

LETTERS

Letters from readers are welcomed. They will be published at the discretion of the editor as space permits and will be subject to editing. They should be a maximum of 500 words with no more than five references. Letters related to material published in *Psychiatric Services* will be sent to the author for possible reply. Address letters to John A. Talbott, M.D., Editor, *Psychiatric Services*, American Psychiatric Association, 1400 K Street, N.W., Washington, D.C. 20005; fax, 202-682-6189; e-mail, psjournal@psych.org.

Family Advocacy

To the Editor: I must object to the immediate rebuttal allowed William Emmet (1) in response to Sylvia Caras' article (2) on the downside of the family advocacy movement in the June 1998 issue. Publishing the rebuttal with the article gave the impression that the questions raised by Ms. Caras had been answered, which is far from the truth.

Recently I attended a meeting where innovative county providers were explaining their triumphs and defeats in establishing a new approach to mental health services. There was general agreement that one of the biggest obstacles was the parents, who either were too overprotective or were totally rejecting of the children involved in the programs.

While I would agree that the entire family can be affected by the severe mental illness of a family member, as mine certainly was, growth and development can happen only when consumers take the reins and are allowed to speak for themselves and control their own destinies.

Ellie Phillips

Ms. Phillips is a mental health advocate in Des Moines, Iowa.

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1. Emmet W: Why consumers and family advocates must work together. *Psychiatric Services* 49:764-765, 1998
2. Caras S: The downside of the family-orga-

nized mental illness advocacy movement. *Psychiatric Services* 49:763-764, 1998

To the Editor: My Webster's dictionary defines "ideologist" as "an advocate or adherent of a particular system or doctrine of ideology." It defines "hegemony" as "preponderant influence or authority." In your June issue, William Emmet voices the vision of the National Alliance for the Mentally Ill (NAMI) that consumers and families become a united voice for ending discrimination. I submit that progress toward that laudable goal will be impeded if NAMI insists that its ideology have hegemony.

Bob Joondeph, J.D.

Mr. Joondeph is executive director of the Oregon Advocacy Center in Portland.

To the Editor: We reacted with disbelief to Sylvia Caras' fantasy about the motivation for the founding of the National Alliance for the Mentally Ill (NAMI) in September 1979.

As the originators of the idea to form an organization of groups across the country concerned about serious mental illnesses of their family members, we know what our motivation was. We can assure Ms. Caras that the Alliance for the Mentally Ill of Dane County, in Madison, Wisconsin, where the meeting was held, and leaders of the other 30-some family groups did not have a primary objective "to protect themselves from blame."

The three objectives then and now remain the same: to improve services for persons with mental illness, to promote research to encourage recovery and alleviate suffering, and to educate NAMI members and society about mental illness.

The excellent reply by NAMI board member William Emmet to Ms. Caras's article deserves a close reading. Even though both of us as early national board members have answered complaints about NAMI over the years (a usual occurrence in any successful movement), we have not seen in print this degree of hos-

tility and negative stereotyping of parents.

Ms. Caras appears not to accept the dilemmas faced by caring families who have mentally ill relatives. NAMI deserves better than being linked to the Salem witchcraft trials.

**Harriet Shetler
Beverly Young**

Ms. Shetler and Ms. Young were founding members of the Alliance for the Mentally Ill of Dane County, Wisconsin.

In Reply: I agree with NAMI's supporters that NAMI's lobbying has been successful. It is the family advocacy end that I question. Mr. Emmet concludes with a call to stand together. But he and I have disconnected. I didn't find the way to his ear. If, as he urges, I stand together with him— beside him— I will have surrendered my voice.

Ms. Phillips has been there. Mr. Joondeph sees the dilemma clearly.

A recent report on trauma indicates that as many as 80 percent of those who later receive a diagnosis of mental illness have been sexually and physically abused (1). I would like the spotlight to shift to the causes of the abuse itself, away from only medicating the effects of the abuse.

The new Treatment Advocacy Center and the finality of involuntary commitment as NAMI's effective solution alienate me. The coercive acts that NAMI advocates are intolerable in a just society. This is as true today as it was in 1776, when this nation cut the cord with England because of what the colonists called the Coercive Acts. I am looking for a morally informed advocacy grounded in democratic due process.

I repeat my request to the family lobbyists: "Listen."

