ISSUE BRIEF

# Supported Education for Persons Experiencing a First Episode of Psychosis

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## Role of Education for Young Adults with a First Episode of Psychosis

Most young adults strongly desire to pursue further education (e.g., complete high school, go to college). Attending school is developmentally appropriate for this age group, a place for young adults to be with their peers and to facilitate the transition to employment. A first episode of psychosis often disrupts academic work, contributing to poor performance and high dropout rates from high school and college (Goulding, Chien, & Compton, 2010; Hartley, 2010). In the U.S., over 4 million young adults fail to graduate from college due to an early-onset psychiatric disability (Mowbray et al., 2005).

Educational attainment is critical for obtaining meaningful jobs and developing social and occupational networks. Educational attainment predicts higher lifetime earnings and other positive employment outcomes in people with severe mental illness, even more strongly than in the general public (Luciano & Meara, 2014; Waghorn & Lloyd, 2005).

Extended periods of inactivity, a common consequence of being out of school and work, have profoundly negative effects on self-esteem, mental and physical health, and well-being in the general population (Blustein, 2008). This is also true for people experiencing a first episode of psychosis. Attending school and/or working may help to prevent or delay entry into the disability benefits system.

## Barriers to Pursuing Education

Psychiatric symptoms are a significant barrier to completing educational programs, and students experiencing these problems underutilize campus counseling services (Megivern, Pellerito, & Mowbray, 2003). Finances are often a major barrier to success in school (Manthey, Goscha, & Rapp, 2015), as is a lack of social support (Salzer, 2012). Students with psychiatric disabilities often feel stigmatized by faculty and students (Brockelman, Chadsey, & Loeb, 2006). Mental health professionals often view coursework as stressful and thus may discourage young adults' decisions to enroll or re-enroll in school (Ennals, Fossey, Harvey, & Killackey, 2014).

## Supported Education Models

*Supported education (SEd)* involves a series of supports to help address these barriers. It denotes individualized, practical assistance for people with psychiatric disabilities to pursue educational goals. SEd encompasses many forms of assistance aimed at: clarifying educational goals; finding academic programs consistent with these goals; navigating the application process; securing appropriate financial support and using educational supports and accommodations to help assure success in meeting academic requirements. SEd programs help people who have dropped out of academic programs to return to school, and they also benefit those who are currently enrolled but are at risk of dropping out.

SEd programs today are available in diverse academic, mental health and other settings, but no consensus exists regarding a single best model or the guiding principles of best practices (Ennals et al., 2014). Many years ago, Unger (1990) identified three types of SEd programs: *the self-contained classroom, the on-site SEd model,* and *the mobile SEd model.* The *self-contained classroom* consists of coursework using a curriculum developed for and provided exclusively to people with psychiatric disabilities. This coursework often includes career planning and strengthening academic skills. These courses typically do not count toward degree requirements. Some of the earliest self-contained SEd programs were offered on college campuses (Unger, Danley, Kohn, & Hutchinson, 1987) and subsequently in psychiatric rehabilitation and mental health agencies (Cook & Solomon, 1993).

In the *on-site SEd model,* a postsecondary institution sponsors and manages SEd services (Hain & Gioia, 2004; Mowbray, Brown, Furlong-Norman, & Soydan, 2002). Some institutions have an office of student services that manages SEd services and ensures accommodations when requested (e.g., more time to take tests). (The name, capacity, and scope of responsibility for this office varies widely across academic institutions.) The on-site SEd approach may provide on-campus services that are available to all students with disabilities, sometimes enhanced for students with mental health problems through specialized mental health staff or peer support groups.

The *mobile SEd model* includes assistance through a social service agency (most often a mental health agency) independent of an academic institution, with students selecting their post-secondary education sites. SEd professionals provide support, assistance, and problem-solving to students at the educational institution or individual's home in an individualized and flexible manner.

