SUPPORTED EDUCATION FOR PERSONS WITH PSYCHIATRIC DISABILITIES

A. What is supported education?¹

BACKGROUND

Supported education may be defined as the provision of support and services to help persons with psychiatric disabilities gain access to and succeed in a postsecondary college or technical school. Since recovery-oriented services are those that support individuals in reclaiming their lives in the community and overcoming the effects of being perceived as mental patients (Tondora & Davidson, 2006), supported education can be one of the most important tools for recovery. It allows individuals to trade the identity of mental patient for that of student and may lead to job and career advancement.

This presentation of supported education is intended to a) situate supported education models in relationship to other mental health programs and to related interventions by educational institutions; b) outline what is known about the extent of implementation of supported education programs, and c) summarize the evidence base for supported education.

THE ROLE OF MENTAL HEALTH

Supported education services can be provided in many ways by many kinds of mental health agency or educational program, making the term a broad descriptive rubric rather than a specific *practice* like ACT or the Individual Placement and Support model of supported employment.

Principles. The common thread to supported education is an adherence to principles grounded in those of psychiatric rehabilitation. Below is a description of key principles drawn from Carol Mowbray (2002) and Ann Soydan (2004), leading practitioners in the field.

Normalization: All program participants are called "students," not patients or clients. Services are consistent with the normal routines of life within the educational community. The most non-stigmatizing and integrated settings and methods should be used, including campus settings for at least some of the services.

Self-determination: The involvement and empowerment of the student is essential. Students participate in all aspects of the program, including serving on a program board, as peer mentors, paid staff, tutors or research assistants. Students retain as much control as possible over their own lives, including setting goals and evaluating progress toward them. The program provides knowledge essential to success in the educational environment. Choices are offered regarding many aspects of services

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¹ There are many resources for finding out about supported education. The most readable introduction (though it may be hard to find except in major libraries) which includes pieces by students, staff, and researchers is the special edition of the CAMI publication: *The Journal of the California Alliance for the Mentally Ill*, 1997, Volume8, Issue 2. For California readers a bonus is a good sampling of the history of early supported education programs in the state and their relationship to the community college system. Easier to find and more systematic may be: Unger, K. V. (1998). *Handbook on Supported Education: Providing Services for Students with Psychiatric Disabilities*: Baltimore: PH Brookes Pub. Co., which is basically a textbook directed primarily at education staff (there is a chapter on what mental disorders are); one chapter addresses students with psychiatric disabilities; another chapter covers the legal framework; another the history of supported education. The focus is on the information needed to provide services on campus.

Support, skills, and relationships: Learning skills for success is a critical part of the program, both explicit (such as how to take notes) and implicit (such as managing symptoms). Supports should be available long-term, whenever students want or need them. One-on-one counseling must be available. Resources need to be available to overcome barriers (such as transportation, child care, and need for financial aid). An important element is assisting students to develop their own informal support networks.

Hope and recovery: Every student is treated with respect and dignity and as a developing person capable of growth, positive change, and recovery from mental illness. An underlying assumption is that academic participation promotes a transformation from "mental patient" to "college student." Persons are not excluded based on diagnosis or mental health history.

Systems change: Problems which need to be addressed in achieving individual goals and objectives do not reside solely within the individual. Programs must support needed accommodations for students with psychiatric disabilities, address stigma and discrimination, and confront other barriers. Programs promote both individual empowerment and group empowerment for all those with disabilities (M. Becker, Martin, Wajeeh, Ward, & Shern, 2002; Bellamy & Mowbray, 1998).

Settings and program models. Supported education has been offered in a variety of settings (Mowbray, 2004) including campuses, club-houses, consumer self-help groups or agencies, mental health agencies, and through mobile programs serving participants on multiple campuses. Perhaps most common is a program in a mental health agency linked to a campus program. There is indication the settings may be becoming more diverse (Mowbray, Megivern, & Holter, 2003).

Despite the diversity of setting, program content is likely to be similar. For example, Unger and Pardee's (2002) cross-site study included a clubhouse, a mental health agency, and a community college in different parts of the country. They used a uniform scale to assess program design and found it very similar in all three types of program.

