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Alaska Mental Health Board
431 N. Franklin Street, Suite 200
Juneau, AK 99801-1121

Re: Departing Thoughts

Dear Chair Lanier and Members of the Board:

After my first Board meeting just over five years ago I wrote the article, "A Consumer Member's Report on Alaska Mental Health Board Issues (http://akmhcweb.org/amhb.htm). Now that I am no longer on the Board and since I didn't have the opportunity to give some "farewell" remarks in person, I am taking this opportunity to put my thoughts in writing. First, though, I'd like to welcome you new members. It is a great public service for which you have volunteered. The Board is facing new and increased challenges and I'm sure you will make valuable contributions to its work.

From my consumer's vantage point after five years on the board, I see a number of very important issues: (1) SSDI/SSI/Medicaid Barriers to Recovery, (2) Housing, (3) Support for Consumer Operated Support Programs, (4) Community Support, Consumer Involvement and Consumer Redress standards to regulation, (5) Voluntary Admissions to API, and (6) Current Level of Reliance on Medication.

1. <u>SSDI/SSI/Medicaid Barriers to Recovery.</u>

Our public mental health system has moved to relying virtually exclusively on Medicaid as its funding mechanism. As pointed out in the Budget Summit Report, adopted by the full Board on August 8th of last year (attached), Social Security Disability Income/Supplemental Security Income/Medicaid essentially require that people be certified that they won't recover as a condition of receiving services. So, is it any wonder that people are not recovering like they should? This issue was referred to the Planning and Evaluation Committee for follow-up, but because of various factors I don't think anything has been done on it. I doubt there is anything more important that the Board could do than find a way to convert the Medicaid system from a chronic illness one to one that promotes recovery and I hope it finds a way to do so.

It is clear we could get a lot more people recovered from a diagnosis of serious mental illness and off of public assistance if we did the things we know work.[1] Removing barriers to employment and providing the supports necessary for successful employment for the many consumers who would like to work is not only the right thing to do, it would save the government tremendous amounts of money. I do understand the Federal Medicaid Requirements

[1] See, "Community Mental Health: A Practical Guide," Loren Mosher and Lorenzo Burti, W.W. Norton & Company, 1994.

may be a potential hurdle for this, but all potential avenues should be pursued in my view.[2] I am no expert on Medicaid, but I have done a little bit of checking and it seems a Demonstration Waiver under Section 1115 might be a possible approach. The federal government might be very receptive because Alaska is potentially a perfect place to pilot such an approach.

2. Housing

It is well known that safe housing in a good environment is among the most, if not the most important thing that can be done for people to recover from serious mental illness. The Board has gone on record on this for a long time now, but until recently it was not given much attention by the system. This has hopefully changed recently. It is important to not let this drop and also to keep in mind that housing should not be refused people because they don't want to participate in other aspects of the mental health program.

3. Support for Consumer Operated Support Programs

The extreme effectiveness and low cost of Consumer Operated Support Programs is well-documented.[3] We have seen this in Alaska too with the organization of a number of consumer operated support programs. However, the legs have been cut out from under this with the last budget. In other states, the "Block Grant" is used to fund these programs and it is my view the Board should insist on this. The Block Grant is perhaps the only place where the Board has any actual budgetary authority and it should use it in my view. My understanding is that the Board has to approve of the Block Grant application before it can be submitted. Despite my extreme protestations the practice has been for all Block Grant submittals to be presented to the Board on an emergency basis where it has to be approved in a very short time frame -- often a matter of days. In my view this is unacceptable. It is my belief the Board should serve notice on the Division that this is unacceptable and also advise it that $750,000 of the Block Grant must be allocated to Consumer Operated Support Services in order for it to be approved by the Board during the next go-round. Two years ago the Consumers Consortium came forward with the goal that there should be an independent consumer operated support program for every community mental health center and it seems to me this should be something the Board should try to achieve. Allocating the $750,000 from the Block Grant would be a good start on that.