Currently most SEd proponents emphasize social inclusion, community integration, and participation in mainstream educational institutions, consistent with the values and principles of evidence-based supported employment (SE). A common variant of the mobile SEd model combines SEd with SE services to form *integrated SE/SEd* services. This approach typically embeds SEd services within evidence-based SE programs, such as Individual Placement and Support (IPS) (Drake, Bond, & Becker, 2012). Recognizing the IPS principle of client choice in developing a vocational plan, SEd is philosophically consistent with IPS. With the development of first episode psychosis programs, IPS services have increasingly included SEd.

Integrating SEd with SE is practical and effective because young adults are exploring several options and may seek employment while enrolled in school or when taking a break from school. SE/SEd specialists provide the integrated services. Many IPS programs in the U.S. have adopted this integrated model (Manthey, Holter, Rapp, Davis, & Carlson, 2012), as have many early intervention programs for young adults experiencing a first episode of psychosis worldwide (Ennals et al., 2014; Nuechterlein et al., 2008). In this issue brief we focus on this approach for young adults with early psychosis, using the label "SE/SEd."

## Core Principles of SE/SEd

Within SE/SEd programs, supported education complements supported employment services, which follow IPS principles. The core principles of SEd build on the core principles of IPS, substituting the goal of mainstream education for competitive employment. As formulated by SEd experts, these principles typically include the following:

| Core Principles | |
|---|---|
| **Focus on mainstream education** | SEd emphasizes mainstream academic programs, which admit students from the general population and award degrees and certificates for successful completion of coursework. |
| **Zero exclusion for eligibility** | All young adults with a first episode of psychosis who want further education are eligible for SEd, regardless of symptoms, substance use, or other personal characteristics. |
| **Attention on participant preferences and strengths** | SEd specialists help develop educational plans with close attention to participants' educational goals and preferences, academic qualifications, and educational strengths. |
| **Rapid engagement and expeditious enrollment** | SEd specialists facilitate visits to community educational institutions that match participants' preferences and help them to initiate their applications and begin their course of study as soon as possible. |
| **Individualized support and advocacy in the application, financial planning, and enrollment process** | These activities may include self-disclosure of a disability, at the participant's discretion. |
| **Individualized ongoing support after enrollment** | SEd specialists directly provide individualized support (e.g., arranging accommodations, managing time, organizing homework, and so on). This support may involve the treatment team, peer support and natural supports such as family and friends if desired by each participant. |
| **Partnership with mainstream educational resources** | SEd specialists collaborate closely with staff members from educational institutions (e.g., deans, academic advisors, testing services, tutoring services, disability services, offices of access or accommodations, and health centers) (Rickerson, Souma, & Burgstahler, 2004). Mainstream support services are the first choice when available. |

| Core Principles *(Continued)* | |
|---|---|
| **Integrated SEd and SE services:** | To the degree to which educational and vocational goals are interrelated, providing integrated education and employment services is desirable (Robson, Waghorn, Sherring, & Morris, 2010). |
| **Integrated SEd and clinical services:** | SEd services are integrated into early intervention treatment teams that follow evidence-based principles (Addington, McKenzie, Norman, Wang, & Bond, 2013). These principles also emphasize client centeredness and direction and a strong emphasis on engagement and outreach. |
| **Emphasis on natural supports:** | Young adults with early psychosis sometimes benefit from regular meetings with peers who have pursued education (Robson et al., 2010). Families often provide natural supports for encouragement, homework, transportation, finances and other tasks needed for success in school. |

## SE/SEd Service Components

### ORGANIZATION OF SERVICES

SE/SEd services are integrated with mental health treatment services. SE/SEd specialists join the early intervention team for first episode of psychosis, have office space co-located with the team, and participate in weekly treatment team meetings. Team members, who often include a psychiatrist, a care manager/recovery coach, a nurse, an SE/SEd specialist, and other specialists, collaborate to help their clients achieve their goals. For example, they share what they know about clients on their caseload and generate ideas to help them succeed.