Elements commonly included in supported education programming are: recruitment, orientation, and assessment; special classes (some leading to certificates or vocational competency); support groups; education and training of college instructors, staff and administrators; individual support including counseling; obtaining legally mandated "accommodations" for disability; developing a consortium of agencies to collaborate in providing supported education; and mounting group efforts to combat stigma. While case managers or employment specialists in existing mental health programs may provide some of these elements for their clients, it is clear from first person accounts in the literature that an actual program on campus is experienced as quite different and particularly valuable. One randomized study showed program-based efforts to be more effective than individual interventions (2000).

A distinct type of intervention provides on-campus training for a specific vocational track, such as being a peer counselor. These programs may be the only component of a supported education project or may be linked to other services and on-going schooling options. Examples are a computer education program at Boston University (Unger & Pardee, 2002) and peer counselor programs at the College of San Mateo (Stringari, 2003), in Houston (Jacobs & Glater, 1993), and in Kansas (McDiarmid, Rapp, & Ratzlaff, 2005).

Criteria for selecting participants in supported education generally include the existence of a psychiatric disability that makes support important in pursuing education, some existing academic skills (although some supported education programs help participants achieve the skills or degree necessary for post-secondary enrollment (Cook & Solomon, 1993; Frankie et al., 1996), and access to treatment services (usually off-campus) and willingness to accept treatment.

Supported education programs have often recruited from limited populations (typically clients at a particular agency or campus), but recruitment can be more inclusive (such as the Michigan Supported Education program that recruited from all mental health programs in a large urban area (Mowbray, 2000)); disabled student offices on campus are likely to find half their psychiatric disability clients through self-referral (Collins & Mowbray, 2005).

Two other types of recovery-oriented mental health practice overlap with supported education: supported employment, which may include education as a focus (Egnew, 1993; Nuechterlein, 2008); and programs for transitional age youth, which typically include support for education (Bullis, Moran, Benz, Todis, & Johnson, 2002). The overlap may be large when career development rather than entry-level employment is a goal (Murphy, Mullen, & Spagnolo, 2005). As noted later, the average age of persons in supported education is 35 or more in contrast to the younger transition age youth. And neither supported employment/education programs nor transitional age youth programs are likely to create campus-based *programs* as opposed to providing individual support.

THE ROLE OF EDUCATIONAL INSTITUTIONS

Postsecondary institutions are charged with protecting the rights of disabled students. The Office of Civil Rights of the Department of Education enforces Section 504 of the Rehabilitation Act of 1973 (Section 504) and Title II of the Americans with Disabilities Act of 1990 (Title II), which prohibit discrimination on the basis of disability (Unger, 1998). Most basically these laws govern admission, re-admission, and accommodations. Typically, positive accommodations are provided to ensure equal access. For psychiatric disabilities these may include: changes in instructional strategies such as more individual tutoring and varied emphasis on auditory versus visual information processing; increased time for assignments; use of technology such as recording devices or computer enhanced note taking; alternate testing methods; and personal support staff assigned to individual students or peer support groups on or off campus.

In order to request this type of accommodation students must document their disability. The condition must substantially limit a major life activity—a psychiatric diagnosis is not sufficient. Students, and rehabilitation staff helping them, are responsible for informing school officials of their disability, providing documentation of the disability, and proposing viable options for meeting their accommodation needs. It is the role of the student and supported employment program, rather than the school, to ensure that students experience success once they are enrolled. A recent survey shows that slightly less than half of students with a psychiatric disability request accommodations or work with a disabilities office (Salzer, Wick & Rogers, 2008).