Sylvia Caras

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1. Auslander MW, Bustin-Baker C, Cousins V, et al: National Association of Consumer/Survivor Mental Health Administrators' Position Paper: Trauma and Abuse Histories: Connections to Diagnoses of Mental Illness, Implications for Policy and Service Delivery, July 1998. <http://www.madnation.org/traumareport.htm>

Employment and Disability

To the Editor: The article by Dr. John Noble (1) entitled "Policy Reform Dilemmas in Promoting Employment of Persons With Severe Mental Illnesses" in the June 1998 issue was well researched and captured many of the essential issues in the current psychiatric vocational services world, where I have worked for more than 24 years. However, the author failed to address the fact that many people with severe mental illness would prefer to work part time and continue to collect some disability payments.

Their preference for part-time employment is due to numerous factors: the stressful nature of full-time employment, difficulty focusing on work for extended periods of time, difficulty meeting the higher interpersonal demands of the workplace for long stretches, and fear of losing benefits when their mental illness is still periodically cycling or symptomatic.

The Supplemental Security Income (SSI) program allows a gradual increase in earnings and a concomitant decrease in SSI benefits. However, the Social Security Disability Insurance program has a strict cut-off point of \$500 for earnings from substantial gainful activity once the nine-month trial work period is over. This limit on earnings creates what consumers call the "cliff effect": if you start working and inch over the \$500 mark, you immediately lose your whole disability check, thus dropping your monthly income dramatically.

Part-time employment still affords the non-income benefits of employment alluded to by Dr. Noble: reduction in hospitalizations, increased self-esteem, decreased symptomatology, structure, social contact, and normalization. These benefits are worth a lot, even if the work is not substantial enough to permit total discontinuation of disability benefits (often the only measure by which success is defined by government program evaluators.)

Federal legislation (H.R. 464 and S.B. 1054) has been proposed to in-

crease the level of earnings from substantial gainful activity from \$500 to \$1,050 (the current level for blind persons only). This change would right an inequity that has existed for many years, as the level of earnings for nonblind persons with disabilities has not increased since 1990. This legislation preceded and is completely separate from the proposed legislation for a major revision of the Social Security disability system, which will likely face more hurdles because of its complexity.

Ruth Arnold

Ms. Arnold is vocational services team leader for the Mental Health Center of Boulder County, Inc., in Boulder, Colorado.

Reference

1. Noble JH Jr: Policy reform dilemmas in promoting employment of persons with severe mental illnesses. *Psychiatric Services* 49:775-781, 1998

In Reply: The preference of many people with severe mental illnesses for part-time employment and simultaneous collection of some disability payments presents yet another policy dilemma facing the U.S. Congress in reforming disability policies. Yes, for many years blind persons have enjoyed the advantage of a higher level of earnings from substantial gainful activity (SGA), more than twice the level permitted for other causes of disability. Applying the same standard would correct an obvious inequity and would help many people pursue meaningful part-time work as a legitimate vocational objective.

But why has Congress resisted such an obvious fix for so many years? Many federal legislators know that there is nothing *sui generis* about "disability." They fear that many more people would seek and become eligible for disability payments as a more secure alternative source of income when periodic worsening of economic conditions curtails employment opportunities for everybody. They also recognize that the change would represent a back-door approach to creating a permanent partial disability program in the United States— a policy

that it has repeatedly rejected in the past on the basis of cost considerations and experience with the intractable issues of administration in state workers' compensation programs (1).

Concerns about the possible negative consequences are reinforced by evidence from countries with a permanent partial disability policy and other, more generous provisions than exist in the U.S. (2). Thus Ms. Arnold's belief that passage of H.R. 464 and S.B. 1054 would somehow bypass the need for a major revision of the Social Security disability system is mistaken. Debate over the administrative feasibility and cost implications of the proposed increase in the SGA eligibility threshold for disability payments will, I fear, uncover the complexities involved and once more underscore the need for more basic reforms.

Regardless of the benefits that would accrue for some individuals, the likelihood that the present Congress will create, either up-front or by the back door, a new permanent partial disability program is remote. After all, this is the Congress that has tightened the definition of disability under the Supplemental Security Income program and forced off the rolls many people who were formerly covered.

John H. Noble, Jr., Ph.D.

