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Programs Promote Ill Effects for Offspring?

To the Editor: In the February Open Forum, Seeman (1) posed the question of whether psychosocial programs for young people with psychosis promote assortative mating. She presented data from research indicating that assortative mating—the idea that individuals choose to mate with those who are similar to them—may hold true for people with mental illness. This point is important to consider in light of what we already know about the increased biological predisposition to mental illness among children whose parents are ill. However, Seeman went further, questioning whether psychosocial programming does recipients a disservice in this regard.

The implication that mating between individuals with serious mental illness is the equivalent of “inadvertently causing misery to a future generation” is blatantly offensive. This type of thinking created the eugenics movement. Currently, it prevents parents with serious mental illness from receiving appropriate assessment and needed supports. As director of a clubhouse program and a clinician who has done research on the experiences of mothers with serious mental illness, I find the author's assumptions to be flawed. Research has

shown that parents with a mental illness are at higher risk of losing custody of their children by virtue of their illness alone, not because of acute symptoms or impaired functional status (2). This sort of bias has no place in psychosocial programs, where the focus is on reducing stigma and promoting recovery. I understand that Seeman was posing questions for consideration rather than stating conclusions. However, I fear that introducing eugenics concepts into current discourse on mental health recovery and rehabilitation will halt further progress.

Questioning the value of psychosocial programs simply because two participants may mate is naive. A different perspective is offered in the January 2012 issue, where Whitley and Siantz (3) suggest that recovery centers should be considered an emerging best practice. Should we consider a support group for cancer survivors or people with diabetes a bad thing because members might meet and fall in love? Should we save their potential children the misery of having parents who share a chronic illness, likely increasing their chances of inheriting the condition? If such arguments sound ridiculous or even offensive, why would we entertain them for mental illness? Perhaps the development of parenting supports and skills training to assist people with mental illness who choose to parent would be a topic for discussion more useful than questioning the existence of programs that allow for socialization and bonding.

Nikole Benders-Hadi, M.D.

Dr. Benders-Hadi is director of the Recovery Center at Rockland Psychiatric Center, Orangeburg, New York.

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In Reply: Whether to encourage socialization among patients with schizophrenia or, instead, to confront the widespread stigma against mental illness head on and attempt social integration within the larger community is an important question that deserves public debate. Well-intentioned interventions can have unforeseen consequences, such as an increase of births of children whose parents both have a serious mental illness.

Benders-Hadi writes, “Perhaps the development of parenting supports and skills training to assist people with mental illness who choose to parent would be a topic for discussion more useful than questioning the existence of programs that allow for socialization and bonding.” Why limit the discussion? The offerings in rehabilitation programs should probably include genetic psychoeducation (1), contraceptive advice (2), preconception counseling (3), parenting training (4), and staff training to help clients retain custody of their children (5).

To give the children of psychiatric patients the best leg up, their parents deserve excellent comprehensive rehabilitation services, preferably in settings not exclusively determined by diagnosis.

Mary V. Seeman, M.D.

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Fountain House and Recovery Centers

To the Editor: It is encouraging to read an article like Whitley and Siantz's Best Practices column in the January issue (1) that advocates for places in the community for people with mental illness. But it is equally discouraging that the authors felt a need to denigrate the source of many of the concepts for which they are advocating. Although Fountain House now describes its approach as a "working community," the term "clubhouse" originated with us. Clearly, a network of recovery places is lacking in the current mental health system. The authors' attempt to misclassify clubhouses is harmful, especially given the dearth of any type of community programs for people with mental illness. Furthermore, it undermines the authors' expressed support for recovery centers.

Myths about and misinterpretations of our work are beyond our control, and we are the first to admit that many programs of dubious quality and fidelity to our practice call themselves clubhouses. In order to distill and disseminate our theory and methods, two Fountain House colleagues and I have written a book, forthcoming this year from Columbia University Press.

Accredited clubhouses are listed as an evidence-based practice on the National Registry of Evidence-based Programs and Practices maintained by the Substance Abuse and Mental Health Services Administration (nrepp.samhsa.gov), and some of the best recovery centers in the country refer to themselves as clubhouses: Genesis Club in Massachusetts, Gateway House in South Carolina, Magnolia House in Ohio, Independence Center in Missouri, and Grand Avenue Club in Wisconsin, to name a few. These high-quality centers offer extensive programs in supported education, supported employment, and supported housing, buttressed by a strong working community where members can develop a social network and a sense of purpose. Over the past five years alone, Fountain

House has supported hundreds of people in colleges and universities. Like many similar programs, we continue to evolve and innovate, with a wellness center, an art collective that sold \$100,000 in artwork last year, a youth initiative, and a local health home.

We have differed with some mental health planners and academics who advocate only for individualized services in vivo, because we know there is a need for places of support in the community. They are not just places of respite but communities with porous borders that promote reintegration of their membership. Individuals reach their fullest potential when they are a part of a community or group. We have great admiration for the housing-first approach, and we agree with many of their concepts. From our perspective, it is much more productive to work together to create more and better places of support for people with mental illness to engage in their communities.

**Kenneth J. Dudek, M.S.W.
Ralph Aquila, M.D.**

Mr. Dudek is president of Fountain House and Dr. Aquila is director of the Sidney Baer Center, both in New York City.

