



## Moving On

Successful early treatment of psychosis means that more than ever before young people are moving on to create fulfilling lives for themselves. Many will want to pick up their lives where they left off when they became ill. With this in mind, Issue Five is devoted to the topic of returning to school or work. Thanks to all who contributed their expertise and experiences to this issue.

Hope you have a happy and hopeful summer. See you in the fall.

*Sharon Scott, Editor*

### Locating Published Journals

A number of mental health journals are referenced in this issue. But, sometimes finding them can be a challenge. Janice Linton, Aboriginal Health Librarian, Neil John Maclean Health Sciences Library in Winnipeg suggests:

- Start with your public library, hospital library (many offer services to the public), College or University library.
- Ask about Interlibrary Loan Services. Smaller libraries provide this service to give the public access to the information they need.
- A list of medical libraries is on the Canadian Medical Association Website, [www.cma.ca](http://www.cma.ca). Select "General Public", select "WebMed Links", select "Medical Libraries".
- Ask the librarian about their Consumer Health Collection.
- If you don't wish to use a public library, the Document Delivery Services provided by CISTI is an option (\$10 to \$14 per article). Their web-site is: [www.cisti.nrc.ca/cisti/cisti\\_e.shtml](http://www.cisti.nrc.ca/cisti/cisti_e.shtml)

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# family to family

FOR FIRST-EPIISODE PSYCHOSIS FAMILIES

## A Student's Story:

### My Experiences with Post-Secondary Education

by Tara Marttinen

When I received my letter of acceptance from the University of Western Ontario (London) I was very excited. In a few short months I would be moving away from my family, friends and the familiarity of my small town. I was excited but apprehensive.

What makes my experience with university unique is that I have schizophrenia. Because of my illness I had to make different choices than my peers. For example, I would only take three classes instead of the usual five and I chose to rent an apartment by myself instead of living in residence or with roommates.

Like any person considering a post-secondary education I had to first decide how I was going to cover tuition and living expenses. I stayed behind a year and worked part-time while living with my parents. This was difficult as I was eager to leave home at the same time as my peers.

I applied for several scholarships as well. I found a few scholarships over the internet that were designated specifically to people with disabilities. One caveat, however, is that in order to be eligible for most scholarships you must be a full-time student. My part-time status made me ineligible for any of the scholarships I had applied for. Also, many of the scholarships currently available are designed for people with "visible" disabilities like blindness or deafness. In my search I did not come across any scholarships that were created specifically for people with psychiatric disabilities.

I also applied for and received three bursaries. One was through the Financial Aid office at Western, another was through the Services for Students with Disabilities (SSD) office, and the last was through a drug company. The bursary

that I received through Western's SSD was actually a provincial endowment of up to \$2,000 that was meant only to cover the cost of medication. I had to submit receipts of my medical expenses and return the unused portion of my bursary.

I applied for OSAP (Ontario Student Assistance Program) as a person with a permanent disability. With status as a disabled person I was given the full OSAP entitlement even though I was only a part-time student. OSAP considers a person with a permanent disability to be a full-time student if he/she is taking a 40% course load.

When I moved to London last August, I immediately booked an appointment with a counsellor at the SSD office. I had to provide the counsellor with a letter from my doctor confirming my disability. The counsellor told me about my options as a disabled student at Western. Through the SSD office I arranged to write my exams alone in a separate room. This took some of the pressure off of me because the exam environment was discreet, quiet, and distraction-free. The SSD office also distributed a letter informing all of my professors of my disability. I chose to do this because I felt it would be beneficial for me if my teachers had this information. My counsellor also promised me that the SSD would intervene if I experienced any problems with any of my professors because of my disability.

I really enjoyed my first year. I'm glad I took the chance and went to school. It's been interesting living on my own and fending for myself. I'll admit, it was hard at times, but it can only get easier in the years to come.

# Ask the TREATMENT TEAM

Written by Harriet Woodside, OT Reg. (Ont.), and Jane Hamilton-Wilson, RN, Family Educator

**Q** Based on the experiences of the Hamilton first-episode program, what advice would you offer to young people who are contemplating a return to school or work?