Despite considerable professional interest, educational disabilities specialists do not have much systematic knowledge about the number of persons with psychiatric disabilities or how they are served (Benton, Robertson, Tseng, Newton, & Benton, 2003; Sharpe, Bruininks, Blacklock, Benson, & Johnson, 2004). Much of what <u>is</u> known is due to a 2005 survey by the mental health researchers Collins and Mowbray (2005). Questionnaires were sent to 597 college disability offices in ten states. There was a 47% return rate. The mean percentage of all disabled students having a psychiatric disability was reported to be 18%. Roughly two-thirds of the colleges had staff with special training and/or special assignments relating to psychiatric disabilities. Approximately 40% reported that there was supported education programming available in their area, but only 37% of these reported having moderate or extensive involvement with these programs. The supported employment programs reported were primarily off-campus (72%) and most were run by a mental health organization (68%).

Based on the survey results regarding availability of specialized staff, one can say it is likely that at least half of postsecondary institutions have "supported education" provided through or in collaboration with

disability service offices. In addition, colleges provide psychological counseling, academic counseling, financial aid, tutoring, cooperative education (credit for work), fitness training, time management and study skills workshops, and other resources useful to students with psychiatric disabilities (Stringari, 2003).

However, it appears that many or most of the individuals having a psychiatric disability who are served by college disability support staff would not qualify for public community mental health services (Rickerson, Souma, & Burgstahler, 2004). Persons with psychiatric disorders of less severity or duration (anxiety disorders and depression) are likely to be the focus of campus programs, including receiving treatment from campus counseling centers. An unknown number of students with serious mental illness do not register as being disabled and thus do not receive campus supports. Many of these are living away from their home community and have psychiatric medications prescribed at home but refilled at the college health center, so they are also not connected with community agencies.

In general, supported education service models and empirical studies to date stem largely from the efforts of mental health and psychiatric rehabilitation professionals. These programs, however, often include orientation or training of college staff and collaboration with various campus departments.

PERSONS WITH PSYCHIATRIC DISABILITIES IN SCHOOL AND OUT

Students with psychiatric disabilities. In this section we use information from the California Postsecondary Education Commission website ("Custom Data Reports," 2007) to profile prevalence and change over the past few years in one large state. In California, the category "psychological disability" was counted in a uniform way between 1998 and 2004. The total enrollment between 1999 and 2004 increased by 5% while the number with psychological disability increased from 7,757 to 9,072, or by 14%. In 2004, those with a psychological disability constituted 12% of the disabled students but only four tenths of one percent of all post-secondary public school students.

Students with psychological disabilities in 2004 differed little from all postsecondary students regarding gender, percentage in non-credit programs, and year of school. A higher percentage of students with a psychological disability are part-time (61%) compared to all students (48%). Persons having psychological disabilities were more likely than all students combined to be Black or White and less likely to be Latino or Asian/Pacific Islander.

The only "outcome" that can be tracked with these data is completion of a degree or certificate. As a percentage of all degrees given, persons with a psychological disability were more likely to have received pre-BA certificates and less likely to have received BA or Master's degrees than were graduates overall. Data do not exist on the percentage of enrollees who achieved a degree or certificate.

Persons with psychiatric disabilities in treatment who could be eligible for supported education. Epidemiological data from the early 1990s (Kessler, Foster, Saunders, & Stang, 1995) indicate that persons with psychiatric disorders comprise 4.7% of all college drop-outs and that a total of 4.3 million persons in the US had pre-existing psychiatric disorders (predominantly anxiety disorders) *and* did not complete college.

We used data from the California Department of Mental Health Clients and Service Information data system to estimate the number and percentage of public mental health clients who might be eligible for supported education programs (Van Hoy, 2007). Although years of education is missing in a substantial number of cases, we have no reason to believe that the data are missing in ways that would bias this analysis. In order to reach numeric estimates we imputed findings from the reported data to missing cases. In 2004 there were 650,990 persons with severe and persistent mental disorder in the public system. Of

these, 66% had less than a high school education and would need remedial education (sometimes provided as part of supported education). Another 21%, or 140,000 persons, are estimated to have a high school degree and would be eligible for post-secondary education. Finally, the most likely group to utilize supported education are those with some college: 13%, or 83,000 are estimated to meet this standard.