Most SEd researchers recommend limiting SE/SEd specialist caseloads to 20 people seeking education and/or employment. Each SE/SEd specialist provides the full range of both employment and education services to all clients on his/her caseload, which is particularly helpful to people who want to work and go to school part-time, or for those who alternate between school and work. The SE/SEd specialist focuses exclusively on SE/SEd services rather than helping with case management.

## SED SERVICES

Education services are individualized based on the strengths and preferences of each student. SE/SEd specialists develop relationships with personnel from local schools, colleges and vocational/training programs. Examples of how SE/SEd specialists assist participants include:

- Participate in Individualized Education Program (IEP) meetings for students who are finishing high school.
- Discuss short and long-term career goals.
- Develop written education plans with each person.
- Offer to introduce the participant to working peers in the program who can discuss the benefits of developing a career path rather than applying for disability benefits.
- Identify strengths and interests related to school by discussing past educational experiences, obtaining school transcripts, and speaking with family members (with the person's permission).
- Arrange informational interviews to meet workers in desired positions in order to learn about future job possibilities, the training/educational requirements and begin to develop networks in the working world.
- Share information about state vocational rehabilitation services and assist accessing vocational rehabilitation services based on each person's preference.
- Facilitate family meetings to discuss the person's progress with education and employment plans.
- Help in selecting a school or training program, including visits to schools and meetings with advisors.
- Assist in completing school applications.
- Plan for transportation.
- Explore options for financial aid and other strategies to pay for school.
- Develop a class schedule and discuss advantages of returning to schooling on a full or part-time basis.
- Review good study skills and set up a homework schedule.
- Gather information about the office for student services and register for services based on student choice. Accommodations provided by the office for student services may include tutoring, assistance with note taking, and/or extra time for test taking, based on student need. SE/SEd specialists build relationships with staff in these offices so that they are seen as credible and can successfully advocate for students on their caseloads.
- Ask instructors for accommodations, such as extra time for test taking and recording lectures.

- Educate instructors about how to support the student and provide effective feedback.
- Explore options to drop classes, take incompletes for classes, or take medical leave, if needed.
- Celebrate success such as good test grades, class completion, degrees, and certificates.
- Provide outreach to students who stop attending SE/SEd appointments.

## ROLE OF MENTAL HEALTH TREATMENT TEAM

In addition to supports from the SE/SEd specialist, other members of the treatment team help to support participants with schooling and training. Examples of support services include:

- Prepare for social interactions with other students at school.
- Adjust medication to help with side effects or symptoms that interfere with learning, if the student chooses to use medication.
- Develop skills to manage a substance use disorder if it is interfering with academic success.
- Practice coping skills to manage symptoms during class or while studying.
- Provide encouragement to continue education, including recognition of accomplishments and strengths.
- Participate in family meetings with the SE/SEd specialist and student to discuss education and career goals if the participant chooses to involve his/her family.

## ENGAGING YOUNG ADULTS

SE/SEd services are implemented within treatment/coordinated care teams that are designed to effectively engage young adults. Consider the following critical issues that relate to engagement.

- Young adults are exploring options and may frequently change their plans, which is a normal developmental process and not an indication of poor motivation, disordered thinking or lack of readiness.
- Young adults often prefer to communicate using texts, emails and instant messaging rather than telephone calls.
- Team members should be hopeful about each person's future and recovery and focus on his/her strengths and opportunities.
- The team's office location is inviting for young people in contrast to some large community mental health agencies serving people of all ages.
- Marketing materials are attractive and appealing to young people and their families.
- Hiring peers with a lived experience of mental illness provides role models of people in recovery and helps with engaging young adults with early psychosis.
- Services are person-centered and employ shared decision-making.

