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February 18, 2004

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. SSDI/SSI/Medicaid Barriers to Recovery.

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

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[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

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[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

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[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

James B. Gottstein

ALASKA
MENTAL
HEALTH
BOARD

Report
By the
Alaska Mental Health Board Budget Committee
On the
2003 Budget Summit With Recommendations

Adopted by AMHB Budget Committee – July 11, 2003
Adopted by AMHB – August 08, 2003

Report
By the Alaska Mental Health Board
Budget Committee
On the
2003 Budget Summit
And Recommendations

June, 2003

I. Table of Contents

II. Executive Summary

The focus of the Alaska Mental Health Board's 2003 Budget Summit was to look at what is being "purchased" by the Mental Health Program (Program) and, if it is not what is desired, make recommendations regarding how to make it do so.

Alaska's Mental Health Program funding, as is true in most of the country, is designed around eligibility criteria and authorized services. This is based on the assumption that the eligibility requirements identify those people who should receive services and the authorized services are what those people need. However, it has become increasingly clear that this may not be the optimal approach because evaluation of the Program rests on what services are provided, rather than whether desired results are achieved for the recipients of those services. The Budget Committee therefore suggests a budget based on the following:[1]

- Funding should be based on achieving desired results and those should be achieving the goals of consumers.
- In order to achieve this, the Mental Health System (System) should be flexible and needs based.
- The System should if at all possible respond before a person is in crisis.
- Medicaid, Social Security Disability Income (SSDI) and Supplemental Security Income (SSI) should allow or, better yet, facilitate people returning to the mainstream, including gainful employment in appropriate jobs.

There were discussions of what data the System should be collecting and using to evaluate and manage the Program as well as whether it was clear enough from the data that the current reliance on psychiatric medications substantially increases chronicity. These and similar items are referred to the full Board/Planning Committee for further development and consideration.

III. Proceedings

The Budget Summit was "kicked off" on March 8, 2003 in Juneau with an advertised public meeting as part of the regular Alaska Mental Health Board meeting. Approximately 25 people attended the meeting, including representatives of the Alaska Mental Health Trust Authority, the Department of Health and Social Services and numerous members of the public. Budget Committee Chair, Jim Gottstein gave a short presentation on the current budget process and posed certain issues and questions that might be addressed. Many attendees provided input and there was a general discussion of the issues among participants.

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[1] This approach essentially follows what the Alaska Mental Health Trust Authority has been urging for the last few years.

The Budget Summit continued in Anchorage on April 11-12, 2003, with all 4 Budget Committee members present (Jim Gottstein, Tony Mander, Barry Creighton, Keggie Tubbs), 3 other Board Members attending, Jeanette Grasto, Tracy Barbee and Bill Hogan, staff Kate Webster and Kay Klose, 3 other Division of Mental Health and Developmental Disabilities (DMHDD) personnel, and 5 or so other people representing stakeholders and the public in attendance all or part of the time. April 11th was devoted to presentations of information, including updated budget and outcome data, public input, and a roundtable discussion over what should be in the final report and recommendations. On April 12th, the discussion of recommendations and conclusions continued. This Report was unanimously adopted in concept on April 12, 2003, subject to approval of final language. Approval of the final language of this report occurred during the Budget Committee's July 11, 2003 meeting.

IV. Budgeting Process

Alaska has a unique budgeting process as a result of the settlement of the Alaska Mental Health Lands Trust Lands Litigation in 1994 (Settlement). The Settlement, among other things, resulted in a cash payment of $200 million dollars and conveyed almost one million acres of land, some of it subsurface only to the Alaska Mental Health Trust Authority (Trust) created as part of the settlement. Under AS 47.30.046:

> (a) The [Trust] shall annually, not later than September 15, submit to the governor and the Legislative Budget and Audit Committee a budget for the next fiscal year and a proposed plan of implementation based on the integrated comprehensive mental health program plan prepared under AS 47.30.660(a)(1). The budget must include the authority's determination of the amount
>
> (1) recommended for expenditure from the general fund during the next fiscal year to meet the operating and capital expenses of the integrated comprehensive mental health program;
>
> (2) in the mental health trust settlement income account, if any, that is not reasonably necessary to meet the projected operating and capital expenses of the integrated comprehensive mental health program that may be transferred into the general fund; and
>
> (3) of the expenditures the authority intends to make under AS 37.14.041 and 37.14.045, including the specific purposes and amounts of any grants or contracts as part of the state's integrated comprehensive mental health program.

