Ottawa Community Coalition for Literacy

Feasibility Study on Literacy and Mental Health

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Summary

The objective of the feasibility study on literacy and mental health was to enable literacy and mental health agencies to develop strategies to help adults who have serious mental illness, as well as literacy needs, to integrate more successfully into the community as learners, citizens, parents, workers and volunteers. There were two parts to the study; a literature review and focus groups or interviews with clients with mental illness, mental health workers and literacy workers.

The Project Coordinator completed the study under the guidance and direction of the Literacy and Mental Health Working Group. We would like to express our appreciation for all their support. A list of the working group members is included at the end of the report. This project was made possible by a grant from **The Ontario Trillium Foundation** and OCCL would like to express our sincere gratitude to them.

Eighteen clients with mental illness took part. Some were already attending literacy programs; others were clients of an Assertive Community Treatment (ACT) team.

Thirty-six mental health workers from ACT teams, the Royal Ottawa Mental Health Centre and Canadian Mental Health Association participated. They came from various disciplines and positions including psychiatrists, occupational therapists, mental health counsellors, social workers, case managers, team managers, nurses, housing outreach workers, recreational therapists and dual diagnosis brokers.

Twelve adult literacy coordinators, instructors and volunteers participated.

Most participants took part in focus groups but some individual interviews were conducted and some participants completed questionnaires online. Participants were given a copy of their responses and asked to confirm the accuracy of the content and make changes or additions. The information was recorded in a database and then analyzed.

The responses from the three groups: clients, mental health workers and literacy staff were all very consistent and clearly defined issues and possible solutions. Current practices and suggestions which constitute best practices are included in the full report.

Mental health workers said that an average of 50% of their clients had literacy issues. Of these, over half could function in a literacy group; more in a one-on-one setting.

Once the information had been analyzed, it was presented to the Literacy and Mental Health Working Group. This group had two meetings with the Project Coordinator to discuss the findings and develop 11 recommendations. The group will continue to meet to work on the recommendations and determine the next steps. This work will be reflected in future Literacy Service Plans developed by the Ottawa Community Coalition for Literacy.

Literature Review

The Facts

Research shows that having a mental illness is a predictor of low literacy (Sentell & Shumway, 2003) and that the incidence rates of low levels of literacy in clients with mental illness are often not accurately assessed or understood, yet this impacts on health care (Grace & Christensen, 1999). It also impacts on all aspects of life including independent living skills and self-esteem of the person

In 2003, the *Journal of Nervous and Mental Disease* published an article; *Low Literacy and Mental Illness in a Nationally Representative Sample* by Tetine L. Sentell, MA and Martha A. Shumway PhD stating that low literacy is a recognized barrier to efficient and effective health care (Ad Hoc Committee on Health Literacy, 1999). They stated that in mental health care, low literacy may have additional detrimental effects, diminishing comprehension of written and verbal diagnostic and assessment measures (Grace and Christensen, 1998), and complicating cognitive impairments associated with mental illness (Miles and Davis, 1995). Furthermore, chronic mental illness may lead to deterioration in literacy by limiting opportunities for reading and writing (Tfouni and Seidinger, 1997).

Sentell and Shumway refer to the 1999 study in which Christensen and Grace found that reading comprehension was not even correlated with educational level. Sentell and Shumway found that their respondents with mental health problems engaged in fewer literacy-related tasks than other respondents. They were less likely to read newspapers, to have read books in the last six months or to write letters and significantly more likely to watch television. Again the research concludes that mental illness is associated with both low literacy skills and limited literacy practice. This has important implications for clinical care. Low literacy is likely to limit the accuracy and validity of standardized diagnostic and outcome measures and the impact of written informational and educational materials (Miles and Davis, 1995; Christensen and Grace 1999).

Gap between perceived and actual literacy skills of mental health clients

Low literacy may interfere with clinician and patient communication because topics discussed in mental health treatment are both subtle and complex – descriptions of emotions and feelings, opinions about medication side-effects and treatment options (Frieman and Zuvekas, 2000). Clinical procedures must be designed to accommodate literacy limitations because individual patients may be unaware of their literacy limitations or too embarrassed to mention them to providers (Ad Hoc Committee on Health Literacy, 1999; Miles and Davis, 1995). This study also underscored previous findings that education level is not synonymous with literacy level in mental health care.

The practice of ‘social promotion’ makes it impossible to use completion of grade 12 as an accurate assessment of literacy abilities

According to R. C. Christensen and G. D. Grace *Psychiatr Serv 49.7, January 1998* literacy is a critical, but largely overlooked, issue in the evaluation and treatment of individuals with mental health disorders. For example, a 44 year-old patient with schizophrenia reported that he had obtained a college degree many years ago. He confidently indicated that he read "very well." However, testing showed that he was reading at the fourth to sixth grade level. They suggest that clinicians should routinely evaluate their patients' literacy skills, using a screening device such as Rapid Estimate of Adult Literacy in Medicine (REALM). This tool allows reading level to be assessed quickly and patients can then receive written information appropriate to their reading level or they can receive information in other formats. Information about REALM can be found in Appendix 1.

Decoding or Reading with Understanding

In 1978 Gerald S. Coles, PhD, Laura Roth, M.S.W. and Irwin W. Pollack, M.D. published a paper on Literacy Skills of Long-Term Hospitalized Mental Patients in the *Journal of Hospital and Community Psychiatry*. Of the 48 patients they tested to determine their literacy level they concluded that both in-hospital and aftercare programs must recognize that literacy level is an important factor in the rehabilitation or recidivism of patients. They found that some patients had difficulty recognizing words and that others could read the words but were unable to extract meaning from them. This has an impact on health issues too. It should not be assumed that someone understands just because they can read.