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1. Berkowitz ED: *Disabled Policy: America's Programs for the Handicapped*. Cambridge, England, Cambridge University Press, 1987
2. Noble JH Jr: Rehabilitating the severely disabled: the foreign experience. *Journal of Health Politics, Policy, and Law* 4:221-249, 1979

Depot Antipsychotic Drugs Revisited

To the Editor: With the advent of atypical neuroleptic medications, psychiatrists have begun switching certain patients from depot neuroleptics to atypical drugs, anticipating a better therapeutic outcome. We set out to reevaluate the effectiveness of depot antipsychotics in our practice.

The case records of all patients attending a depot clinic at University College Hospital in Galway, Ireland, were examined. Patients were classified as being off depot medication if at the time of hospital admission they had not received an injection in the last three months or any time previously. Length of hospital stay was totaled cumulatively for each patient and classified as either on-depot or off-depot. Data were analyzed using Wilcoxon's signed rank test.

We identified 113 people currently on depot injection treatment in a general population of 33,614 in the West of Ireland, or approximately three in every 1,000. In comparison, 1 in 1,500 were identified in a previous study by Crammer and Eccleston (1) of a general population in the Northern Regional Health Area of the United Kingdom. The majority of our patients, 84 (74.3 percent), had a diagnosis of schizophrenia; 13 (11.5 percent) had schizoaffective disorder; and eight (7 percent) had bipolar disorder.

We compared data for individual patients for periods when they were receiving depot drugs with periods when they were not on depot, either before the drugs were initiated or during periods of noncompliance or discontinuation. The mean \pm SD number of admissions for patients not on depot injection treatment was 4.5 \pm 4.3 but fell to 3.4 \pm 5.3 after depot treatment was implemented, a significant difference (Wilcoxon test, $z = -3.317$, two-tailed $p = .001$). The mean length of stay while off depot was 132.16 \pm 152.2 days, compared with 101.8 \pm 160.4 days while on depot ($z = -2.17$, two-tailed $p = .02$).

Depot effect was most significant for patients with schizophrenia; their mean number of admissions fell from 3.89 \pm 3.43 while off depot to 2.64 \pm 4.19 on depot ($z = -3.122$, two-tailed $p = .001$). Their length of stay fell from a mean of 129.2 \pm 170.7 days to 91.8 \pm 125.0 days ($z = -2.208$, two-tailed $p = .02$). The effect of depot prescription was not evident for those whose illness had an affective component. An increase in both mean number of admissions and length of stay was not-

ed for the eight patients with schizoaffective disorder or bipolar disorder.

Previous studies that looked at the efficacy of depot versus oral medication found that depot medications reduce the rate of relapse (2-4). Our study further confirms this finding, which obviously may relate to better compliance. However, we demonstrated a diagnostic effect, whereby schizophrenic patients had reduced hospital stay, and depot medication was less effective for patients with affective illness.

Our study has obvious methodological limitations. The selection of patients was not random and probably included a group with a history of poor compliance with treatment. The sample was limited to patients receiving depot injections; we are unaware of the number of "depot failures," or patients who showed no response and whose depot injections were discontinued. Hospitalization may not be a sufficient index of clinical course. Frequency of episodes of illness may be a more reliable indicator, but unfortunately we were unable to assess its importance.

Atypical antipsychotic drugs have proved beneficial for many patients, particularly as they appear to be associated with a lower rate of extrapyramidal side effects and possibly tardive dyskinesia. However, an economic analysis that compared depot antipsychotic treatment with a traditional oral neuroleptic and an atypical medication (risperidone) concluded that

switching to depot medication for outpatient therapy could result in lower treatment costs (5). Furthermore, it is clear that certain patients, mainly because of noncompliance, will require maintenance depot antipsychotics. Our study strengthens the argument that depot medication remains a useful tool in psychiatric treatment.

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2. Freeman H: Twelve years' experience with the total use of depot neuroleptics in a defined population. *Advances in Biochemical Psychopharmacology* 24:559-564, 1980
3. Devito RA, Brink L, Sloan C: Fluphenazine decanoate vs oral antipsychotics: a comparison of their effectiveness in the treatment of schizophrenia as measured by a reduction in hospital readmissions. *Journal of Clinical Psychiatry* 39:26-34, 1978
4. Davis JM, Metalon L, Watanabe MD, et al: Depot antipsychotic drugs: place in therapy. *Drugs* 47:741-773, 1994
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