Centre for Addiction and Mental Health

1001 Queen St. West
Toronto, Ontario
Canada M6J 1H4
Tel: 416.535.8501

Centre de toxicomanie et
de santé mentale
1001, rue Queen Ouest
Toronto, Ontario
Canada M6J 1H4

www.camh.net

Barriers to ODSP:

Experiences of People with Mental Health and Addictions

Developed By:

Community Support and Research Unit
Social Work Council
Centre for Addiction and Mental Health

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Affilié à l'Université de Toronto

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Introduction

Many clients of the Centre for Addiction and Mental Health receive income support through the Ontario Disability Support Program (ODSP). Over the years, our clients, like others on social assistance, have not been awarded increases to their social assistance benefits and have, in some cases, been absorbing the costs of former entitlements that are no longer provided by the plan. This creates significant hardship for them, and interferes with their ability to recover and/or maintain their mental health. CAMH clients, like others on ODSP, are also encountering difficulties when dealing with offices that administer their social assistance payments. Clients complain about rude treatment by workers, and inadequate or incorrect information. Many experienced social workers at the Centre have also reported similar difficulties when advocating on behalf of their clients.

CAMH Income Support Program

Difficulties accessing social assistance benefits are not new to clients of CAMH. The Centre's Income Maintenance Advocacy Program (IMAP) was initiated in 1983 to respond to recommendations from a research initiative of the former Queen Street Mental Health Centre. The research findings indicated that 70 % of the Centre's clients were not receiving the higher income from the former Family Benefit Allowance to which they were entitled, but were on the lower income of the former General Welfare Allowance. The IMAP was formed to initiate a conversion process for these clients.

The role of the program has evolved and it now provides a wide range of income services to help clients access and navigate income support systems. These include: facilitating the application process; assisting clients to maintain their eligibility for benefits, engaging in individual and systemic advocacy, and providing income support education to clients, their families, and Centre staff.

IMAP has been successful in eliminating access barriers for the Centre's mental health clients. From 1998 – 2003, IMAP processed 202 applications for ODSP. Only three of these applications were initially denied and two were subsequently won on appeal. The third application was denied because the applicant had substance use problems. Nevertheless, as this paper will describe, CAMH clients continue to experience many problems with the ODSP system.

The Purpose of this Report

This report has been prepared to highlight the impact of ODSP barriers on the clients we serve. The first half of this paper will focus on the importance of adequate income for the well-being and quality of life of those with a serious mental illness or addiction problem. The second half will examine the problems associated with the manner in which the income support programs are administered.

Direct experiences of clients and staff at the Centre have been included throughout this report. In addition, a more detailed description of one client's experience with ODSP has been included in appendix "A" to provide a first-hand report of what it is like for someone with mental health issues to "go through the system".

Social workers at the Centre began collectively to recognize that clients were finding it increasingly difficult to live on the benefits provided by ODSP. The Centre's social workers approached the IMAP program to discuss their fundamental concerns with the current ODSP. Not surprisingly, IMAP experiences were consistent with those identified by the social workers and clients of the Centre. Recognizing that this situation needed more attention, staff members approached the Policy Review and Development Committee (PRDC) of the Centre for Addiction and Mental Health to seek advice and an endorsement to move ahead to address this issue. The Centre's social workers then partnered with the Steering Committee on Social Assistance of Ontario Legal Clinics and began collecting case examples that illustrated the problems regarding the provincial income support systems. The Legal Clinics were finding that the majority of their resources were being devoted to ODSP access appeals and they recognized that a larger-scale advocacy initiative was warranted to address the many problems.

This partnership developed into the ODSP Action Coalition that now includes many community social services and mental health agencies concerned about this issue. Throughout 2002, the Legal Clinics organized community forums across the province of Ontario to identify the barriers and highlight the problems encountered by clients. Findings were then summarized in a series of reports, and recommendations for changes to the system were generated. The forum findings were consistent with the experiences of CAMH clients.