Becoming an Adult literacy Learner

The *Friends with Pens* Literacy Outreach Project for agencies serving the homeless population, developed by the Literacy Group of Waterloo Region draws attention to the fact that homelessness and low literacy experienced together can lead to greater challenges than either experienced on its own. This would be compounded if the person also had mental health issues. Not only is learning a process, but so is becoming a learner. *Friends with Pens* recognizes the fact that adults who have dropped out of school, given up on learning or had their motivation and self confidence taken from them often find it difficult to recapture the drive to learn. It is neither a quick nor an easy process. Community capacity building helps in the process. The project organizers found that support team of agencies helped to minimize the barrier of low literacy in accessing services. Therefore, it seems reasonable to expect that a collaboration between mental health workers and adult literacy providers would help to minimize barriers to learning.

The question used by *Friends with Pens* was "*How do we help this specific individual, in this specific place, achieve this specific goal?*" If we use this question to inform our research we will find that certain issues need to be identified and addressed, namely:

- Does the client have literacy issues that he or she would like to address?
- Is the client ready?

In other words, does the client meet the eligibility criteria for entering an adult literacy program?

Additional Literacy Programs

Literacy/Numeracy Provision and its Effectiveness in Psychiatric Hospitals by A. M. Borikar and J. M. Bumstead, published in the *British Journal of Occupational Therapy*, November 1988, draws attention to the fact that it is often the occupational therapist who deals with the lack of literacy/numeracy skills of people who are psychiatrically ill. It states how psychiatric illness affects patients who are hospitalized and lists the additional problems to be overcome in addition to those of the general population. Motivation, concentration and mood are affected and make the learning process more difficult; in addition, there are drug side-effects to be considered. If clients have been in hospital for some time they may not have had much opportunity to use literacy skills and they may have been cushioned from the demands of daily life. It mentions the importance of establishing a good relationship with staff at the hospital library. Providing a stock of appropriate reading at lower levels was recommended.

The conclusion from this report was that there was no set standard for the provision of adult literacy/numeracy tuition within psychiatric hospitals. The report stated that, given the pressure to prepare patients suitably for discharge into the community, there is an obvious gap in the resources presently available. One recommendation was that occupational therapists should inculcate literacy/numeracy needs in their treatment/training programs.

Note: At Royal Ottawa Mental Health Centre the library contains medical information only. The book cart has donated books. There is no requirement to return these books.

Basic Skills for Learners with Mental Health Difficulties

Freedom to Learn is the report of the working group looking into the basic skills needs of adults with learning difficulties and disabilities in England. It sets out ways in which access to good basic skills teaching and learning could be improved for adults with learning difficulties and/or disabilities. Details of *Freedom to Learn* are provided in Appendix 2.

Just Ask!

This is a handbook for instructors of students being treated for mental disorders. It was conceived by students. Every student and instructor involved in the process of writing the handbook said that a successful educational experience depends on the willingness of both learners and instructors to talk openly with each other about their respective needs. While the characteristics of some mental disorders and the side-effect of many drugs used to treat them have a profound adverse effect on learning, these are not the only or greatest barriers to learning. An unwillingness to speak openly, for whatever reason, creates the greatest obstacle. **Just ask**, and if for some reason the person does not want to answer, then respect her / his decision to keep information private.

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Analysis of Information from Focus Groups and Interviews

Key Findings

The responses from the three groups: clients, mental health workers and literacy staff were all very consistent and clearly defined issues and possible solutions. Current practices and suggestions which constitute best practices are included in this report.

Mental health workers said that an average of 50% of their clients had literacy issues. Of these, over half could function in a literacy group; more in a one-on-one setting.

Literacy staff recognized the work done by the Literacy and Mental Health Working Group in developing a better working relationship with mental health agencies that refer clients to literacy programs. Clients/learners are better served because of this collaboration. Literacy staff also reported that, as a result of literacy awareness training by OCCL, fewer inappropriate referrals were being made by mental health workers.

Staff from literacy programs see the benefits of belonging to the OCCL network for information sharing and mutual support. They recognize the key role OCCL plays in getting support and funding for research, such as the literacy and mental health project.

Mental health workers were pleased to take part in this research. They hope that publicity is given to the findings so that more of their colleagues can realise that literacy is an issue and a barrier for many clients. There are many positive benefits resulting from improved literacy skills. Mental health workers need to deal with literacy in their work with clients. Mental health workers who are aware of the literacy issues faced by some of their clients also found working with literacy programs resulted in successful, positive partnerships that have benefited their clients.

Clients with literacy issues may suffer negative impacts on health when they don't understand their medication. They may have trouble reading food labels or getting to appointments in different parts of the city when they can't read maps and timetables. They often have poor decision-making skills and are liable to be taken in by marketing ploys.

Clients identified social progression in school as being a negative experience. Because of social progression, grade level does not accurately reflect literacy skills. Clients often go to great lengths to cover up their lack of literacy skills. They are used to keeping the issue well hidden. Often clients give the impression that they understand but then something comes up to show that they don't. Mental health workers have to check in a respectful way by asking questions about how their clients function on a day-to-day basis. Clients do not self-disclose until trust has been established. They feel it is too much to disclose literacy issues on top of mental illness. Our research also showed that medical professionals had not discussed this issue with their clients. The only exceptions were

people who were involved directly or indirectly with the Literacy and Mental Health Group of OCCL.

Mental health workers may think that clients are disorganized when, in fact, they have literacy issues. Staff sometimes interpret clients as being lazy and dependent when in fact they are asking staff to do things because they cannot read the information and so they do not know what to do for themselves.