## Professional Development for SE/SEd Specialists

SEd services embrace a broad range of educational opportunities and settings. Because many IPS specialists are unfamiliar with skilled trades and adult vocational education programing, these options may be underutilized. People should have opportunities to consider the full range of job opportunities and careers available to them. Individuals who do not succeed in college due to problems with concentration or learning disabilities may be interested in and suited for training programs to qualify them to work in a trade (e.g., construction or auto repair), which often may be completed over a comparatively brief time period. All SE/SEd specialists should visit a variety of education and training programs in their areas to learn about the degree and certificate programs available. In addition, specialists can speak with state vocational rehabilitation counselors to learn about local education and training programs.

Other areas for SEd specialist training include developing a repertoire of coping strategies to be used in the academic environment (McGurk & Mueser, 2006). Specialists need more than the strategies they used during their own education, recognizing different styles of learning and specific challenges that may confront their clientele. Specialists need to become familiar with student services at postsecondary education institutions. They also need to address disclosure issues, because specialists help students consider their options for sharing personal information with professors or others.

Program leaders seeking to hire SE/SEd specialists look for guidance in the selection process. In addition to considering competencies of effective employment specialists (Glover & Frounfelker, 2013), program leaders should also consider candidates' knowledge of educational institutions, as outlined above. IPS practitioners in the U.S. have a variety of backgrounds including marketing, social service, or other experiences. To help people plan careers, it is helpful for SE/SEd specialists to possess undergraduate degrees in vocational rehabilitation or have related experience.

## Financing SEd Services

For a practice to be widely adopted, it must have a clear and predictable funding mechanism. At present, SEd does not have such a mechanism. In many communities, supported education is offered in conjunction with supported employment, with braided funding for SE/SEd specialists provided through a combination of state budgets, Medicaid, and the state vocational rehabilitation (VR) system. In the case of Medicaid, SEd services are typically billed under medically necessary supports or under a case management code for assisting clients to access community resources. Most VR offices seem willing to pay for education if it is directly tied to what they determine is viable career goal for the individual. But local practices vary widely and funding for SEd services remain a challenge.

## **Assuring Program Quality:** SEd Fidelity Measurement


Any successful program will have processes in place to monitor the delivery of the program as well as its outcomes. Fidelity scales are measures assessing adherence to a program model (Bond, Evans, Salyers, Williams, & Kim, 2000) and can be very helpful in characterizing the functioning of the program as well as assessing quality by gauging function against program standards. Fidelity scales are essential tools both for evidence-based practices and for emerging practices (such as SEd), which have not yet established a strong evidence-base. Researchers use fidelity scales to aid interpretation of findings from outcome studies and to permit comparisons between studies of the same emerging practice. Variations in fidelity can be related to variations in outcomes suggesting the processes through which the program is operating.

Several SEd fidelity scales have been developed that generally comport with the models discussed earlier. To date none has been systematically studied nor widely adopted. Unger was the first to develop a SEd fidelity scale (Unger, 2008). A later version of her scale is found on the Substance Abuse Mental Health Services Administration (SAMHSA) web site (SAMHSA, 2011a). University of Kansas researchers developed the most comprehensive SEd fidelity scale accompanied by a detailed assessment manual (Manthey, Coffman, et al., 2012). Finally, another recently developed tool is a combined SE/SEd fidelity scale designed for transition age youth who were previously in the foster care system (Ellison et al., 2015; Frounfelker, Bond, Fraser, Fagan, & Clark, 2014).

The content of all these scales is similar because all have been modeled after the empirically-validated IPS fidelity scale, either the original 15-item version (Bond, Becker, & Drake, 2011) or the current 25-item version (Becker, Swanson, Bond, & Merrens, 2011; Bond, Peterson, Becker, & Drake, 2012). The similarity in the IPS model and major features of the SEd program recommend this strategy as a basis for developing an SEd fidelity instrument specific to the early psychosis population. None of these SEd fidelity scales were developed specifically for early psychosis programs.