Literature Review

A search of the indexed research literature was conducted to identify research related to income and quality of life for people with serious mental illness. A search was conducted of the PsycInfo database using combinations of the keywords and phrases such as: income support/income maintenance, poverty, quality of life/well being, mental health, unemployment, and so forth.

In addition, the tables of contents of a number of journals were scanned for relevant articles (e.g., Psychiatric Services, Social Science and Medicine, Hospital and Community Psychiatry). Finally, a web-based search was conducted for non-indexed published and unpublished reports.

Although income is a key determinant of health, its importance in the recovery and well being of people with mental illness and addiction has received scant attention. This stands in stark contrast to the considerable research on the benefits of various treatment approaches and community supports such as housing or case management services. The majority of the research that was identified focuses on homeless individuals who are at the extreme lower end of the economic scale. These studies identify the health problems of people who are homeless and who receive no income supports (see for example, Gelberg & Linn, 1988; Sullivan, Burnam, Koegel & Hollenberg, 2000).

Only one study was found that directly examined how increases in income could lead to improvements in quality of life for individuals with serious mental illness. Lafave, deSouza, Prince, Atchison, & Gerber (1995) randomly divided 54 individuals with serious mental illness who were living under the poverty line into two groups. One group was given allowances and forgivable loans that raised them above the poverty line. The second group also received additional funds, but they were not sufficient to raise them above the poverty line. Findings showed that during the project period hospitalization decreased more than 70% for all participants. This represented a decrease in the cost of hospitalization from $47, 300 to $13, 500 a year per participant. Additionally, both groups showed significant subjective

improvements in quality of life (as measured by the Quality of Life Interview) at six and 11 months after the project start up. No significant differences were found between the groups in the number of hospitalizations or in improvements in quality of life, suggesting that even small improvements in income among people with serious mental illness are associated with improvements in quality of life and in need for hospitalization.

Working is one of the ways that people with mental health or substance use issues can increase their income. Unfortunately, regulations governing most income support programs place restrictions on those who receive benefits but also want to work. Notably, there is evidence of potential health care cost savings associated with work. For example, Polak and Warner (1996) found that the mean monthly costs of psychiatric treatment for the unemployed participants in their study (US$2,083) were significantly higher than the costs for those who worked part-time (US$910) or full-time (US$290). The authors of this study note that the unemployed individuals in this study may have had greater mental health challenges than those who were working. Alternatively, those who worked more may have experienced some benefit from their work that lessened the need for treatment. If it is indeed the latter, then there are economic as well as health benefits that may accrue from providing economic incentives, rather than disincentives, to work.

Whereas there is little research on the benefits of stable income, there is some research documenting the challenges associated with accessing the benefits to which individuals are entitled. Studies show that access to community supports and treatments can improve access to income supports (e.g., Lehman, Kernan, DeForge, Dixon 1995; Rosenheck, Frisman, Kasprow 1999) and help people to exit homelessness (e.g., McBride, Calsyn, Morse, Klinkenberg, Allen, 1998). Segal and Choi (1991) have noted that poor and erratic administration of a U.S income support program often results in revoked or discontinued benefits without proper cause. Often individuals with mental health problems require additional support to acquire the benefits to which they are entitled. In an ethnographic study of homeless women with mental illness, Baldwin (1998) found that being a client of a Mental Health Clinic was a significant influence on the duration of homelessness. More specifically, one of the factors that facilitated the exit from homelessness was the assistance of clinic staff in expediting applications for social assistance.

A study by Estroff, Zimmer, Lachicotte, Benoit and Patrick (1997) on the disability income application process in the U.S. found that applications initiated by family members or staff and social workers were more likely to be accepted than those initiated by the individual him or herself. Eighty-three percent of those applications instigated by the family were successful. The percentage was only slightly lower for those completed by staff members. A report from the Income Security Advocacy Centre, “Denial by Design…The Ontario Disability Support Program”, highlights that due to systemic barriers preventing access to benefits, thousands of people who should be receiving ODSP supports are not. This report points out that no supports are built into the application process, and individuals are left to navigate this complex system themselves. For people with special needs, the barriers to access and the ongoing difficulties in interacting with the system are often insurmountable.