Staff that have worked with OCCL are much more aware of literacy issues. However, not all staff have yet had this opportunity. Mental Health staff emphasized the importance of this training. Literacy staff also recognized that medical professionals, such as doctors, psychiatrists, social workers and counsellors, often don't pick up on literacy issues and highlighted the important role of OCCL in helping to disseminate information.

Clients reported that they had never been asked about their literacy skills. They confirmed that they would not talk about their literacy issues unless they had a lot of trust. They also said that it helps when teachers have world experience and a sense of the real-life situations that their students might be facing. Regular attendance was also an issue. Clients need more time to complete courses than is currently offered by college and adult high school programs. Clients identified that while staff may be supportive, social situations and other students can cause stress. Other students are not always supportive or knowledgeable about mental health issues.

Mental health workers identified areas where they could support clients with literacy issues including:

- identifying clients with literacy issues
- providing information about literacy programs
- preparing clients for the new environment
- reducing stress levels

They also stressed the importance of allowing clients the opportunity to observe sessions in a literacy program without pressure to make an immediate commitment. Literacy staff reported that it would be helpful to have clients complete a checklist showing what literacy skills the clients need to focus on that relate to their everyday lives.

Literacy staff recognized that they must be clear about their acceptance criteria and that they should only accept learners who are a good match for their programs. They recognized the importance of letting people know why they had not been accepted so that the potential learner could work with a support person on the skills and behaviours necessary for attending a literacy program. Literacy staff do not want students to have another negative learning experience.

All groups talked about the importance of having a meeting between teachers, clients/learners and mental health workers to have a frank discussion about issues that might arise while the learner is in the program.

Some programs are not connected to counselling services. If learners do not have a support worker, literacy coordinators and teachers find themselves supporting learners. A connection with a community program providing counselling would be beneficial.

Literacy staff agreed that it would be helpful to have written information about different mental health conditions and how they might affect learning. They suggested providing a manual for literacy instructors and volunteers, including guidelines on how to deal with depression. It would need to be clear and concise and be in French as well. Frequently asked questions could be included, together with a list of useful DVDs and information about how to borrow them. Contact information should be included together with hotline information for a support person who can give guidance to literacy staff.

A forum for literacy and mental health workers to discuss some of the issues and recommendations from this research project would be very well received by mental health workers and literacy staff. Literacy staff hope this project will be instrumental in opening the doors of communication between the two groups.

The findings highlight best practices in literacy programs that are often already in place. This report will confirm for many that they are already providing a program which supports the needs of mental health clients. It will encourage programs to review their current practices and consider all the challenges of working with mental health clients.

Several issues were brought up that were outside the scope of this research, one being the issues faced by English as a Second Language (ESL) clients and the other services for clients with developmental delays. In the second case, the research dealt with some of the issues but more work could be done to discover the different types of programs that are available and how literacy issues are currently being addressed.

Staff from both groups asked for the report and to be informed of future developments.

Best Practices

Recognizing that clients have literacy Issues

Literacy issues in clients usually come to light when clients start working on specific activities with mental health workers. These activities highlight issues such as completing forms, reading information, understanding and taking medications, following group schedules. Mental health workers often discover literacy issues when taking the initial history of their clients' school experience.

Clients have usually developed coping strategies such as saying things like... *you write it... I don't have my glasses... I can't focus, could you write it down… I'll take information home and figure it out.* Sometimes clients rush through forms answering in a random manner with no consistency. Others look at the paper for a long time, sometimes without eye-movement.

Often, when the subject of literacy is broached, clients say they want to get their grade 12.

Mental health workers noted that companies often take advantage of their clients, e.g. phone companies.

Mental health workers noted the importance of having a process for identifying literacy issues and talking about whether or not a client would be interested in attending a literacy program. Literacy assessment needs to be an integral part of their work with clients. Even asking a question as simple as, "Do you read and write as well as you would like?" could elicit some very useful information. Discuss the possibility of creating literacy screening as part of the mental health intake process, e.g. REALM.

Talking about literacy Issues

This may be the first time a client has talked to a mental health professional about literacy issues. It is important to be sensitive. Mental health workers reported that it would be helpful to have a list of possible questions together with a checklist that they could discuss with their clients. This would include literacy-related real-life activities that a person needs in order to function well in society.

Participants stressed the importance of mental health and literacy staff using language so that clients are not put off, for example with words like 'initial assessment.' Often clients perceive the word 'assessment' as being negative because it is used extensively in the mental health field.

Readiness – preparation by mental health workers

Mental health workers feel they can promote the idea of improving literacy and have information about literacy programs readily available. They can explain to clients how improving their literacy skills can be meaningful in their lives and show how it links to vocational goals. When clients make contact with a literacy program, they will need to explain their goals. Mental health workers can help to provide motivation for attending a program. Clients are often scared about going back to school and sometimes find it difficult to follow through because of negative experiences with learning in their past. Setting foot inside a school building again can be traumatic. Mental health workers can help them overcome this fear.

Mental health workers identified that clients often have a pre-conceived idea about what they want to do but it may not always be practical and they could be setting themselves up for failure. Mental health workers could suggest alternatives and get them to explore options. Peer support would be useful. Clients would hear about the ways other people had been successful; sometimes hearing from peers sends a stronger message.

Mental health workers felt they could help alleviate stress by providing support for approaching a literacy program. They could be available to go to initial assessments with clients who are often anxious, hesitant and fearful. Mental health workers explained that clients find it difficult to take the initiative for new ventures. They are not good at

organizing themselves. There is a lot for them to work through – getting up, lunches, buses. Many are dependent and are just learning to make their own decisions. Change does not come easily.