The disparity between the number in California postsecondary education having a psychological disability (9,000) and the number of mental health clients with a high school degree or above (223,000) is very large, but is difficult to interpret. One recent study (Stein, 2005) of 80 persons with serious mental illness who were *not* currently involved in supported education found that two thirds had thought about enrolling in a college or vocational course in the past year and 48% had actually enrolled in some kind of post-secondary education in the past five years. So postsecondary attendance may be higher than is often thought.

Number of supported education programs. There is apparently no systematic administrative data about the number of supported education programs in the United States. Mowbray, Mcgivern and Holter (2003) conducted a national survey of supported education programs and identified 104 around the country. Fountain House had received a federal grant to disseminate supported education to clubhouses, and the study found 70 that provided supported education (out of 166). Only eight college-operated programs were identified through their websites. A total of 26 other programs were identified through literature citations or other referrals. Yet, the Collins and Mowbray (2005) ten state survey of college disability offices found that about 40% of campuses answering the survey reported the availability of some form of specific supported education program for persons with psychiatric disabilities. Applying this percentage to the roughly 4,275 postsecondary schools in the United States (Education, 2008), we get 1,710—so the 104 programs identified by Mowbray may well be a substantial undercount.

B. Evidence of effectiveness

WHAT YOU CAN EXPECT: OUTCOMES IN THREE KEY STUDIES.

The earliest empirical report of supported education outcomes dates back to a 1984 article entitled, in the language of the times, "Education for the young adult chronic client" (Beardsley, Kessler, & Levin, 1984). The literature in the succeeding 15 years documents outcomes from many programs but few are methodologically sophisticated (Mowbray & Collins, 2002). In this section, we detail results from the three strongest studies and briefly summarize the evidence for another 16 empirical reports. Our goal is to reach an overall assessment of the level of evidence for supported education.

The Community Scholars Program study took place in Chicago at the well-known psychiatric rehabilitation agency Thresholds (Cook & Solomon, 1993; Razzano, Pickett, & Cook, 1997). Outcomes are reported for 102 clients as they prepare for and enter post-secondary academic and vocational/trade school settings during a three year study period. Eighty-four percent of the participants entered Thresholds with a high school diploma or GED, and 50% of these graduates had attended college, with 11% having received a college degree. Participants averaged 29 years of age and reported a lifetime number of psychiatric hospitalizations of 4.6; 86% were taking psychiatric medications. The program consisted in remedial education if needed, assessment, three types of skills building modules, and mobile support on a campus by a case manager.

At least one class was completed by 42% of participants. Of those taking any classes, the average was 3.6. Six students completed a degree. During the study period, 78% of the clients held at least one job even though 90% were unemployed at baseline, and 47% of these clients were employed on the date of their follow-up interview. Self-esteem increased (correlated with the number of courses taken), coping mastery scores increased, and satisfaction with the program was high.

The Michigan Supported Education study was conducted between 1992 and 1995, with information about implementation and empirical findings reported in several articles (Collins, Bybee, & Mowbray, 1998; Collins, Mowbray, & Bybee, 1999a, 1999b, 2000; Mowbray, 2000; Mowbray, Bybee, & Collins, 2001; Mowbray, Bybee, & Shriner, 1996; Mowbray, Collins, & Bybee, 1999). A total of 397 participants were assigned to one of three conditions: support group, classroom, and individual (control). Mean age was 36, with a range of 17 to 75. Half had some postsecondary education, but a quarter had not yet completed high school. The average duration of the participants mental disability was 14 years. At the 12-month post program completion time, 262 of 378 participants were re-interviewed. Forty-three percent of the participants never continued beyond the orientation session. Nonetheless, the percentage of individuals enrolled in school or vocational education at follow-up (21%) was more than twice that reported at baseline (10%). After a year, 65 participants were still in college. At graduation from the program significant differences in program participation rates were found; group members participated most, followed by classroom participants, then those assigned to the individual condition. No group difference was found in rates of school enrollment at 12 months, but the support group and classroom *improvements* were statistically significant. Forty-six percent of the support group members were employed or in school (vs. 19% at baseline); statistically higher than the control group, which changed little. Major transformations of self in line with recovery goals occurred. Predictors of success in a multivariate model were productive activity at baseline or having a partner. Mental health related variables (diagnosis, symptoms, duration of illness) were not related to productive activity at a statistically significant level.