In conclusion, research from the U.S. demonstrates that there are potentially significant barriers to individuals accessing and maintaining those benefits to which they are clearly entitled without support from professionals or family members. This review also demonstrates that there is a substantial gap in research on the role of income in the lives of people with serious mental illness. Although a sufficient income has been identified as a critical determinant of health, there

has been little research to understand its role in the recovery and community integration of individuals who are among the most vulnerable and marginalized in Canadian society.

Recent Trends in Social Assistance Reform in Ontario

In 1998 the government of Ontario adopted new legislation to reform the social assistance program that had been in place in Ontario for over thirty years. Two crucial elements of the government's social assistance reform consisted in establishing a unique income supplement program for the disabled and seniors, which would be separate from the program for all other social assistance recipients, and adopting stricter enforcement mechanisms with respect to welfare recipients (Wilkey et al., 2002). Also critical for clients at the Centre for Addiction and Mental Health was the exclusion of addiction as a disability and consequently a statutory ban on eligibility for ODSP for these clients was instituted.

Integral to these reforms was the implementation by the government of new computer technology that would shift the system away from individual case management to a call-center or "team" style of case management. This new service delivery model also includes an interactive voice response system. Both of these reforms have proven to be problematic for our clients, as telephone calls go unanswered, messages are not returned, and special access needs are not addressed. The "team" style of case management is impersonal and inadequate and there is no accountability within the system. In fact as the Access Forums point out, the new system appears to be used to avoid client problems rather than resolve them.

Experiences of CAMH Clients with the Current ODSP System

Dealing with the provincial income support programs has grown increasingly complex and has proven to be a considerable source of stress for CAMH clients. Difficulties understanding and traversing the application process are the chief complaint of those who use and work with the income support system. Once an application is approved, further administrative errors can slow the process of actually receiving money. Even when funds are received, individuals still live well below the poverty line. Further, regulations governing the receipt of these funds often create disincentives to meaningful daily activities such as work. Finally, recipients will find their eligibility periodically reviewed, which also can be difficult for vulnerable individuals.

An Unresponsive System

It is common for clients to receive inadequate responses, or no response at all to their questions, concerns, or complaints. This leaves clients powerless to comply with program guidelines because they are unable to get information about what they must do to maintain their benefits. They are given little information, guidance or assistance by ODSP regarding their rights and responsibilities under the program.

Computer Generated Letters

It is common for communication between the ODSP program and applicants or clients to occur through standard, computer-generated letters. The way in which these letters are used in place of direct contact with clients creates not only systemic barriers to the program for people with mental health issues, but also results in significant emotional hardship for clients who are

already very vulnerable. This is particularly the case when computer-generated letters are used to communicate information as critical as the potential loss of benefits.

Receiving a standard letter announcing the potential loss of benefits is a traumatic experience. A loss of benefits not only means losing a primary or sole source of income, but also means losing access to the medications and other supports that the program offers.

To make matters worse, the letters are often difficult to understand or are inaccurate. Contact information is rarely included and when it is, follow-up with ODSP staff is frustrating. ODSP clients, as well as agency staff who advocate on their behalf, report that clients receive very poor treatment when they attempt to contact the ODSP program – even on matters of such grave importance as the loss of benefits.

Under these circumstances, clients understandably react with much anxiety and there are documented instances of clients threatening to harm themselves if their benefits are suspended. Clients have also resorted to over-medicating themselves to alleviate the stress associated with the receipt of these letters and have said that they continue to overmedicate when they are unable to get any explanation as to why their benefits are being threatened.

In one example, a client reported receiving repeated computer-generated letters that threatened to suspend her benefits. No explanation of why benefits would be suspended was provided. Benefits continued to arrive each month, although they were late. During one month in particular, her drug benefit and dental card did not arrive until the 23rd day of the month. Both the client and her worker attempted to get an explanation but none was ever provided.

Eligibility Reassessment

Long-term ODSP recipients are required to complete an eligibility reassessment every two years. The reassessment and application process is error prone, causing clients considerable anxiety for fear that benefits may be terminated even though their condition has not changed.