Clients have been encouraged by mental health professionals to talk about their mental health issues. Mental health workers suggested they could prepare their clients for the new environment (literacy program) by discussing what information the literacy program will need and what information the teacher will need. Mental health workers can help clients describe their coping strategies and any signals or flags to literacy program staff. Clients need to learn about themselves and get to know their own issues so that they can describe what a bad day is like and what a good day is like. (*It's a good day when.....*) Mental health workers recommended talking to clients about questions that it is all right to ask. They also said that clients need to know that a mental health worker is available to answer questions and to discuss any issues.

One of the goals of literacy programs is to prepare clients to move on by improving commitment to attendance, memory and concentration. Clients should be ready for this. Literacy staff suggested that mental health workers read *Working Together*.

Literacy staff expect learners to be accountable for their attendance and encourage them to make appointments outside the scheduled learning times. This is something that mental health workers could explain to their clients.

> **Comment:**
> Clients need to recognize that they need to make a commitment to learning. However, although literacy is probably one of the biggest things to affect a client, it probably will not get the most attention. Clients will always need to put housing and relationships first.

If a client has attended an intake interview at a literacy program and has not been accepted, it is important to find the reasons and work on the issues that were identified so that the client can try again when those issues have been resolved.

Types of literacy programs

The Occupational Therapy Service at the Royal Ottawa Mental Health Centre (ROMHC), in partnership with Urban Christian Outreach (UCO), offers an Adult Education Program at the ROMHC. Clients working with a ROMHC occupational therapist can attend the ROMHC/UCO Adult Education Program. The program offers ROMHC clients the opportunity to achieve specific learning objectives in literacy, basic education and high school upgrading, in a semi-tutorial setting. This on-site partnership means the instructor has instant access to an occupational therapist in the event of a student therapeutic issue or crisis. This program accommodates 15-20 students a year and can act as a bridge to programs in the community.

There is one drop-in program that is available at four different sites; Shepherd's of Good Hope, St. Andrew's Residence (residents only), Centre 454 Drop-In and Capital City

Mission. This program is run by the John Howard Society. The goal is to make literacy accessible for people who are homeless, transient, socially isolated and under-housed.

> **Comment:**
> From pastoral work on the street (separate from the hospital) it is likely that literacy issues affect about 70% of that population. It is very good that the drop-in programs are being offered in a few excellent locations.

Breaking the Technology Barrier is run by three education technology specialists at Causeway. Clients must have an IT-related education or employment goal – volunteer or paid. Achieving education-related goals usually involves getting a high school diploma or GED. In this case they would use computers for assignments, on-line courses or distance education. Clients come for one hour twice a week plus additional practice time.

Algonquin College, in partnership with ALSO, John Howard Society and People, Words & Change, has started a new program called ACElinks which offers the ACE Certificate (Academic and Career Entrance) Grade 12 Equivalency in downtown locations. It is free and qualifies successful participants for entrance to college and apprenticeship programs. It is recognized by employers. Participants study part-time, at their own pace.

Literacy and Basic Skills (LBS) programs in Ottawa serve adult learners who have a variety of goals, learning styles and life situations.

Programs provide the following services to learners:

- information and referral
- initial and ongoing assessment for learners intending to register in a program
- training plan development
- delivery of training
- exit and follow-up

Services are available in several locations, both full-time and part-time, during the day and in the evening and there are services in English and in French. LBS programs serve both adults with employment-related goals and adults who are seeking greater personal independence.

For further information on the range of services provided, consult the *Quick Guide* posted on the OCCL web site at www.occl.ca.

Some clients do not want to go to a program on-site at the Royal Ottawa Mental Health Centre. They feel they go there enough already. They would prefer to go to one out in the community.

The Director of Residential and Family Services, Royal Ottawa Place noted that she would like to have a literacy program in the building.

Referrals to literacy programs

Literacy staff reported that, as a result of literacy awareness training by OCCL, fewer inappropriate referrals were being made by mental health workers.

Mental health workers need to know more about the work of literacy programs. They need to find out whether the client would work best in a one-to-one situation or in a small group. One-on-one programs were often identified as being the best for mental health clients by workers and clients. However, it is important to note that some clients have made lifelong friends in literacy programs.

Literacy program staff said they are not able to handle students who are disruptive or who have severe anger management issues.

Literacy programs have to be careful about tying up valuable staff time on issues not directly related to literacy. It is important to recognise that programs cannot spend an undue amount of attention on 'counselling' of the learners, especially when there is no certainty that the learner is going to make progress in the literacy program. In situations like this the learner often forms an attachment, and it is difficult to move on. It is not usually possible to refer the learner to another LBS program, but staff don't want to be part of yet another 'failure' on the part of that learner. For this reason it is important to insist on a meeting with a support worker, where the *Working Together* groundwork is thoroughly discussed, roles and expectations are clearly laid out.

Intake

Participants suggested allowing clients to visit a literacy program that they think might meet their needs. Clients could observe a session without making a commitment. They need to know that the program is a safe place to be. This would be followed by an intake interview if everyone agreed it was a good match. No program is right for everybody and a trial period allows an opportunity to try out a placement. This could be followed up with a conversation between client, mental health worker and instructor to discuss issues and if necessary to find suitable ways of addressing them.