Under AS 37.14.045 and the Settlement Agreement, the Trust has the power to spend Trust Fund income (MHTAAR)[2] directly without an appropriation; however state

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[2] The statute refers to this as Mental Health Trust Authority Authorized Receipts which becomes the acronym MHTAAR.

agencies need an appropriation to spend the funds. In order for the Trust to develop its budget recommendations, it requests recommendations from the four Trust beneficiary boards[3] (Request for Recommendations or RFR).

The Trust explains the process this way:

> **The Separate Appropriation Bill**
>
> The separate appropriations bill for the Comprehensive Integrated Mental Health Program includes several components. They are:
>
> **General Fund/Mental Health Base (GF/MH Base)**: This is the amount established by identifying the mental health services funded within the state's general fund budget. The Trustees calculated that amount to be $131 million for fiscal year 2003. These general funds are designated as general fund/mental health dollars, or GF/MH Base. The final budget from the previous fiscal year establishes the GF/MH Base.
>
> **Adjustments to the Base:** As The Trust and the associated boards and commission further refine the definition of beneficiaries and accurately track funds for the Comprehensive Integrated Mental Health Program, the Trustees suggest adjustments to the base each year.
>
> **GF/MH Increments:** When the Trustees identify better and more cost efficient ways of providing on-going services or providing for unmet needs, they make recommendations in the form of GF/MH increments.
>
> **Capital Budget:** The separate appropriations bill includes that portion of the state's capital budget that funds mental health projects. This often includes funds from the Alaska Housing Finance Corporation to provide housing for beneficiaries as part of the Comprehensive Integrated Mental Health Program.
>
> **Mental Health Trust Authority Authorized Receipts (MHTAAR):** The Trustees authorize state agencies to spend Trust funds for specific operating and capital projects. These state agencies must have legislative approval to receive and expend Trust funds.
>
> The Trustee's recommendations for the mental health bill are due to the governor on September 15th for the following state

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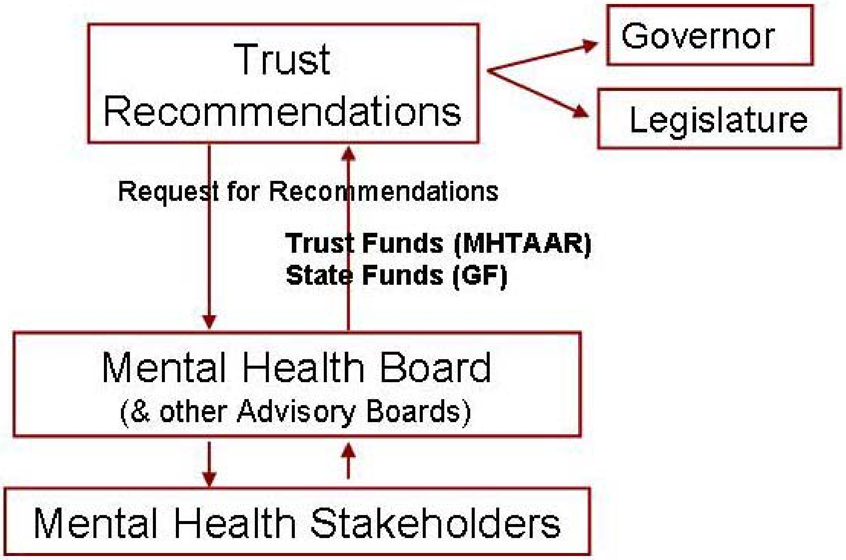
[3] Alaska Mental Health Board, Alaska Commission on Aging, Governor's Council on Disabilities and Special Education, and Advisory Board on Alcohol and Drug Abuse.

fiscal year. However, because the Trustees rely heavily on the recommendations of the four Advisory Boards, the Trust budget process actually begins early in the calendar year when the Trust sends the Advisory Boards a Request for Recommendations (RFR). The Trustees review these recommendations in late summer and make their funding decisions in time to meet the September 15th deadline.

The Board also seeks input from its stakeholders in the Request for Recommendations process and many stakeholders identify mental health service needs that they would like to have funded. The Board takes this information and then makes decisions on what to recommend to the Trust. In doing so, the Board does not normally recommend that any particular program get funding; rather it takes specific proposals that it receives and converts them into a "generic" budget category.