**A** We interviewed eight clients in our program last year about what helped them to be successful at work. Sam, age 23, who had his first episode during his early years at university, summarized what we heard: "Just get over it... Whatever it is, you've got to work through it... You do it slow; you try your best..."

*Here's more advice that comes from our clients' experiences<sup>1</sup>:*

**Make positive life style changes.** When you are recovering from any illness, you need to get some balance and activity in your life before tackling school or work. Reduce substance use if this is an issue. Figure out ways to cut down on stress. Participate in leisure and recreational activities. It wasn't easy, and there were problems, but early on Sam got better control of his alcohol consumption and he connected with a few close friends.

**Figure out what you want to do.** This is often tough but everyone needs direction. Talk about your ideas, even the off-beat ones, with other people. This can take time, but set some goals: big (like choosing a career) or little (like taking a daily walk).

**One step at a time.** Your full-time job is regaining your health: patience and pacing are important as people recover. Sam tried returning to university but it didn't work out. He wasn't well enough. Instead Sam took the smaller step of returning to his part-time job with a graduated return to work plan. He and his occupational therapist worked out a schedule which was approved by his doctor and his employer. As he adjusted to work, Sam added more hours, then more responsibilities.

**Take control of your life.** The people we talked to who were successful at returning to work were the people who made their own decisions, set their course, and took personal control. Some of you will have trouble getting motivated and feeling energetic but remember that no one can "rehabilitate" you! We've learned that people flourish when they make the decisions and then we support them with their ideas. That's what happened with Sam. After some setbacks, and uncertainty about his goals, he came in with a clear plan that was his own plan. Right now, he's studying a new field at college.

**Q** What are the best ways, or "best practices," for enabling young people in first-episode programs to be successful at school or work?

**A** We used to think that if we put people with serious mental illnesses in segregated pre-employment programs and trained them, they could then go on to be successful and satisfied in regular work settings. There is now research evidence that suggests there is a better way. The current "best practice" is called "supported employment (SE)," "individualized placement and support (IPS)," or "place-train." The key elements of these approaches are "continuous, time-unlimited individual support; attention to client preferences; and a place-train philosophy with on site job specific skills training."<sup>2</sup>

Here's an example of how this approach works.

**Client preference:** Susan wants to work and her counsellor, Jim, has helped her find a job as a restaurant dishwasher.

**Place-train philosophy:** Together they agree that Jim will work along side Susan for her first shifts to help her learn the routine. They arranged this with the manager who is happy for the extra help during Susan's orientation period.

**Continuous support:** Susan feels ready to handle the job on her own after two shifts. She does well until she goes drinking one night and becomes very suspicious. She calls in sick and contacts Jim because they agreed she would contact him if she was having a problem. Jim encourages her to return to work the next day. They meet after this shift and discuss what happened. Jim makes a point of phoning Susan frequently to find out how work is going if she hasn't called him.

While the SE approach is known to get good results, first-episode clients are often reluctant to disclose their illness which changes the way a support person can help with their training. We often modify this approach to provide a lot of support outside of work without entering the workplace. For example, Harriet (Occupational Therapist) will travel with someone to his first day of work but not go in or she will call to check in after each shift for the first few days.

**Q** What can families do to support this important transition?

**A** Families can play a vital role in helping their relative successfully navigate the transition back to work or school. They can be a valuable source of support and encouragement. For most clients, the family is the most consistent and vocal cheering section. Families are in an ideal situation to encourage forward movement towards

small goals. Helpful families understand the need for patience and the potential for small setbacks. They also understand that recovery from psychotic illness is a slow and tedious process but that recovery is possible. Families can be the champions of hope.

Families can help the recovery process by setting an example of healthy lifestyle choices and establishing regular routines within the household. They can also encourage behaviours within the family setting which would support success in other community settings. Families can encourage standards of grooming, hygiene, alcohol and substance use, medication adherence, regular exercise and well-balanced nutritional choices.