During the intake process literacy staff try to find out as much as possible about the potential learner. Literacy and mental health staff suggested that assessors ask if there are any health problems that might affect learning. Alternatively, assessors could mention learning disabilities, special education and ADHD or ask if the person has any special needs or medical conditions that staff in the program should know about. If the person discloses mental health issues the assessor could follow up with the following questions:

- *Do you take any medications that might affect your learning program?* (i.e. to determine the best time of day for the learner to concentrate.)
- *You mentioned you are being treated for depression (or other condition). How might that affect your being able to attend regularly, do homework, etc?*
- *Do you have a support worker? Is she aware that you want to join this program?*

Literacy staff recommended that, depending on the severity of the condition, a meeting with the potential learner and support worker should be arranged. They recommended sending the *Working Together* document to the support worker in advance of the meeting. If there is no support worker, they suggested asking the client if there are any potential situations to be aware of, e.g. bouts of depression, anger issues, etc. The more information the assessor has, the easier it is to make an informed decision. If it is obvious that there are mental health issues but the assessor feels the person would benefit from the program, they could suggest a trial period of one month.

When there are obvious mental health challenges, participants suggested trying to find out as much as possible about those challenges and how they impact on the potential learner. They said that very often this information arises naturally in the conversation. Many participants stressed how important it was that literacy staff get permission to speak to other professionals/support people in the learner's life if it would be helpful and appropriate. Participants suggested creating a potential attendance plan looking at identified barriers and possible solutions. Some of the barriers would include:

- fear
- high anxiety
- inability to focus
- difficulty accessing transportation
- physical symptoms resulting from medication
- depression
- problem getting up in the morning
- losing track of time/day of week

Participants suggested that the assessor in the literacy program should ask who the client would like the program to call if there is a problem and ask learners to sign a release of information form. If necessary, literacy staff should wait until trust has been established.

Literacy coordinators recognized the need to protect other learners and staff. They stressed the importance of being explicit in saying why they were not accepting a person. This can be difficult to do; being very open and honest is most helpful for the potential learner. Program staff could suggest that they return in a few months.

Communication between mental health workers, literacy staff and learners

Participants suggested that it would be useful to have a checklist of issues to be discussed at an early meeting of the coordinator, client/learner and mental health worker. This could include issues such as the policy if a client needs to take time off because of illness. In cases like this, it might mean that clients who thought it was all over once they had missed some sessions may stay in the program. All they or their support worker would have to do is contact the program to let them know the situation. The situation might not get out of hand and the learner might not feel so threatened.

Initial meeting with teacher, mental health worker and client/learner

All participants said it is important to make sure everyone is clear about responsibilities and how to deal with issues. Teachers need to talk about issues that might arise with clients and be up front about asking questions such as what to do if the client is having a bad day. *"What needs to happen if you are too unwell to be here?"* Clients can explain how the teacher can recognize problems. *"You can tell I am not doing well when ..."* or *"I can't always tell when things are going wrong. If you see ... happening you need to ..."* They suggested asking about potential triggers such as stress, noise or being around men. They recommended being open with questions about medication, for example what it is for and its impact on learning. They stressed the importance of being explicit, including letting the client/learner know what will happen if they stop coming to a program. They suggested explaining procedures and asking if it would be all right to call a contact person if the program couldn't get in touch with the client directly. Participants recommended giving clients an opportunity to explain what they would like staff to do and under what circumstances there should be contact between mental health staff and teachers. It was also suggested that staff ask clients to let them know the questions that it is all right to ask.

Participants recommended having ongoing communication between teacher and worker, if the client is open.

Attendance

Literacy staff suggested agreeing on an attendance schedule that will not overwhelm the client/learner. It is important to start slowly. Mental health workers said that clients may agree to commit but they may not be able to follow through. They should be given the chance to change their minds. Mental health workers suggested checking in to see how clients are doing and finding out if the schedule is working – be open to re-negotiation.

Participants suggested encouraging learners to practise or complete homework assignments within reasonable limits, as long as it is not reinforcing obsessive behaviour.

Comment:
Mental health clients work best in the middle of the day. They cannot attend classes early in the morning as their medication often makes it difficult to start a class until mid-morning. Also, evening classes do not work well as some clients take medication around 7 p.m. and are then too tired to focus on learning.

It was recommended that instructors talk to learners if attendance becomes an issue, for example if the client is often late because he or she misses the bus. Often talking through the issue and providing explicit information about alternatives can help the client to find a solution. If attendance continues to be an issue and the learner is working with a support person, the instructor should follow the protocol that was agreed upon when the learner entered the program.

Medications

Clients don't always understand about the medications they are taking.

The mental health workers suggest asking questions about medication, and have even suggested ways to ask questions that are not offensive. Honesty and clarity from the start is the way to go.

Mental health workers wanted teachers to be aware that there might be a response delay. Clients might not show many emotions externally.

The clients said:

- *My medication makes me sleepy so it is hard for me to wake up. Once I am awake I don't have a problem with learning.*
- *Medication affects learning. It slows you down. It shuts your brain off. It makes you tired. It feels like a hangover. You can't study for long periods. You need to take lots of breaks. It takes longer to learn.*
- *I am useless after 7 p.m. after I have taken my medication.*

Dealing with Issues

The clients said:

- *Sometimes we don't notice that things are going badly for us. We may not see the signs that are obvious to others. It is helpful if the teacher says something and we talk about the issue.*
- *We need to do breathing or yoga. We may need to go to a safe place until we are calmer. Sometimes a cup of tea helps.*
- *If I am having a panic attack it helps to journalize. I can tear it up or show it to the teacher so the teacher understands how I was feeling.*

Memory

Most clients identified having problems remembering what they read. Mental health and literacy staff reported that it is common for clients to say, "*On a bad day I can't remember what I have just read.*"

Concentration

Participants said that some students may be happier with the door open and they suggested having a few work stations that face away from the class, but not too many.