The Comprehensive Verification Process (CVP) is another reassessment mechanism used by ODSP. Clients receive an extensive package, with an attached timeline, requesting a great deal of information in order to maintain their benefits from ODSP. The information requested can include, but is not limited to, requests for copies of various pieces of ID, lease, tax assessments from previous years, proof of assets, proof of income, employment history, dependant information, etc. If the requested information is not provided within the timeframe allowed benefits are put on hold.

IMAP has actively promoted the importance of compliance with Centre clients and staff, and is available to assist Centre clients and staff to comply with these requirements. During the period Sept 01 to Oct 02 IMAP responded to 15 interventions and 26 consults concerning CVP's.

Reinstating Benefits

ODSP has a policy of suspending benefits to people who are incarcerated. When benefits are suspended, it is often very difficult to have them reinstated. It can take a well-organized person two to three months to become reinstated if he/she has proper identification. Many of the Centre's clients are not so organized and many have lost their identification. In some cases this suspension of benefits has resulted in clients becoming homeless, when they were unable to maintain their rental payments.

As the report, “Denial by Design…The Ontario Disability Support Program” highlights, former recipients should be able to get back onto ODSP quickly and simply. In practice, however, the Ministry often fails to apply its rapid reinstatement policies, forcing these applicants to start from scratch and to go through the entire application process. This is particularly problematic for former Family Benefits recipients, who will then lose their “grandparented” status and may find it difficult to meet the current ODSP definition of disability. This also particularly impacts our clients in the addictions programs who have been grandparented. Addiction problems are excluded under the new definition of disability, and so these clients risk being deemed ineligible.

Barriers to Employment

Clients who are working find the process for reporting earnings very confusing. Many are not sure how to report their earnings, when to report, what the exemptions are, and how their monthly cheques will be affected. During the period Sept 01 to Oct 02 IMAP responded to 129 interventions, 9 assessments and 51 consultations concerning earnings.

Perhaps largely due to these difficulties and those associated with eligibility reassessment and reinstatement of benefits, many clients express concerns about trying to work. There is often confusion or misinformation about the rules related to working while collecting ODSP. Many clients and workers believe that working will result in an automatic termination of benefits and a loss of drug and dental benefits. This is in fact one of the many misperceptions regarding the employment provisions under ODSP.

Clients who work and continue to receive ODSP can maintain their drug and dental benefits indefinitely; however, they must apply annually to maintain these benefits. This annual reapplication option is not at all well known by clients or workers. Those who are aware and apply, normally experience a two – three month period without coverage. For some this means discontinuing medication and risking a relapse. Those who can manage it, pay for very expensive medication themselves, although they are entitled to the benefit.

Many working clients also report difficulties getting reinstated when illness prevents them from continuing to work. As a result of all these problems with the system, clients who are interested and able to return to work are discouraged, for fear of losing their benefits.

Delays in Accessing Start-up Benefits

Many workers have reported excessive delays when their clients are trying to access “Start Up Allowances”. One client waited four months to get a start up allowance prior to beginning a job placement set up through the Centre’s Work Adjustment Program. Clients and workers have indicated that they receive contradictory information about the rules governing the availability of the allowance, discover that their applications have been lost or misplaced, do not get their calls returned, and are told that they are ineligible, when in fact they are.

The majority of IMAP's direct service is devoted to helping clients access benefits and other entitlements. Even when all the necessary documents are submitted, there are usually delays with discharge allowances, community start-up benefits, requests for redirection of housing money to CAMH for rent payments, personal needs allowance and regular monthly entitlements. There is a considerable backlog at the ODSP local offices. As a result paperwork gets lost and must be faxed and re-faxed. Follow-up is time consuming and frustrating. ODSP, in most cases, is the only source of income for clients.