Finally, family members need to avoid becoming too illness focused. Communicating about normal, everyday things, unrelated to psychotic illness or rehabilitation gives a message of acceptance to the ill relative that life goes on. Recovery efforts should never become the singular focus of family attention.

<sup>1</sup>Adapted from Woodside, H., & Schell, L. (2001). Factors influencing vocational success following a first episode of psychosis: The consumer perspective. Paper delivered at the 2001 IAPSRs, Ontario Chapter, Conference, Thunder Bay, ON.

<sup>2</sup>Health Systems Research Unit (1998). Review of best practices in mental health reform. Ottawa, ON: Health Canada, p.103.

## The Psychotic Disorders Clinic

### Hamilton Health Sciences, McMaster University Medical Centre Site

Founded in 1986 by the noted Canadian clinician/ researcher Dr. Jock Cleghorn, and located at McMaster, we are affiliated with the University's Department of Psychiatry and Behavioural Neurosciences. Our early intervention programme developed right from the start, although we do not work solely with first-episode. Around 35% are first-episode clients.

#### **The aims of our programme are to:**

- connect with clients as early as possible in their first episode, treat symptoms and limit disability;
- provide and foster an environment that nurtures and supports recovery;
- support members of the clients' natural social network - family and other significant folks.

We offer service to everyone over 16 with psychosis, in a mixed urban, suburban and rural catchment area of some 160,000 persons. The area contains both the university and a community college. Over 90% of clients live with family. Referrals come from in-patient units, Emergency Rooms (ER), family doctors and other clinicians. Every effort is made to connect with clients within a week of referral. We offer a hospital-based clinic service with a special relationship with the in-patient unit, and are part of a well-integrated regional network with centralized psychiatric ER and mobile response team, a range of rehabilitation opportunities and several case-management programmes. The clinical team offers an interdisciplinary approach. It includes a psychiatrist, two RNs, who serve as care-coordinators, an occupational therapist and a family educator. In-patient admissions are avoided as much as possible. After comprehensive

assessment, treatment is offered which espouses the values of hope and empowerment.

Our conceptual model of Therapeutic Partnership holds that clients and their families are full partners in treatment, with treatment goals negotiated and shared. The five components of Therapeutic Partnership are Alliance, Accompaniment, Agreement, Action and Accessibility. Medications are the cornerstone of treatment and are prescribed in low dose/slow increases, making every attempt to avoid or quickly contain side effects. Auxiliary treatment includes individual and group education, coaching and support in stress management and problem solving, cognitive behavioural strategies, stigma management, goal setting, vocational and social reintegration, family support and education, and substance use counselling.

There is no set time limit to treatment. Clients can remain in active treatment with the clinic, as long as there are goals. After initial treatment, clients can choose to transfer to community case-management or to "graduate" to the clinic "Alumni" follow-up programme. Alumni continue with agreed upon treatment plans, supported by their family doctors, with check-ups in the clinic every six to twelve months. Clients are welcome to return to the clinic for subsequent treatment whenever indicated.

#### **Team members are:**

Suzanne Archie, Psychiatrist; Jane Hamilton Wilson, Family Educator; Heather Hobbs, RN/Care-Coordinator; Jean McNiven, Research Nurse; Shelley Osborne, RN/Care-Coordinator; Harriet Woodside, Occupational Therapist.

**Contact: Heather Hobbs RN, BScN: (905) 521-5018**

#### **Publications:**

- Hamilton Wilson, J. & Hobbs, H. (1995). Therapeutic partnership: A model of clinical practice. *Journal of Psychosocial Nursing and Mental Health Services*, 33 (2), 27-30.
- Hobbs, H. & Hamilton Wilson, J., Archie, S. (1999) The alumni program; redefining continuity of care in psychiatry. *Journal of Psychosocial Nursing and Mental Health Services*, 37 (1), 23-29.
- Hamilton Wilson J. & Hobbs, H. (1999) The family educator: A professional resource for families. *Journal of Psychosocial Nursing and Mental Health Services*, 37 (6), 22-27.