Medication might produce blurry vision and concentration might be affected. Participants recommended providing a range of activities and change activities frequently. The medication often means that they are tired all the time and that they have trouble focusing. Clients asked literacy staff to provide plenty of breaks. Often they get flustered when they have to work quickly.

Clients said:

- *I need to work at my own pace.*
- *I need plenty of time.*
- *Side conversations are frustrating. I think people are talking about me.*
- *We can't learn if we are nervous. We need to feel comfortable.*

Social Situations

Clients identified social situations in colleges and high schools as being challenging. Mental health workers said that clients may not know how to socialize or they just may not be interested in it. They reported that sometimes clients feel isolated in social situations because they hear about social interactions that they wish were happening in their lives. They also have less money than a lot of other students. Clients did not report problems with social situations in adult literacy programs. They may be happier if they know socializing is not a requirement and that there is somewhere they can go during breaks to avoid socializing.

Learners often get themselves into difficult situations because they do not have good decision-making skills. They need help to improve their skills in this area.

Teaching

These are recommendations from literacy staff, mental health workers and clients for providing a good learning environment for people with mental health issues. They are often already in place.

- Clients/learners need a clear framework – give explicit explanations and directions. Provide structure and set clear boundaries. Be open about issues.
- Don't do all introductions immediately (too overwhelming).
- Take time to listen. Help learners separate their home life from school. However, it might be necessary to let them know when they are disclosing too much information and that they should talk to their mental health worker.
- Build confidence, establish rapport and don't be judgmental.
- Be flexible and responsive to the needs of the learner. If the learner is having a bad day, encourage the learner to practise rather than learn new work. Ask if it is a *people* (interaction) or a *paper* (working alone) day.
- Some students need to read under their breath to help them absorb information. If they don't do this, they race through the work and think they have read it but don't remember what they have read. Teachers may want to give the student one page at a time and cover up the next part of the activity so that they are not distracted. Teachers may also want to cover up multiple choice questions until the student has understood the content.
- Be patient. Encourage students to try. They often find they can do more than they think. Push gently.
- Provide regular feedback. Focus on strengths. Celebrate success and give certificates.
- Provide stimulating activities.

- Work on practical literacy issues such as cheques, banking, menus, mail, street signs, bus routes, maps, classified ads in newspaper, basic recipes, information about medical conditions and medications.

Dealing with Issues – literacy program staff

Participants suggested that, if an issue comes up, staff should listen empathetically and provide an engaged response. A lot of mental health clients have trouble verbalizing and it is important to listen when they find a way to express their thoughts. Literacy staff may need to refer learners to their worker if it is an issue outside the scope of the program. They could say something like, "*You know what, we are focusing on ... You should go and talk to your worker about that.*"

It was recognized that it is important to link mental health clients to a support person if they do not already have one and if necessary, someone from the program may need to accompany the learner to a counselling session. The level of trust has to be very high. Literacy staff need information about where to go for support.

Clients will often disclose when they change or forget medication; participants recommended saying something like, "*How does that affect your learning?*"

Often other learners may not be accepting of learners with mental health issues. Literacy staff suggested doing some awareness training with students. For some, recognizing the issues and accepting them can take a leap of understanding, especially in cultures where there is a stigma to mental health issues. Developing a module that presents this information in an interactive format would be something that could benefit learners. It could be accompanied by a DVD/video if one is available.

Support for literacy staff

It was suggested that it would be helpful if support workers prepared their clients by discussing how much information to disclose and by encouraging clients to describe their coping strategies and any signals or flags to literacy program staff.

All the mental health workers who took part recognized the importance of meeting with teachers and said they would be able to find time to do this. They believe it would be beneficial to go over important issues and make sure that everyone is clear about responsibilities and how to deal with issues such as what to do if the client is having a bad day. It is important to be explicit.

Mental health workers said they could provide education so that teachers understand how to deal with clients who have serious mental illness. They could help translate the mental health component and let teachers know more about different illnesses and how that might affect learning.

Literacy staff wanted written information available in their programs that would help them work with people with mental health issues.

Literacy staff said that although they could deal with most issues it would be beneficial to have a support person that they or their students could contact.

Literacy staff also thought it would be beneficial to provide informal sessions where a mental health support person can discuss issues with coordinators, instructors and volunteers so that they can talk about issues that have come up.

Support for mental health workers

Mental health workers wanted to know what questions literacy staff might be asking so they could help clients to prepare for meetings with literacy staff.

Mental health workers don't know as much as they would like about learning disabilities. It is hard to know how the clients process and respond to information. It is hard to separate learning disabilities and other issues. They are all overlaid.

Recommendations from the Feasibility Study on Literacy and Mental Health

Recommendation 1

Apply for funding to create a training package for mental health workers. The package would be used to train key personnel and team leaders in mental health organizations. This train-the-trainer session would be delivered in a half-day workshop. Mental health staff would take the information back to their agencies and deliver a short presentation to their colleagues.

The package would consist of a PowerPoint Outreach Presentation with speaker notes and supporting information on OCCL's website. The training package would include information on issues identified during the research phase of this project, for example:

- background information about adult literacy issues and how to recognize them
- suggestions on when and how to broach the issue of literacy with a client
- a checklist of reading and writing activities that clients are likely to need, such as banking and getting around the city
- issues that are stumbling blocks for admission to a literacy program and suggestions that would help clients work on these skills and behaviours

Recommendation 2

A focus group of clients and members of the Literacy and Mental Health Group will develop a checklist for reading and writing activities that the clients are likely to need, such as banking, getting around the city and shopping. It could be called: *What I Need to Know*. Clients can check off activities with their mental health worker and then take it to an intake interview in a literacy program. This would help literacy staff to focus on the specific skills that the clients need. Once this checklist has been created, it will be included in the Outreach Presentation identified in Recommendation 1.