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In Reply: Dudek and Aquila state that it is "discouraging that the authors felt a need to denigrate the source of many of the concepts for which they are advocating"—the source being the clubhouse model developed by Fountain House. They also take umbrage at our alleged "attempt to misclassify clubhouses."

We simply do not agree that we denigrated or classified (let alone misclassified) clubhouses in any way in our Best Practices column. It is notable that Dudek and Aquila do not provide any evidence or direct quotes from our column to support their assertions. Thus we will present the evidence for their claims and allow the

reader to judge whether we engage in denigration or misclassification.

Our column was an in-depth case study of a recovery center that is unaffiliated with the clubhouse movement. No data were collected from any form of clubhouse. In fact, we did not discuss Fountain House, and no inferences were made regarding clubhouses. In fact, the word "clubhouse" is used only twice in our column of more than 2,500 words. First, in the introduction we state that "clubhouses . . . often focus on providing a place of refuge and slow adjustment to living with a psychiatric disability." We did not conjure up this statement. Our assertion was supported by a reference to a description of the Fountain House program published in this journal in 1999 (1), when Fountain House received an award from the American Psychiatric Association. The article states that clubhouses provide "services to ease the community adjustment of people with serious mental illness." Dudek and Aquila themselves state in their letter that clubhouses "are not just places of respite," implicitly acknowledging that provision of respite and refuge is an important component of clubhouse services. Thus we do not see how our original statement could be labeled as inaccurate, let alone denigrating or misclassifying.

The second (and final) time that we used the word "clubhouse" in our column was in the conclusion, where we state that "a focus on education, employment, and functional improvement overlaps with many of the activities provided by progressive day treatment centers and clubhouses." This statement was empirically based, as one of us (RW) previously conducted evaluations of a clubhouse-type facility, as well as progressive day treatment settings, and found much overlap with the recovery center offered by Pathways to Housing (2,3). Again, we do not see how such a statement could be considered denigrating or misclassifying.

We absolutely agree that it is important to work together to create more and better places for people with mental illness. We also look forward to the authors' upcoming book on clubhouses.

es. From our standpoint, Dudek and Aquila have made a stout and admirable defense of an effective organization that they have honorably served for many years. However, their defense is raised against a nonexistent attack.

Rob Whitley, Ph.D.
Elizabeth Siantz, M.S.W.

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The Health Literacy of Adults With Severe Mental Illness

Studies show that about 36% of U.S. adults have low health literacy, defined as “the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (1). Low health literacy is associated with a lower level of education, racial-ethnic minority status, age 65 years and older, male gender, poor health status, lack of private insurance, and risk of hospitalization (1,2). In psychiatric populations, health literacy is correlated with education and verbal, visual, and intellectual abilities (3). In addition, the presence of psychotic disorders is associated with an increased likelihood of limited health literacy (3). Previous studies have acknowledged the importance of including health literacy assessment in standard psychiatric evaluation protocols, because low health literacy has an impact on the effectiveness of current best-practice treatment approaches, which may require adequate literacy (3).

We examined factors related to the health literacy of 256 individuals with serious mental illness who were receiving services in an urban community mental health center (CMHC). The parent study was a randomized trial assessing the effects of a medical care management intervention for individu-

als treated at the CMHC (4). Participants were recruited on site and were required to have the ability to provide written informed consent before enrollment. We hypothesized that low health literacy would be associated with lack of health insurance, worse health status, the presence of a psychiatric diagnosis, more inpatient hospitalizations and emergency department visits, and lower use of preventive services.

We examined cross-sectional data related to participants’ demographic characteristics, general health information, general medical and psychiatric diagnoses, and hospitalizations. Health literacy was assessed with the Rapid Estimate of Adult Literacy in Medicine (REALM), a brief validated measure considered suitable for use in psychiatric populations (3,5). It measures a patient’s ability to pronounce 66 commonly used medical words in an ascending order of difficulty. Scores of 0 to 60 indicate a third- to eighth-grade reading level; scores from 61 to 66 indicate a reading level of ninth grade and above (5).

The mean±SD age of the sample was 46.05±8.13 years, 207 participants (81%) were African American, 132 (52%) were male, 168 (66%) reported at least a 12th-grade education, and 106 (41%) were insured. Overall, 117 participants (46%) had low health literacy, and the mean REALM score was 55.18±15.60. In adjusted analyses, low health literacy was associated with increased odds of inpatient medical hospitalization when the analysis was controlled for education, race, gender, age, and schizophrenia diagnosis (odds ratio=3.71, 95% confidence interval=1.49–9.22, $p=.005$).

Low health literacy and cognitive or functional impairments may affect this population’s abilities to effectively interpret health information or to meaningfully engage in psychiatric interventions, which may result in poor self-care management, increased disability and morbidity, and adverse health outcomes, such as hospitalization. Clinicians should consider integrating health literacy assessment and targeted patient education

with standard psychiatric evaluation procedures, so that treatments are administered in a manner understandable by persons with low health literacy. Future studies should consider using more comprehensive health literacy and cognitive assessment tools and investigating the effectiveness of targeted patient education in improving health outcomes in psychiatric populations. In research environments, limited literacy may have a similar effect on participants’ understanding of materials, such as informed consent documents, and it is important to ensure the readability of all written materials.

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The authors report no competing interests.

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