

- Eliminate the *mandatory* Internal Review step. Internal Reviews should be completed upon the request of the applicant, should allow new medical reports to be submitted, and should be reviewed promptly by the DAU.
- Provide more resources to the Social Benefits Tribunal for faster hearings and decisions.
- When an SBT appeal is pending, the DAU should review all new medical evidence as soon as it has been notified by the appellant that no new reports are expected and the matter is ready for hearing
- Internal Reviews of local office decisions should be carried out in a more timely fashion. If the 10-day window is insufficient, it should be extended to make it a meaningful process.
- There should be ODSP office staff dedicated to undertaking internal reviews of decisions when requested by clients, and communicating the results to clients in a timely manner.

2g) Role of Community Agencies

The Issues: Community agencies do not receive enough funding to advocate for their clients or accurate information to disseminate to recipients. This is especially a problem for small agencies that cannot keep a constant watch/liaison with ODSP issues.

PHA Impact: Many AIDS Service Organizations cannot dedicate a staff person to advocate on ODSP issues as a significant portion of their time. This makes it difficult to keep up with the complexities of ODSP, and to maintain relationships with ODSP managers.

Recommendations:

- See 1(i) above

Issue 3 – Benefits On ODSP

3a) Level of Basic Benefit

The Issues: The ODSP benefit is inadequate to meet basic needs of food and shelter. It has not increased since 1993, while the cost of living has increased 18%. CPP disability benefits are adjusted annually, but these increases are deducted from the ODSP payments. Clients who get CPP and an ODSP top-up end up with less income support than clients who rely 100% on ODSP for their income support, because CPP benefits are taxable.

PHA Impact: Lack of access to adequate nutrition, shelter and security can be life threatening to someone with a weakened immune system.

Recommendations

- Benefit rates should be increased to reflect real current market rents and costs, and should be adjusted regularly for cost of living

- ODSP should not deduct gross CPP benefits.

3b) Transportation

The Issues: Medical transportation is narrowly defined and accessing it is cumbersome. The benefit has to be renewed - in some jurisdictions every 6 months, in others a year.

Recommendation

- All recipients should be provided with transportation costs, including transportation to social recreation programs where medically recommended

3c) Special Diet

The Issues: Accessing this benefit involves more paperwork, i.e. doctor verification of needs. The paperwork must be renewed every year.

PHA Impact: After a recent revision, the special diet allowance does allow for vitamin supplements or herbal medications. However, it has a maximum of $40 per month. Doctors may need coaching on how to complete paperwork for maximum benefit.

Recommendations:

- Expand the list of products supported for special diets, and increase the benefit ceilings.

- The OHTN should consider provincial distribution of a doctor's guide to special diet requests (The Toronto People with AIDS Foundation has produced a local version).

3d) Dental Coverage

The Issues: ODSP has set a $400 limit per year for Dental coverage. The dentist needs to complete paperwork explaining the need for increased coverage, and get pre-approval, before any extras are covered. Even so only about half of the extras are paid for by ODSP. Dental coverage remains at the 1999 standard of entitlement, while the Ontario Dental Associations fee guide increases at a rate of 4% per annum. ODSP pays $17.21 twice a year for emergency visits. Anything over that would be billed to the client or absorbed by the dentist. ODSP covers filling, extractions, root canals, dentures (only if involves front teeth) and cleanings (up to 4 a year if Dentist does extra paperwork). ODSP will not cover dentures for back teeth (even though they are necessary for proper chewing of food). ODSP will pay for fillings only once a year. ODSP will only pay for one procedure per appointment (1 filling, 1 extraction), not a combination of work. This means extra appointments if multiple procedures are needed. This is time consuming for both the dentist and the client.
The Dental College dictates that dentists are expected to see any patients they have taken on, regardless of payment. This means most Dentists end up doing free work for their ODSP patients. This results in some Dentists not accepting new patients whose form of payment is ODSP. Some clients feel they are discriminated against or treated differently than other patients.