Develop a checklist of issues and possible questions relating to responsibilities, mental health issues and behaviour in a literacy program.

Recommendation 3

Mental health workers link with the Canadian Mental Health Association (CMHA) to explore the possibility of setting up a peer support network of speakers and mentors for their clients, literacy tutors and literacy staff.

Recommendation 4

Arrange a forum to discuss issues related to literacy and mental health with representatives from the following disciplines and agencies: mental health, literacy, employment preparation and Ontario Works. One of the topics identified for discussion was boundaries and appropriate questions about a person's mental health when it relates to delivery of services.

Recommendation 5

Make copies of *Working Together* widely available to mental health teams. Ask for it to be discussed at staff meetings. Post it on the OCCL website. Give a copy to each support worker who refers a client to a literacy program.

Recommendation 6

The Literacy and Mental Health Working Group will explore the possibility of establishing a literacy program in the broader mental health community.

Recommendation 7

If mental health agencies are not clear on criteria for entry to a literacy program, offer them the opportunity to meet with the Executive Director of OCCL to discuss the *Working Together* document.

Recommendation 8

Discuss the following issues at a meeting of the Literacy Planning and Coordination Committee (LPCC):

- possibility of visits/observations of literacy programs, without obligation, by mental health clients before the intake process begins
- a review of forms and means of exchanging confidential information between mental health workers and literacy staff
- importance of including teachers in meetings with the literacy assessor, support worker and client to discuss roles, responsibilities and issues early in the placement – possibly after the trial period

Recommendation 9

Ongoing professional development to allow literacy staff to get information that helps them to understand the mental health issues of their learners.

Recommendation 10

The Working Group creates a checklist of people literacy staff can contact for information in crisis intervention situations. It would include, family doctor, CMHA, Mental Health Crisis Line (fully bilingual service) and contact information. The Working Group identifies agencies that can provide advice to literacy staff on mental health issues.

Recommendation 11

Develop a module to introduce mental health issues to adult literacy learners. This will be considered by the LPCC and the Working Group as a potential project in the future.

Appendix 1: REALM

A patient's literacy level can easily be measured in about two minutes with an instrument called the Rapid Estimate of Adult Literacy in Medicine (REALM). The REALM is a word recognition test, in which subjects read from a list of 66 medical words arranged in order of complexity by the number of syllables and pronunciation difficulty. Patients are asked to read aloud as many words as they can, beginning with the first word and continuing through the list as far as possible until they reach words they cannot pronounce correctly.

The REALM yields a score that estimates a patient's reading level (i.e., grades 0–3, grades 4–6, grades 7–8, grade 9 and above). Patients who score in grades 0–3 and 4–6 have literacy skills that correspond approximately to International Adult Literacy Survey levels 1 and 2, respectively. Because the REALM uses medical words, the test provides not just an assessment of general reading skills, but also an indication of the individual's health literacy. The main limitations of the REALM are that it is available only in English and that it tests word recognition, not reading comprehension.

Davis TC, Long S, Jackson R, Mayeaux EJ, George RB, Murphy PW, et al. Rapid estimate of adult literacy in medicine: a shortened screening instrument. Fam Med. 1993; 25:391-395.

RAPID ESTIMATE OF ADULT LITERACY IN MEDICINE

((REALM) Examiner's Instruction Sheet

Terry Davis, PhD, Michael Crouch, MN, Sandy Long, PhD

The Rapid Estimate of Adult Literacy in Medicine (REALM) is a screening instrument to assess an adult patient's ability to read common medical words and lay terms for body parts and illnesses. It is designed to assess medical professionals in estimating a patient's literacy level so that the appropriate level of patient education materials or oral instructions may be used. The test takes two to three minutes to administer and score. The REALM has been correlated with other standardized tests (Family Medicine, 1993: 25:391-5).

Directions to the Examiner:

1. Examiner should say to the patient: "*This survey is to help us figure out the best type of patient education materials to give you. The survey only takes 2 to 3 minutes to do*"
2. Give the patient a laminated copy of the "REALM" Patient Word List.
3. Examiner should hold an unlaminated "REALM" Score Sheet on a clipboard at an angle so that the patient is not distracted by your scoring procedure.
4. Examiner should say:
   "*I want to hear you read as many words as you can from this list. Begin with the first word on List 1 and read aloud. When you come to a word you cannot read, do the best you can or say "blank" and go on to the next word.*"
5. If the patient takes more than five seconds on a word say "*blank*" and point to the next word, if necessary, to move the patient along. If the patient begins to miss every word; have him/her pronounce only known words.
6. Count as an error any word not attempted or mispronounced. Score by:
   - (/) after each mispronounced word.
   - (-) after each word not attempted.
   - (+) after each word pronounced correctly.
7. Count the number of correct words for each list and record the numbers in the "SCORE box. Total the numbers and match the total score with its grade equivalent in the table below.
8. Record the "Realm" generated reading level on the Examiner's Score Sheet and in the Education/Learning History section of the Social and Patient Education History assessment form in the Medical Record.

GRADE EQUIVALENT

Raw Score	Grade Range	
0 – 18	3rd Grade and Below	Will not be able to read most low literacy materials. Will need repeated oral instructions, materials composed primarily of illustrations, or audio/videotapes.
19 – 44	4th to 6th Grade	Will need low literacy materials. May not be able to read prescription labels.
45 – 60	7th to 8th Grade	Will struggle with most patient education materials. Will not be offended by low literacy materials.
61 – 66	High School	Will be able to read most patient education materials.