The third major study measured outcomes in three separate programs, two on the East coast and one in California (Unger, 2000; Unger & Pardee, 2002). For five semesters a total of 124 students were studied. Study participants were randomly selected from program participants or else all participants were included. Study group members were likely to have been hospitalized (86%), to be taking psychiatric medication (85%), and to live independently (85%). Some 29% had been homeless and 38% had been arrested at some point. The mean age was 40.5 years. However, at enrollment in the study, 49% had earned income. Fifty of the 124 students already had at least an AA degree. Study attrition was 15%. Overall, 83% enrolled in school and 90% completed courses, completing an average of 6 units with a grade point average of 3.14. While, 78% stopped attending school during the 2.5 years, 21% received a certificate or degree. Increases were noted in the number of students living independently. Type of psychiatric diagnosis was not a predictor of school completion but having one's own car and number of psychiatric hospitalizations prior to program participation were. The employment rate of 42% during the study was lower than the rate for other part-time students but higher than the rate for persons experiencing severe mental illness generally. There were no significant changes in either quality of life or self-esteem. Students who worked reported their education helped them do their jobs (71% of an indeterminate number); and 50% reported their job fit their educational level. The study design also included a test of whether the outcomes differed by program; few statistically significant differences were found, perhaps due to many common program elements.

SUMMARY OF EVIDENCE.

We conducted our own assessment of these three and the other 16 supported education outcomes studies, rating each study both with regard to quality of the study and strength of the evidence for supported education. These ratings are presented in the full report which is available on the CIMH website.

Virtually all programs report some positive results on some measures. However, the studies as a whole have many methodological weaknesses. Only the Michigan Supported Education Program had a randomized control group. In most cases the N is small, limiting statistical power. In general the process of selection into supported education programs and reasons for attrition are not clearly described. Most studies use self-report exclusively. Only a couple of studies have a follow-up period of 2 years or more. In summary, out of eight possible points for quality and strength of evidence, one study received a 6, four studies received a 4, eight studies received a 2, five studies received a 1, two studies could not be rated, and one study showed negative change rather than positive.

The evidence reviewed above indicates that supported education is what CIMH would term an effective practice. Effective in this case means that at least one randomized control trial supports the intervention and there is positive evidence from multiple studies with less rigorous designs. The evidence base overall, however, leaves much to be desired. There are few methodologically sound studies and none conducted within the last 9 years.

Program models have varied widely and the evidence is not sufficient to clearly determine the most effective elements. A fidelity scale developed at the University of Kansas provides a principle-driven model that is likely to be of use in a variety of settings and programs. As used here "fidelity" means concordance with principles rather than adherence to key elements of programs proven effective. The evidence does not constrain program development into one narrow model. Given the range of the program and participant characteristics studied so far, program planners might with some justification assume that many approaches can be effective. Adaptation to local campus conditions and populations will be required for any model. For example, Cooper discusses the pros and cons of developing a mobile support program (Cooper, 1993).

Tracking educational outcomes over a sufficient period of time to see career consequences has been a part of only one study. Three to five year studies of supported employment show high competitive employment rates in the first year or so, but considerably less favorable outcomes over longer periods of time (Becker, Whitley, Bailey, & Drake, 2007; Salyers, Becker, Drake, Torrey, & Wyzik, 2004). Studies of supported education, similarly, need to measure short-term outcomes such as enrollment but also need to extend several years in order to assess completion rates and the effect of education on employment and career.

Finally, research to date has focused on re-entry students. But given the recent strong interest in serving persons experiencing a "first break," (Penn, Waldheter, Perkins, Mueser, & Lieberman, 2005) there is a need for research on supported education interventions that attempt to keep young students in school or help them return very quickly. To illustrate the promise of this approach, a UCLA program that combined supported employment and skills training for persons with recent on-set schizophrenia reported that 36% returned to school, 31% were employed, and 33% both worked and returned to school (Nuechterlein et al., 2008).