PHA Impact: Many HIV medications and anti-depressants cause a decrease in the production of saliva, causing dry mouth, which causes fillings to fall out. Many HIV patients easily exceed the annual $400 ceiling. Many PHAs cannot find a dentist and suffer ill health as a result.

Recommendations:

- Increase the dental coverage rates, increase the range of dental services covered, and increase the annual ceilings.

- Consider comprehensive and less cumbersome dental coverage for people whose medical conditions contribute to dental problems.

3e) Complementary Therapies

The Issues: There is no fundinging for complementary therapies beyond what the drug card or special diet allowance covers.

PHA Impact: Many PHAs rely on rely on herbs, supplements, Chinese medicines, and other naturopathic products to maintain their health.

Recommendation:

- Expand the special diet allowance or create a new allowance to cover naturopathic, Chinese medicines, homeopathic and other complementary medicines as prescribed by a regulated practitioner.

3f) Speed of Processing Benefit Claims

The Issues: Decisions as to eligibility are usually made by the DAU in 8 weeks. Upon decision, the recipient is paid retroactively to the date the DAU received their completed medical forms. If the client was on OW during this time, ODSP benefits begin the first day of the month following the month in which their application was complete. If there are delays in processing the application it may result in a loss of benefits.

Recommendation:

- Speed up the processing of benefit claims and ensure full retroactivity

3e) Lack of Information about Entitlements

The Issues: Clients are not sufficiently educated about their rights to entitlements.

Recommendation:

- Improve the initial orientation session/package for ODSP recipients, and build in regular reminders about entitlements.

3f) Paperwork

The Issues: Clients report grievances with the amount of bureaucracy required to maintain benefits, as well as the difficulty in accessing ODSP through technology such as fax or internet. Decisions on eligibility, etc are not communicated clearly in writing, and challenging decisions is made difficult; people are often just told to launch an appeal.

Recommendation:

- Improve the customer service model for ODSP workers and processes.

Issue 4 – Getting Off ODSP (And Returning to ODSP)

4a) Training/Education

The Issues: Information about options for accessing training and education is not seen to be widely accessible.

Recommendation:

- Improve the information package around training and education opportunities.

4b) Drug Card

The Issues: Recipients are often afraid to return to work out of fear that they might lose drug, dental and optical benefits (through the drug card). "Grand-fathered" clients who return to work are eligible for rapid reinstatement for a year. Maintaining access to the drug card during this employment period is dependant on a complex formula relating income and drug costs (STEP). Some clients are advised by ODSP staff to apply for Trillium instead, even though Trillium covers fewer health costs (i.e. no dental, vision, hearing).

PHA Impact: Fear of losing benefits is a critical issue for PHAs, who also fear the possibility of a relapse in their health condition. Some fear that even accessing training will signal that their health condition no longer warrants ODSP.

Recommendations:

- Increase the period where clients returning to work are eligible for rapid reinstatement should their health deteriorate.
- Allow clients to maintain drug card access (with drug, dental and vision) during this period.
- Improve information about and access to the Extended Health Benefit.

4c) Return to Part-time Work (levels of income allowed)

The Issues: The level of income clients are permitted to earn before it affects their ODSP benefit is insufficient to serve as an incentive to work. Recipients are often hesitant to return to work in case the income is not sufficient to sustain them. In such an event they would have to re-apply and endure the lengthy process of being reinstated.

Recommendations:

- Statutory and policy disincentives to work attempts should be eliminated - the income reporting system should be improved, the rapid reinstatement rules relaxed, and ODSP recipients should be given more assistance and support to find meaningful work

- Improve information about and access to the Extended Health Benefit

4d) Returning to ODSP

The Issues: For some people who leave ODSP because they return to work, leave the province, or are incarcerated, there can be a lengthy process to get back on benefits. (There have been improvements lately for incarcerated people). Many people who were on ODSP and have no review date are wrongly directed to the OW office and start lengthy new applications, when they should be notified that they are still medically eligible and go directly to ODSP for a financial update and reinstatement.