The following graphic illustrates this budget building process:



V. Budget Data

It is not possible at this juncture to say what the total mental health budget is because it is spread across so many different budget categories and agencies. No one has attempted to compile such a total since the early 1990's when it was done in connection with the Mental Health Trust Lands Litigation. In addition there is not agreement as to what expenditures should be included as being part of the Mental Health Program. What could be identified follow:

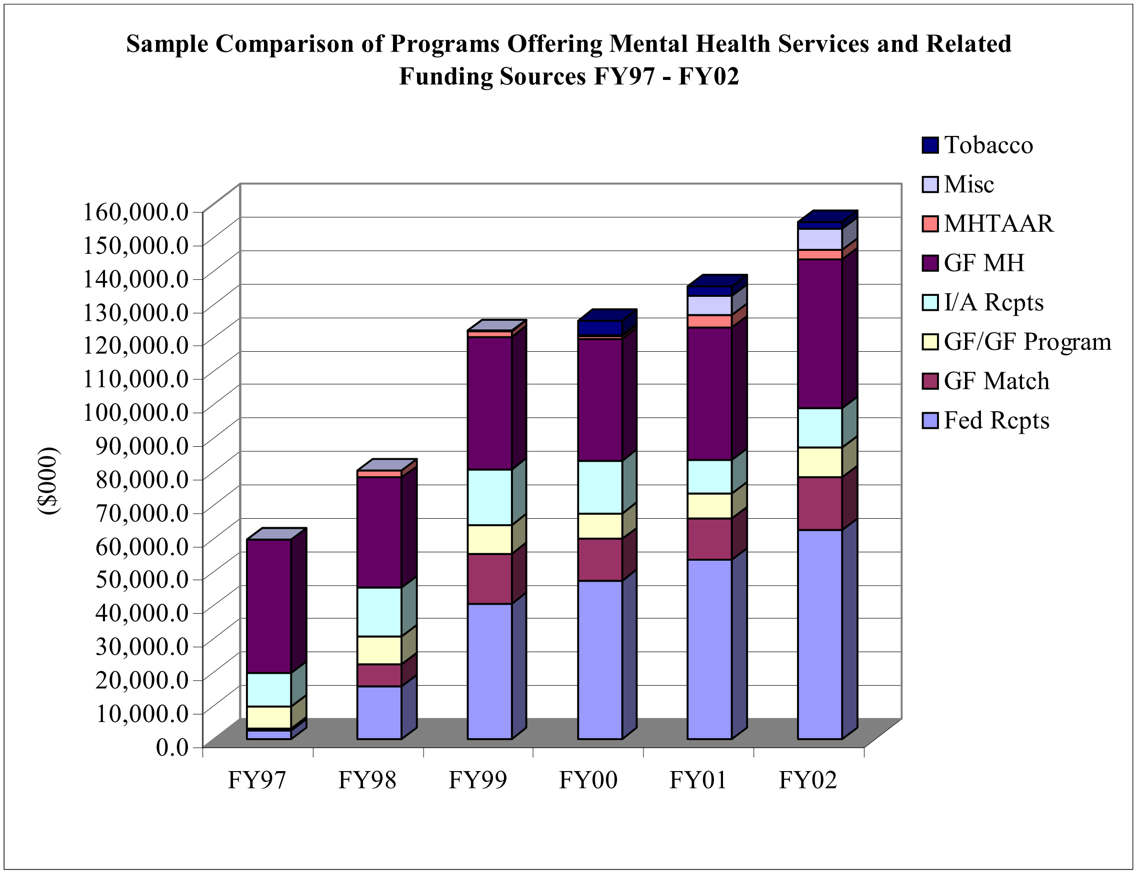
AMHB Sample Comparison of Programs Offering Mental Health Services and Related Funding Sources FY98 - FY03