## Effectiveness of SEd

Published and unpublished reviews of the SEd and related literatures have identified over 20 SEd outcome studies (Becker, 2012; Carlson, Eichler, Huff, & Rapp, 2003; Chandler, 2008; Ellison, Rogers, & Costa, 2013; Leonard & Bruer, 2007; Mowbray et al., 2002; Mueser & Cook, 2012; Rogers, Kash-MacDonald, Brucker, & Maru, 2010; SAMHSA, 2011b; Soydan, 2004). These studies have many limitations, notably the underutilization of randomized controlled designs (Rogers et al., 2010). Other deficiencies include the use of small and highly selected samples, poor model specification, proliferation of program models with little attention to replication, brief follow-up periods, and measurement problems. Weaknesses in outcome measurement have included heterogeneity of outcome measures, with rare attention to school completion; trivial outcomes, such as course enrollment; frequent use of unstandardized measures; overreliance on self-report; and use of global scales that combine employment and education outcomes into a single measure. Absent well-defined interventions, common metrics, and rigorous methods, a cumulative science of SEd has not developed.

A review of empirical studies of early intervention for young adults with early psychosis found that programs with IPS services were more effective than programs without IPS services in improving competitive employment outcomes, but had at best a very modest impact on educational outcomes (Bond, Drake, & Campbell, 2014).

Although SEd programs have been located in a wide range of mental health, rehabilitation, and academic settings (Mowbray, Megivern, & Holter, 2003), we hypothesize that SEd is most effective when integrated in IPS programs. Our rationale is that academic and vocational goals are closely linked and that providing these in separate programs is less effective than integrating them. One study has most thoroughly documented this integration (Nuechterlein et al., 2008). No controlled study has directly compared SEd embedded in IPS to alternative SEd programs.

Two recent NIMH initiatives (Recovery After Initial Schizophrenic Episode or RAISE) have incorporated SEd in the service models but have not yet published findings on educational outcomes (Dixon et al., 2014; Mueser et al., 2015). A recent webinar reported improvement in education outcomes over time within the New York RAISE Connection programs (Scannevin, Watkins, & Glynn, 2015).

## New Directions in SE/SEd Research

Given the early stage of the SEd research and its importance in first episode programs, we recommend a specific concentration on strengthening the research literature. This may begin by convening an expert panel to identify a consensus list of core SEd principles, facilitated by the use of a Delphi procedure (Addington et al., 2013) or a related approach. An established list of core principles, if rigorously tested through research, would facilitate the development of a SEd fidelity scale that could have scientific and practical benefits if adopted broadly.

SEd researchers need to conduct rigorous outcome studies, including randomized controlled trials with sufficient follow-up periods, using credible outcome measures. Some continuing areas of disagreement include ambiguity regarding:

Which is more effective: a freestanding SEd program or SEd services embedded on IPS teams?

Should employment specialists on IPS teams also provide SEd, or should this be a separate role for staff members who exclusively focus on education?

Researchers also should explore and evaluate alternative models for helping people experiencing a first episode of psychosis achieve their educational goals. For example, are mainstream academic institutions equipped to provide the necessary supports described earlier, in partnership with early interventions services for people experiencing a first episode of psychosis who are enrolled in coursework (or taking a medical leave of absence)?

## Conclusions

A first episode of psychosis represents a crisis and an opportunity. Decisions made at this critical time can have far-reaching influences on life trajectories. Supported education, defined as systematic assistance in pursuing educational goals, aims at maximizing vocational aspirations and minimizing disability. Most experts agree on a set of core principles of supported education, which are well described in the literature. The most promising approach to supported education integrates it with evidence-based supported employment services using a set of parallel principles. Research is now needed to evaluate the effectiveness of supported education, studied using a well-validated fidelity scale. Wide-scale implementation of supported education programs will require stable funding mechanisms, which are currently unavailable.

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