Recommendations*:*

- Improve rapid reinstatement for those who leave the system but whose medical eligibility has not changed

- Improve the capacity for incarcerated individuals to start ODSP reinstatement process, or book appointments in anticipation of release date

- Ensure that ODSP and OW coordinate information so that clients wrongly directed to OW to start the ODSP application process can be correctly directed to the ODSP office for rapid reinstatement

4e) Barriers to Employment Supports

The Issues: Employment Supports are often difficult to access. There are not enough job coaching services or ongoing support services. The community agencies working with Return to Work are inundated with paperwork and are not adequately funded to cover costs. The process to research training programs is not easy for individuals with physical challenges. Transportation costs are not adequately funded when individuals are accessing the ODSP application process or job search process. People who access both ODSP & may be ineligible for ODSP training because CPP has a Employment Program; however, it is time sensitive and riskier. ODSP will not cover General Education Diploma programs or transportation – and therefore the individual is ineligible for most training programs due the lack of a diploma

Recommendations:

- Improve marketing of employment support programs.
- Increase job coaching services.
- Increase funding for the Employment Supports program and extend the costs covered.
- Increase collaboration between CPP and ODSP to better support PHA and other disability groups

4f) Inconsistency of Decisions

The Issue: There appears to be great inconsistency on how the rules of STEP income, drug card access, etc are interpreted.

Recommendation:

- Encourage greater consistency in application of the rules.

4g) Role of Community Agencies

The Issue: Community advocates have greater responsibility in guiding disabled people through their rights and responsibilities related to earning income, but they are not sufficiently funded.

***Recommendation*:**

- Provide funding to community agencies to provide support to ODSP clients to enter or re-enter the workforce.

Appendix A: Bibliography and Advisors

Bibliography:

R. Cain & S. Todd (2002). *Shifting Sands: The Changing Context of HIV/AIDS Social Services in Ontario.* McMaster University.

J. Fraser, C. Wilkey & J. Frenschkowksi (2003). *Denial by Design: The Ontario Disability Support Program.* Income Security Advocacy Centre.

D. Herd & A. Mitchell (2002). *Discouraged, Diverted and Disentitled: Ontario Works New Service Delivery Model.* Community Social Planning Council of Toronto.

Ministry of Community, Family and Children's Services (2003). *Presentation to the Ontario AIDS Network.* Government of Ontario.

Ontario Disability Support Program (2002). *ODSP Handbook; ODSP Policy Directives; ODSP Employment Supports Application Package.* Government of Ontario.

ODSP Action Coalition (2003). *Access to ODSP Campaign Summary of Forum Reports.*

M. Spigelman (2002). *HIV/ADIS and Health Determinants: Lessons for Coordinating Policy and Action.* Ministerial Council on HIV/AIDS, Health Canada.

G. Williams (1995). *HIV/AIDS and Income Security: Literature Review and Annotated Bibliography.* Canadian AIDS Society.

Advisors:

This project was guided by two working groups of the OHTN and informed by three technical advisors. The project was launched and guided in its early stages by the OHTN's Active Living, Work and Health Working Group. In May of 2003, the OHTN restructured its advisory groups and issues related to income supports have since been guided by the Health Services and Access to Care Working Group. The technical advisors provided invaluable expertise about the rules, regulations and frustrations of dealing with ODSP. We also interviewed a number of "key informants" knowledgeable about ODSP issues; in the interests of confidentiality we have not listed them below. We are grateful to all working group members, technical advisors and key informants for their advice and for their commitment.

Technical Advisors: Kathy Dickson, Paul Landers, & Matthew Perry

Active Living, Work and Health Priority Working Group: Louise Binder, Pamela Bowes, Ken King, Stephanie Nixon, Don Phaneuf, Dr. Greg Robinson, Dr. Patty Solomon, Robert Vanidour

Health Services and Access to Care Working Group: Pamela Bowes**,** Dr. Roy Cain, Dr. Alan Li, Anne Marie DiCenso, Sarah Flicker, Jennifer Furtney**,** Ken King, Dr. Deborah Kopansky-Giles, Mathew Perry, Ron Rosenes