Bare Bones Mental Health Budget FY97-02

	Fed Rcpts	GF Match	GF/GF Program	I/A Rcpts	GF MH	MHTAAR	Misc	Tobacco	Totals
FY97	2,649.0	564.4	6,575.8	9,982.1	39,789.7	37.5	0.0		59,598.5
FY98	15,742.9	6,682.0	8,309.6	14,530.6	32,886.5	2,039.0	142.4		80,333.0
FY99	40,528.8	14,740.5	8,766.0	16,516.5	39,559.4	1,769.9	146.5		122,027.6
FY00	47,269.6	12,500.0	7,586.6	15,871.2	36,465.0	696.6	247.2	4,314.2	124,950.4
FY01	53,611.2	12,419.5	7,389.2	9,908.9	39,628.2	3,917.5	5,562.3	2,956.8	135,393.6
FY02	62,399.1	15,994.5	8,696.0	11,895.9	44,466.6	2,897.5	6,264.0	1,963.6	154,577.2

Notes:
FY97 Does not include any Medicaid Funding--Not included in Enacted Summary
Tobacco revenue begins in FY00 with majority of funds supporting Medicaid services
All Medicaid Expenses calculated at 15% of total Medicaid (Tobacco tax also calculated at 15%)
FY00 $25,447.7 went into Medicaid Services

Miscellaneous categories, depending on FY, include: 1047, Title20; 1050 PFD; 1077 Gifts/Grt; 1091 GF/Desig; 1061 CIP Rcpts; 1108 Stat Desig; 118 Pioneers;1156 Rcpt Svcs; 1171 PFD Criminal


Sample Comparison of Programs Offering Mental Health Services and Related Funding Sources FY97 - FY02

As can be seen from the below figures expenditures for inpatient services is very close to that spent on Community Mental Health.

Some Mental Health Services Purchased FY '02		
Inpatient Medicaid	$ 44,000,000	
API GF/MH	$ 17,000,000	
DET GF/MH	$ 3,000,000	
Total Inpatient		$ 64,000,000
Community Mental Health		$ 75,000,000

Also, Medicaid paid $19 Million for psychiatric drugs in FY 02.

Another comparison raising questions is the per capita and per client range of Community Mental Health Grant and Medicaid Expenditures:[4]

Catchment Area Ranges

	High	Low	Avg
Per Capita	$ 233	$ 44	$ 117
Avg Client Cost	$ 7,068	$ 361	$ 4,120
Medicaid (per capita)	$ 203	$ 0	$ 65
Grant Funds (per capita)	$ 197	$ 21	$ 52

While it is clear there are great disparities in per capita and per client expenditures between community mental health centers it is important to be careful in drawing conclusions because of various factors. For instance, there is a high probability that high needs clients migrate to the larger cities where more intensive (costly) services are provided and that community mental health centers with small catchment populations can not spread their overhead across as many people. Having said that, however, there are still great differences that suggest widely varying Medicaid billing practices and possible over reliance on grant based services.

As to where Community Mental Health dollars are going, the available data revealed:

Community Mental Health Grand Funding FY '03		
General Community Mental Health	$ 3,377,700	9%
Psychiatric Emergency Services	$ 8,368,400	23%
Services to Seriously & Persistent Mentally Ill	$ 15,450,700	43%
Designated Evaluation & Treatment (DET)	$ 1,836,800	5%
Severely Emotionally Distrubed Youth	$ 7,165,500	20%
Total	$ 36,199,100	100%

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[4] A detailed analysis of these expenditures for all of the community mental health centers in the state is attached as Appendix A.

VI. Results Data

At the end of the "Kick-Off" in March, the following question was posed. Is the Budget Purchasing?

Housing		Protection
Relationships	Or	Control
Jobs/Meaning		Stabilization
In life		Dependency
Recovery		

The system increasingly talks about the items on the left as being the desired results, but with the possible exception of "dependency" the other results have also been seen as desirable. In fact, "protection" and "control" have been suggested as the primary reason that the public pays for mental health services. Protection includes the community as well as the recipient and is clearly a highly valued result. While perhaps not viewed as positively, controlling disturbed and disturbing behavior has also been a major goal of the public mental health system. Stabilization is a good outcome when compared with deterioration and also if the course of mental illness is assumed to be a steady or progressive worsening of condition. However, good housing, relationships, being productive and recovery are all preferred and, to the extent they are achieved, the other goals no longer need to be achieved.

It is being accepted around the country that recovery from mental illness is possible for many people that have previously been considered to be destined to a life of great disability. The most important factors identified in recovery are Hope, Housing, Relationships, and Employment/Meaningful Activity. As the focus of the program shifts towards improvement in the lives of mental health system recipients the question arises whether we are purchasing these results. There is even more limited data regarding these results.