4. Community Support Services, Consumer Involvement in Grantee Agencies and Grievance Redress Standards.

Three years ago, after a concerted effort by the Board, the Division included these three sets of standards into Community Mental Health Center grants. We wanted them promulgated as regulations because that gives them more permanence, but the Division refused and put them in as "grant conditions." A couple of years ago, the Board formally requested that these be put into

[2] The Ticket to Work and the Work Incentives Improvement Act of 1999 was enacted to address some of these barriers, but seems to have been a pretty dismal failure for what seem to be resolvable reasons.

[3] See, e.g., Consumer/Survivor-Operated Self-Help Programs: A Technical Report by Substance Abuse and Mental Health Services Administration, Center for Mental Health Services (2001), which is available on the web at http://akmhcweb.org/docs/selfhelp.pdf.

regulations and offered to draft them if that was a problem. The Division declined. Finally, last October I drafted a set of regulations incorporating the standards and the Board formally adopted a resolution urging the state to adopt them. (See attached memo and documents). I think this should be vigorously pursued by the Board. In my mind it is a lack of good faith by the Department to continue to refuse to put these into regulation.

5. Voluntary Admissions to API.

A number of years ago it was discovered that API refused to admit anyone outside of Anchorage unless they were involuntarily brought there. In other words people are not given a choice to come in voluntarily instead of having court orders, etc., issued against them. I think this is a violation of law[4] and it certainly is a fundamental violation of human dignity. I drafted a proposed legislative amendment that would make it clear. See, attached Memo. This was referred to the Legislative Committee and I believe the board formally passed a resolution at its last meeting urging the legislature to enact it or something like it.

6. Current Level of Reliance on Medications

The Budget Summit Report (adopted by the full Board) also recommended that the Planning Committee conduct research on how the current heavy reliance on psychiatric medications impact desired results (i.e., recovery). The research shows that the way we almost exclusively rely on these medications is at least doubling the number of people who become chronically mentally ill. See, e.g., "The case against antipsychotic drugs: a 50-year record of doing more harm than good" (attached). This has been in the Planning Committee since last August.[5]

At my first meeting as a member of the Board five years ago, I said I was impressed with how much consumer input there was into the process and how there were a lot of good words written about the system being responsive to consumers' needs and perspectives. At that time I said it seemed like our mental health system was "walking the talk," but I didn't know if it was really "walking the walk." After five years, I think frankly the answer is no. What I have found is that to a large extent, when challenges are made to the current system by consumers with suggestions for change, they are largely dismissed. In other words, only lip service is being given to consumer involvement. That is a harsh criticism I know, but, for example, there is simply no reason why the grant standards haven't been promulgated as regulations. There is no reason why people aren't given the basic human dignity of being allowed to come to API voluntarily.

I was dismayed last month, in what was my last official meeting as a member of the Board I think, to be presented with a draft outline of the new plan and see that the proposed goal was set

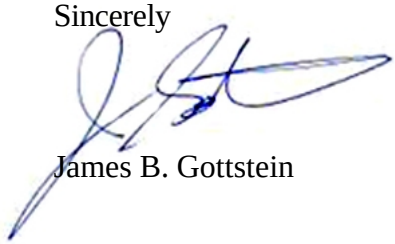
[4] The state's legal position seems totally untenable (it certainly is not supported by citation to any authority). This is certainly an issue that a lawsuit could be brought over, but it is ridiculous for the State not to just remedy it.
[5] This is an issue that has already spawned litigation (see, Myers v. API, S11021, which is described at http://psychrights.org/States/Alaska/CaseOne.htm), with another lawsuit in the wings (see, http://psychrights.org/States/Alaska/CaseTwo.htm). It would be much better for this to be resolved at a policy level through discussion, dialogue and negotiation, but failing that litigation will continue to ensue.

as "providing services," rather than getting people better. That is a provider driven system orientation, not a consumer driven system orientation.

People have exhorted me to stay involved and I absolutely will. In fact, I am willing to do all the same kinds of work I did while on the board, such as writing memos, drafting regulations and statute changes, serving on workgroups, etc. I will also keep up the effort as best I can in support of consumer issues in other venues.

I wish you all the best in your efforts.

Sincerely



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