C. Implementation resources

Consultants

Tim Stringari, Rick DeGette, and Sylvia Thomas currently provide training and technical assistance to community colleges and local mental health programs throughout California to develop supported education agreements and partnering arrangements to assist persons with psychiatric disabilities to achieve success in college. They work under contract with the California State Departments of Mental Health and Rehabilitation's Cooperative Services Unit. They can be reached: Tim Stringari, tim.stringari@sbcglobal.net, 530-587-7170; Rick DeGette, ricder@yahoo.com 510-846-6693; Sylvia Thomas, justsylviaT@sbcglobal.net, 951-222-8620

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² Categories used by CIMH are: Effective—achieves outcomes in controlled experimental research (random assignment or consistently strong comparison groups) with a range of typical clients in usual practice settings; Efficacious—achieves outcomes in controlled experimental research (random assignment or consistently strong comparison groups) with a homogeneous group of clients in a highly controlled setting; Promising—some positive research evidence, (i.e. pre- post designs), of success and/or expert consensus.; Emerging practice—recognizable as a distinct practice with "face" validity or common sense test; Not effective—significant evidence of a null, negative, or harmful effect.

Karen Unger developed the supported education philosophy and program at Boston University in the 1980s and early 1990s. She edited the 1998 *Handbook on Supported Education: Providing Services for Students With Psychiatric Disabilities*. She also spearheaded a five year program to disseminate supported education to an additional seven sites. She is now a consultant in Portland Oregon: (503) 232-7085; kvungerOR@comcast.net

Diane McDiarmid was the principle developer of the supported education fidelity scale presented in Appendix I. She recently left the University of Kansas School of Social Work and now provides training and consultation through her own Austin, Texas based business. She can be contacted at: dianem@ku.edu or (512) 906-2417.

The Center for Psychiatric Rehabilitation at Boston University also provides a wide range of resources at its website: http://www.bu.edu/cpr/

It offers training, technical assistance, and access to supported education experts: 617-353-3549 Voice; 617-353-7700 FAX . Email access on the website: http://www.bu.edu/cpr/contact/index.html. A manualized supported education curriculum was developed which uses small group exercises and experiential learning. It is organized around a) coping with the academic environment, b) stress management, and c) developing career choices, covering academic and social skills; it incorporates verbal and written assignments focused on the use of the library and other campus resources.

Professional resources

Educational staff dealing with disabilities have a number of active professional organizations. Some of these organizations also include students. Examples are the Association on Higher Education and Disability (AHEAD: ahead@ahead.org) and California Association for Postsecondary Education and Disability (CAPED: http://www.caped.net/). These organizations, and their websites, are good resources for mental health professionals as well—both for specific information and for understanding psychiatric disabilities and education in the larger context of support for all persons with disabilities. In particular the AHEAD website provides information on many professional and consumer organizations: http://www.ahead.org/resources/dss profs/dss profs/dss

The federally funded National Center on Secondary Education and Transition (NCSET) offers *technical assistance* and disseminates information related to secondary education and transition for youth with disabilities. The website offers a wide variety of helpful publications, mostly from the perspective of college disability staff: http://www.ncset.org/default.asp Contacts: ncset@umn.edu; 612-624-2097 (phone); 612-624-9344 (fax).

An exemplary California program

In San Mateo County, Caminar (a psychosocial rehabilitation agency) has since 1991 provided an award-winning supported education program—Transition to College—in conjunction with College of San Mateo. The San Mateo County Department of Mental Health, two supported employment agencies, two consumer groups, the local Mental Health Association, and NAMI are all collaborators. See Appendix III for a flow chart.

The Peer Support Services Certificate of Completion is described on the website. Other very useful information for mental health staff and contact data is also available at: http://www.smccd.net/accounts/fiori/atcenter/ttc/main.htm

The person to contact for further information about Transition to College is: Tim Stringari, tim.stringari@sbcglobal.net or PH: 650-333-0275

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