A. Housing

Data from the Division of Mental Health and Developmental Disabilities' Management Information System on housing status indicates that 29 % of community mental health center clients live either alone or with an unrelated person(s) and 54% live with a relative(s) (54%). The remaining 17% are shown as "Housing Unknown." It does not seem safe to assume that all of the unknown are homeless, nor is there great confidence that the other categories exclude being homeless. The Mental Health Board, as part of its planning process, has estimated there are approximately 1,400 of its beneficiaries who are homeless. Another factor that is not addressed is whether consumers consider their current housing situation ‘ideal’ or whether they even consider it safe and affordable.

B. Employment

One area that there is some data on is employment:

- Only 1% of Community Mental Health Center clients are receiving employment services from the Community Mental Health Center.
- Less than 1% of people go from SSDI to Employment
- Less than 10% of people on SSI are gainfully employed.

This data starkly shows that under the present system once a person gets placed on SSDI they are very unlikely to ever return to the workforce. Since placement on SSDI and SSI are criterion for receiving Medicaid services, and that people have to be both disabled and very poor to be in these programs, the clear result of this funding mechanism is that **the Medicaid/SSDI/SSI eligibility and funding mechanism is essentially a one way ticket to permanent disability and poverty**. This is probably the single most important information contained in this report.

VII. Evaluation of The Budget Building Process

The Trust was extraordinarily successful in leveraging its relatively small financial contributions to the mental health program to not only prevent budget declines, but increase the mental health program budget during a time of budget declines. It was able to do this at least in part through the process outlined above by recommending "increments" (increases) and using Trust Funds to get programs going and then moving them to other funding sources, which was typically the General Fund.[5] The value of being able to bring even the relatively small amount (but in the millions of dollars) it has "to the table" is much more than the amount it has to contribute and the Trust has been incredibly skillful in this process. However, due to the financial crisis the state is facing, it appears that for the first time this strategy was unsuccessful and Program funding is faced with a substantial General Fund decline.

All processes should be periodically reviewed to determine if they continue to optimize results. The state's budget crisis, the new administration resolved to reduce spending to address this crisis, the increasing reliance on federal funds (e.g., Medicaid) and data results suggests this is a good time to re-evaluate Alaska's mental health budget building process.

A number of things leap out from the circumstances and data. The first is the absence of consideration of Medicaid mental health expenditures in the budget building process, which equals or exceeds the parts of the budget that is part of the Trust's Request for Recommendation process. The second is that the focus on increments (increases) may no longer be tenable. Perhaps even more important is by not looking at the effectiveness of expenditures in the "base" (which this Report suggests should include

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[5] The Trust calls this an "Exit Strategy" meaning that the Trust, as a general matter, is not prepared to continue funding programs indefinitely.

Medicaid) in achieving desired Results, there has been little, if any incentive or requirement to achieve desired Results. In other words, the entire mental health budget program should be evaluated.

Therefore, it is suggested that the Board should regularly and rigorously review results and identify gaps, rather than relying so heavily on stakeholders bringing specific proposals for consideration. A somewhat similar proposal, known as "Strategic Budgeting" has been before the Board as a proposal for a number of years. The Budget Committee believes results based budgeting (i.e., the Friedman Model) will be a beneficial way to proceed in the future.

VIII. Recommendations

The Budget Summit proved to be a useful endeavor and resulted in a number of recommendations, which can be categorized into these four broad categories:

- **A.** Funding Should Be More Explicitly Tied to Desired Results
- **B.** Medicaid/SSDI/SSI Should Be Re-Tooled as Possible to Achieve Desired Results
- **C.** The Planning Committee Should Review Whether the Current Level of Reliance on Psychiatric Medications is leading to Desired Results.
- **D.** The Budget Building Process Should be Re-evaluated.

There are a number of parts to each of the main recommendations.

A. Funding Should Be More Explicitly Tied to Desired Results

The Budget Committee wholeheartedly supports moving to results based budgeting that the Trust has been advocating for a number of years, known as the "Friedman Model." In essence, the approach is to (1) define what results (also known as outcomes) are desired, (2) develop measurement(s) for determining how well the system is doing in "purchasing" desired results, and (3) this data should be regularly collected, analyzed and acted upon. In other words, what does the data reveal about effectiveness of programs? Where are the gaps? What changes in program funding should be made to achieve desired results? In order to achieve this the Budget Committee recommends that:

1. The Planning Committee develop a recommendation to the full board regarding the desired results; and
2. The Planning Committee determine/develop recommendations to the full board regarding what results to measure
3. Programs should be evaluated and funded based on recipient results. In other words, goals and benchmarks should be established and funding based on the extent to which these are achieved.