Particular attention should be given to the request for community start-up. This benefit of $799 can be accessed once in a twelve month period when a client is moving from hospital to the community or from temporary housing to a more permanent home (e.g. boarding home to subsidized apartment). The benefit is intended for household items, furnishings, deposit on accommodation, deposit on utilities and moving expenses. The amount of this benefit does not meet the cost of any of the items it is intended to cover. Further, it is not provided until housing is secured or the client is discharged from the hospital. Clients often do not actually receive this allowance until they have been in the community from 2 weeks to 1 month. To ease the transition process many workers must scramble to find funds to cover some of the necessary furnishings (e.g. bed) prior to discharging their clients. Also, providing the allowance earlier to assist with the deposit on accommodation would help many clients to secure housing in this competitive rental market.

Inadequacy of Funds Allotted

The subsequent stories describe 2 situations in which clients have been unable to cover their daily expenses with the benefits provided.

One client receives $650.00 per month from ODSP and lives in a Metro Housing apartment. Although her rent is subsidized, she runs out of money towards the end of the month and resorts to prostitution. She has been apprehended, charged and put in jail. Spending time in jail has resulted in an extreme exacerbation of psychiatric symptoms. In spite of this experience, she continues to resort to prostitution. She also has been so desperate for food that she has shoplifted from local grocery stores, been banned from some stores and charged and sued by a local grocery store seeking restitution, that she cannot afford, for the stolen goods.

Another client had been homeless for 7 years, living in shelters, but still receiving $780.00 per month from CPP. The social worker helped him acquire rent geared to income housing. An effective medication regime was also established, with medication costs of $400.00 per month. ODSP was approached to determine the client's eligibility for their drug plan. Although normally ODSP regulations allow this expense, when clients are also receiving geared to income housing they do not, as the two programs are linked. As a result, the client did not qualify for the ODSP drug/dental plan. Although the client eventually secured some Trillium coverage, his medication costs continue to eat into his monthly allowance.

Reductions to the Transportation Assistance Program

ODSP no longer provides transportation assistance to clients for appointments that are considered recreational or psychosocial in nature. Pharmacy appointments are also not funded. This means that clients in the methadone program who come to receive necessary pharmacological treatments cannot receive transportation assistance for these clinic visits. Only appointments with physicians are funded. Also, there is no ODSP system mechanism to increase the Transportation Assistance Program when fares increase. The client must apply for the TAP increase when fares increase. Thus again the onus is on the individual clients to advocate for their basic entitlements, with no recognition of the supports that clients need in order to do so.

The province has made some positive changes to the TAP since taking over its administration from municipalities in 2000. These include eliminating log sheets, providing the benefit with the client's monthly entitlements and permitting renewals for an indefinite period. These

improvements took considerable advocacy by the IMAP to achieve. However, there is still a need for clear guidelines as to what constitutes a medical appointment. The answer to this question varies from office to office. Also, there needs to be an ODSP system mechanism to identify clients in receipt of TAP, so that fare increases are reflected in the benefits as soon as they occur.

Conclusions and Recommendations

The issues documented in this report demonstrate that even when clients are successful with their applications for income support their financial concerns are often not addressed. Administrative errors can result in delays in payment, lost cheques, inappropriate termination of benefits and so forth. For most clients, the benefits received do not last for the entire month. Furthermore, restrictions on transportation support and barriers to employment make it hard for recipients to take steps to improve their financial situation.

It is important to note that people who need ODSP benefits are also facing other tremendous personal struggles and require support and assistance. What they encounter is an unresponsive system that creates undue stress and hardship and often interferes with recovery. It is for this reason that CAMH has put the IMAP program in place and continues to dedicate staff resources towards assisting clients to navigate this system. We have highlighted recommendations for reform that specifically refer to the problems outlined in this paper and also strongly endorse the other recommendations put forward by the ODSP Action Coalition in their report "Access to ODSP Campaign Summary of Forum Reports", as well as those illustrated by the report of the Income Security Advocacy Centre, "Denial by Design…The Ontario Disability Support Program".

Inadequacy of Funds

- First and foremost ODSP rates should be increased.
- Rates should be adjusted annually to reflect cost of living increases.