# Financial Assistance for Students with Mental Illness

by Heather McKee, Project Manager

Promoting the Rights of Students with Psychiatric Disabilities Project, CMHA National

A very important piece of information for students to know is that mental illness is considered a “disability” by universities and colleges. As such, students with mental illnesses are legally entitled to financial aid for disabled students, and access to supports and services, usually provided by the Disability Services office on campus.

Financial aid for students with disabilities is provided by the federal and provincial/territorial governments. Each province and territory has different rules and procedures for applying for aid. Some provinces provide bursaries, which is money that does not have to be paid back, as well as loans, which must be paid back. An excellent resource for financial aid for students with disabilities is the National Educational Association of Disabled Students web-site at [www.neads.ca](http://www.neads.ca). As Tara writes in her wonderful article, students with disabilities are entitled to receive full time Canada Student Assistance Loans through the Government of Canada while actually only taking a part time course load. This is allowed because the students with disabilities have taught the Government that it is a full time job negotiating disability, medical and other supports and services, in addition to the work of being a student.

Even though students with mental illnesses have a legal right to access disability services, many universities and colleges don't have much experience working with our community, and they often don't provide help until they are specifically requested to do so. The Disability Service office on campus may be your best advocate, but sometimes students have to first educate Disability Services about the reality of living with a mental illness. The local CMHA, family group or other mental health organization could be a resource in this task. CMHA has a web-site on access to higher education at [www.cmha.ca/english/highered](http://www.cmha.ca/english/highered) with information on financial aid, examples of academic accommodations, links to local resources, and newsletters and

brochures that can be downloaded, copied and distributed at your local college and university.

Although there is not a lot of discussion of the topic, people with mental illnesses can and do succeed as students in college and universities. Information on financial aid, academic accommodations and other supports that help make students successful is often difficult to come by. Having an advocate on your side, such as a Disability Service provider, a mental health professional, friends and family, as well as developing self-advocacy skills, can make a huge difference in negotiating the maze of services. Student life can be a wonderful and empowering experience, and with support and perseverance, people with mental illnesses do succeed and contribute to academic life.

## RESOURCES

### Follow up from Issue No 4 Resources – Substance Use

Addington, J. & Addington D. (2001). Intervention Strategies for substance use in early psychosis. *Journal of Psychiatric Rehabilitation*, 25, 60 – 67.

Addington, J. (in press) (September 2002). An Integrated Treatment Approach to Substance Abuse in an Early Psychosis Program. In Graham H., Mueser K., Birchwood M., & Copello A. (eds), *Substance Misuse in Psychosis: Approaches to Treatment and Service Delivery*. Wiley: Chichester, Sussex.

### Locating Published Journals (con't)

Check first with your local library. Some journals are also available electronically.

- Journal of Psychosocial Nursing. [www.psychnurse.org](http://www.psychnurse.org) lists indexes of past issues. Journals may be ordered through SLACK Inc. at [www.slackinc.com](http://www.slackinc.com).
- Journal of Psychiatric Rehabilitation. Article reprints are available (\$15.00 ea). Contact: [allymig@bu.edu](mailto:allymig@bu.edu) or call 617-3538-1837.

## We would like to Hear From You!

We are very interested in your ideas, comments, stories and suggestions regarding what you would like to see here. So if you'd like to share with us please contact...

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This newsletter was compiled by Sharon Scott and Brenda Wentzell with the help from families across Canada.

This newsletter is intended as an additional source of information and support and does not replace the advice of your family's health care team. The views expressed in *Family to Family* are those of the writers.

Our resources are limited and we are looking for sites in each province to assist with distribution of this newsletter. If you are associated with an organization, agency or clinic that would find this newsletter useful for clients and could help by distributing a number of copies, please contact the Editor.

We also encourage everyone to photocopy and distribute this newsletter.

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## upcoming

**IEPA – International Early  
Psychosis Association  
3rd International Conference  
on Early Psychosis  
“A Bridge to the Future”**

September 25th –28th, 2002  
Copenhagen, Denmark  
For more information contact:  
[iepa@vicnet.net.au](mailto:iepa@vicnet.net.au)

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