4. Financial incentives should be given providers for producing desired results.

5. Grants should be re-tooled to produce desired results.

6. Non-traditional and flexible approaches should be part of the Program and evaluated for achieving desired results along with traditional approaches.

7. The following data should be acquired:

    a. Who Are the Recipients of the Mental Health Program?
    b. What services constitute the Mental Health Program?
    c. What is spent on the total Mental Health Program, including Indian Health Service spending (Alaska Native Tribal Health Consortium)?
    d. Who are receiving services?
    e. What are the results for various populations? In other words, are there differences in results for different groups of people, such as Natives or other minorities?
    f. What are the SSDI/SSI Recipient Population Trends?
    g. What are the Indian Health Service Population Trends?
    h. What Are the Results Geographically?
    i. Which Programs are Achieving Desired Results and Vice Versa?
    j. Why is There Such a Difference in per capita Medicaid Billing?

B. Medicaid/SSDI/SSI Should Be Re-Tooled as Possible to Achieve Desired Results

The Medicaid/SSDI/SSI eligibility mechanism has come to dominate Program financing. Thus, to the extent possible within federal requirements, this mechanism should be reviewed and adjusted to achieve desired results. To the maximum extent possible:

1. Eligible services should be based on achieving desired results.

2. Eligible services should be flexible in order to allow services to be tailored to what individuals need to achieve desired results including, if possible, non-traditional approaches.

3. Disincentives to achieving desired results should be ferreted out and corrected, where possible.

C. The Planning Committee Should Review Whether the Current Reliance on Psychiatric Medications is leading to Desired Results.

The Mental Health System currently relies heavily on psychiatric medications. It is recommended that further research on how the use of these medications impact desired results should be conducted.

D. The Budget Building Process Should be Re-evaluated.

1. In developing budget recommendations, the entire Program budget and desired outcomes should be considered.

2. While stakeholder input should always be sought, it should be evaluated in the context of results based budgeting that considers the entire mental health budget.

3. The Trust should consider reviewing its RFR process to determine if it is producing optimal results. Specifically, in addition to taking the entire Program budget into consideration, the Trust might re-evaluate its policy of requiring an Exit Strategy to be eligible for Trust funding.

4. The Board should remember that its budgetary responsibilities are broader than the Trust's.

5. Existing and potential revenue sources should be more seriously pursued, such as:

   a. Federal Medicaid
   b. Federal Discretionary
   c. Community Mental Health Services Block Grants
   d. State
   e. Recipients
   f. Foundations
   g. Trust Lands - Find Oil and/or Gas on Trust Land.
   h. Partnering
   i. Federally Qualified Health Centers
   j. Others

IX. Conclusion

The Budget Committee's conclusions arising from the Summit are (1) more data needs to be developed and regularly evaluated to help steer program funding to achieve desired results based on data, (2) the precise desired results need to be determined, based on consumer and community values, and (3) the budget should be built around purchasing the desired results.

ALASKA MENTAL HEALTH BOARD

MEMORANDUM

To: Tom Brice, Chair, Legislation Committee Date: October 27, 2003

From: Jim Gottstein

Subject: Proposed Amendments to Alaska Administrative Code to implement the Community Support Services, Consumer Involvement in Grantee Agencies, and Grievance Redress Standards

Discussion

A couple of years ago the Board was successful in getting the Division of Mental Health and Developmental Disabilities to implement some consumer oriented standards in the following areas:

- Community Support Services,
- Consumer Involvement in Grantee Agencies, and
- Grievance Redress

These became part of all the FY '02/'03 grants to the community mental health centers. See, attachments 1, 2 & 3. In order to ensure that these standards would not just be dropped in some future grant cycle, at its June 16, 2002, meeting the Board adopted a motion requesting the Department to translate these into regulation. See, attachment 4. The Board even offered to produce an initial draft because Dr. Abel said that the Department wouldn't be getting to it.