Eligibility and Reassessment

- Lengthen the reassessment period from the current two years for clients whose condition essentially remains unchanged.
- Simplify the reassessment process to include only a medical summary of the current condition.
- Addiction should be recognized as a disability and the statutory ban on eligibility for clients with addictions should be eliminated.
- Rapid reinstatement policies should be applied to clients already granted ODSP, but whose benefits are temporarily discontinued due to hospitalization or incarceration.

Client Services

- Individual ODSP case workers should be assigned to clients in order improve access to information and to increase accountability.
- Service standards should generally be improved and clients should be treated with basic courtesies and respect.
- All clients should be given clear and accurate written information that outlines their entitlements and responsibilities under the ODSP system.

- Provide clear written information regarding start-up allowance benefits and process requests in a timely fashion.
- Any written information sent to clients should be checked for accuracy, be clear regarding the purpose, and include a contact name and number that clients can **easily access** to receive clarification.

Transportation Assistance

- Extend eligibility for more than just medical appointments to reflect the need for a multidisciplinary approach to recovery.
- Automatically increase the allowance when transit fares increase rather than having the client apply for an increase.

Employment

- Clients should be given clear, written information regarding the income reporting rules.
- Clients should also be given clear, written information regarding their entitlements to drug and dental benefits while working.
- The one-year extension for drug and dental benefits should be lengthened.
- Drug and dental benefit applications should be processed in a timely manner.
- Increase the amount of monthly money that clients can keep before they receive a reduction in monthly ODSP allowances.

Appendix "A"

One Client's Experience

One client described a set of similar problems that he had experienced in his efforts to deal with ODSP.

On a number of occasions, he tried to contact a worker to get some clarification on ODSP forms he needed to complete. He received no calls in return. He also called several times seeking information on the ODSP job-retraining program. When he finally spoke to someone at ODSP they were unable to give him any information about the program, did not forward his call to anyone else, and did not even give him any suggestions on how he might follow up to get the information he was looking for.

The client has a serious physical condition that requires expensive maintenance medication. Although he is able to work part time, he was receiving some ODSP benefits as well as coverage for his medication. He asked an advocate to review his case to determine if he might be eligible for additional benefits. The advocate told him that he qualified for extended benefits. When he contacted a worker at ODSP, he was simply told that they didn't know anything about it.

Subsequently his drug card was cut off, forcing him to go off his medication. When he contacted ODSP to find out why he'd been cut off, he was told that he was reported to have excessive assets. The worker refused or was unable to provide any details, beyond saying it "could be artwork or jewellery." The client reports that his artwork consists of posters and his jewellery was purchased from street vendors. Neither have any significant financial value. After some investigation, he was reinstated and went back on his medication. Unfortunately, his system rejected the medication, apparently because of the lapse, causing him serious health problems including a trip to emergency.

When he recovered, he signed a waiver to get off ODSP except for the drug card. This was to preclude further problems. He also enquired about a disability expense, which someone had described to him as an allowance to cover expenses related to returning to work. One worker said they would fill out an application for him, but no application was submitted on his behalf. In his efforts to pursue this potential benefit, another worker did not return his calls. When he complained about this situation to yet another worker, the worker stated or implied he was lying to them. He has since involved a lawyer to handle all contacts with ODSP.

On his return to work, he specifically asked ODSP not to contact his employer, and requested that any contact with him be through his lawyer. He was working in a retail setting and was the first and only openly gay staff member working for this company. He says someone from ODSP called his employer and three days later, he was fired. In addition, other staff members would not use the same washroom after the phone call. He believes that ODSP revealed something about his medical status to the employer, and that it got out to other employees.

After losing his job and getting legal assistance, ODSP agreed to provide him with a new worker. The previous worker had hung up on him, snapped at him, and told him she had a heavy caseload and didn't have time to discuss his concerns. It is also his understanding that she had instructed a clerk in her office to contact his place of employment, which he feels resulted in the job loss.

The nature of the ODSP-related stress the client reports, and its continuation over a protracted period, no doubt had a significant impact on his mental health, particularly when combined with the other health issues he was dealing with.

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