Red Lake Hospital
Red Lake, MN 56671
4/98/JMcD

RAPID ESTIMATE OF ADULT LITERACY IN MEDICINE

(REALM) Examiner's Instruction Sheet

Terry Davis, PhD, Michael Crouch, MN, Sandy Long, PhD

Chart #			Examine date:
Name:			Birth date:
REALM			Grade completed:

List 1		List 2		List 3	
Fat		Fatigue		Allergic	
Flu		Pelvic		Menstrual	
Pill		Jaundice		Testicle	
Dose		Infection		Colitis	
Eye		Exercise		Emergency	
Stress		Behaviour		Medication	
Smear		Prescription		Occupation	
Nerves		Notify		Sexually	
Germs		Gallbladder		Alcoholism	
Meals		Calories		Irritation	
Disease		Depression		Constipation	
Cancer		Miscarriage		Gonorrhoea	
Caffeine		Pregnancy		Inflammatory	
Attack		Arthritis		Diabetes	
Kidney		Nutrition		Hepatitis	
Hormones		Menopause		Antibiotics	
Herpes		Appendix		Diagnosis	
Seizure		Abnormal		Potassium	
Bowel		Syphilis		Anaemia	
Asthma		Haemorrhoids		Obesity	
Rectal		Nausea		Osteoporosis	
Incest		Directed		Impetigo	
# of (+) responses in list 1:		# of (+) responses in list 2:		# of (+) responses in list 3:	

Legend: (+) correct, (-) word not attempted, (/) mispronounced word	**Raw Score:**

Appendix 2: Freedom to Learn

Freedom to Learn is the report of the working group looking into the basic skills needs of adults with learning difficulties and disabilities in England. Section 2 deals specifically with basic skills for learners with mental health difficulties.

Section 2: Access to Basic Skills for People with Mental Health Difficulties

48. About one in five people will have mental health difficulties at some stage in their lives. People at all levels of educational ability are affected. Those with mental health difficulties may need flexible forms of provision which reflect the episodic nature if mental ill health. Learners may need to take breaks from learning during periods of ill health, which will affect the continuity of learning and the degree to which material is retained. Medication may interfere with learning and memory function. Some people may have a history of institutionalisation which makes it a struggle for them to deal with everyday tasks; for example, using money, where others have previously looked after their finances. Confidence and communication skills are often adversely affected. Some people with learning difficulties and/or disabilities may have additional mental health difficulties.

49. The main additional barrier for people with mental health difficulties is the widespread ignorance and prejudice about mental health. This can present an attitudinal barrier to people improving their basic skills. Training for all tutors should include an awareness-raising element on mental health difficulties. The side effects of medication may interfere with cognitive processes and create a further barrier to learning.

50. The views of learners, trainers and teachers were as follows. Learners would like opportunities to regain lost skills and thereby to increase their confidence and self esteem. They wish to be regarded as students to escape the label of 'patient' or 'client' and to be encouraged to learn in a welcoming environment. Tutors would like more training in mental health awareness and felt that service users should be involved in its delivery. They believe that it is necessary to acknowledge learners small steps of progress and to recognise the importance of social skills, confidence and relationships when measuring achievement. More guidance, outreach and effective learner support were also needed.

51. What should the ideal basic skills arrangements look like? Ideally, basic skills provision would be developed to include an inter-agency framework in which health, social services and voluntary organisations work with adult and further education providers to plan and review provision. There should be well-established outreach provision in day centres and hospitals, which would link into adult and further education. This should enhance the availability of support and would enable, for example, courses in communication and self-expression to be linked to basic skills as a means of helping individuals to progress and gain self-confidence. Provision must be flexible so that learners can take breaks from learning when unwell, then have fresh opportunities to start again. Recognition of learning should include accreditation of achievement as part of an appropriate progression route. Mental health awareness training should be an integral part of training for all basic skills tutors.

Examples of Programs

Dearne Valley College has a very successful creative writing course for people with mental health difficulties. Lancashire's *Stepping Stones* programme involving the Local Education Authority and 10 colleges offers a model for agencies working collaboratively. New College in Nottingham has close links with its local health authority and has a well-established programme which includes outreach provision, discrete classes and inclusive provision. Sandwell College and West Nottinghamshire College make extensive provision for people with mental health difficulties, developing a curriculum around their expressed wishes, which includes basic skills.

Some providers offer a range of provision, which includes classes in hospitals, day centres and other community centres. In other cases, the provision offered is not flexible enough to meet the needs of learners with mental health difficulties.

Recommendations specific to this group:

- The impact of mental health difficulties should be openly acknowledged.
- Learning opportunities for people with mental health difficulties, including basic skills provision, is under-developed nationally. There should, therefore, be funded pilot projects relating to mental health and basic skills.
- More flexible provision, allowing for periods of illness without penalty to learner or provider, should be developed.
- A multi-agency framework should be established in which partners from different agencies can plan, deliver and evaluate learning programmes. Partnership agreements which facilitate mutual support and exchange of information should be encouraged.
- A training programme should be developed to raise awareness of the needs of learners with mental health difficulties who have basic skills needs. This should be readily available as part of all initiatives to improve teaching standards and raise awareness. It should emphasise the importance to learning of increasing learners self esteem and confidence.
- Support must be available at any transition stage.
- Materials for use in learning basic skills should take account of the particular needs of those with a mental health difficulty.

Ottawa Community Coalition for Literacy

Literacy and Mental Health Working Group

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