On October 16, 2003, the Department issued notice of proposed changes to the Community Mental Health (and other) regulations that did not address any of these standards. When queried about this, Director Hogan indicated the intent was to make wording changes to reflect the reorganization into the Division of Behavioral Health. However, when reviewing the proposed amendments it is clear the Department took the opportunity to propose other regulation changes as well. It therefore seems this is an opportune time to move forward with adopting the grant standards as regulations. I have therefore drafted a set of amendments (attachment 5).[1] The Legislation Committee and then the full board can decide if it would like to forward these as part of its comments on the proposed regulations, which are due by December 1, 2003.

One thing to note is there has been some confusion over whether community mental health centers can satisfy the consumer representation criteria with non-disclosed consumers. I don’t' see how, but understand some centers claim this. With the one noted exception, I tried to just translate the standards into regulation form so I didn't address this concern. It is something that might be considered, however.

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[1] It should be noted that not everything in the standards seemed appropriate for inclusion in regulation. Also, in addition to attempting to incorporate the standards, I added that when prescribing medications, the doctor should include infomation about the short and long term prognosis with and without the medications to 7 AAC 71.130(b)(3). The draft is a classic example of "if I had more time I could have made it shorter" and can no doubt be improved. However, it seems sufficient unto the day to move forward with, of course, any modifications the committee and full board might deem desirable.

Standard: An agency receiving a grant to serve adults with a severe mental illness and that has been designated as the comprehensive community mental health center for the catchment area must submit a plan to serve those adults in the catchment area. At a minimum, the plan must include:

1. A description of the population, including the number of adults with severe mental illnesses in the catchment area and their general situation - e.g. number homeless, number living alone, number living with families, number employed, etc.
2. An analysis of the treatment status of the population, including the number in treatment with the center and with other providers in the catchment area.
3. A description of an outreach plan to locate un-served consumers and help them get treatment and other services.
4. A description of the specific outreach, case-finding, treatment and rehabilitation services to be provided.

An agency with a grant as a single service or limited service agency must submit a description of the specific services it will provide to the population, and how those services are coordinated with the community mental health center, including the provision of data to the center for catchment area analysis.

Discussion: A designated community mental health center has the responsibility for the population of adults with severe mental illnesses in the catchment area. The population should be monitored to determine the penetration of catchment area services into the population, with a target of at least 50% of all adults with severe mental illnesses in treatment at any point in time. The center is also responsible to have a general knowledge of the portion of the population served by other agencies in the area. A grant agency that is not a comprehensive center is responsible for the specialty services it provides, and to link those services, as needed, to the services provided by the center.

Standard: A grant agency providing treatment services to adults with a severe mental illness must provide immediate response, either directly or through affiliated resources, to situations in which an adult with a severe mental illness is likely to decompensate – the person has not appeared for a medication renewal, has lost his/her medications, has lost housing, etc. The agency must allow for consumer choice, to the extent practical, in the manner of response and the choice of responders.

Discussion: Due to the nature of severe mental illnesses, appointments are often missed, meds are lost, and crises occur. Agencies need to be flexible enough to accommodate these events, and can usually do so by rearranging schedules. Rapid response outreach services should also be employed as needed.

Standard: All clinical records of adults with a severe mental illness must have a relapse plan, as part of the treatment plan, and that plan must be followed with each relapse. Failure to have a relapse plan, or to follow it, will be a QA exception. The consumer must be involved in the development of the relapse plan, and consumer choice in the development of the plan must be considered.

Discussion: Adults with severe mental illness tend to relapse in highly predictable ways. The first signs might be withdrawal, stopping medications, quitting work, dropping out of treatment, etc. After a few predictable steps, the person is in crisis and in the hospital. Hospitalization can be prevented if the treating agency plans for these events, and mobilizes its resources when the first signs appear.

Standard: Adults with severe mental illnesses may not be excluded from treatment because they are do not agree with, or do not follow, one or more parts of their treatment plan. Adjustments must be made to accommodate the person in the areas of the treatment plan they do follow, until their situation becomes so unstable that inpatient care becomes necessary. Discharge of an adult with a severe mental illness, or failure to accept one for treatment, if the adult refuses to accept one or more parts of the treatment plan will be a QA exception.

Discussion: Adults with a severe mental illness often disagree with one or more parts of their proposed treatment plan, or do not follow the plan. Sometimes the issue is simply disagreement. At other times it may be due to confusion, or an attempt to deny the illness. If the treating agency refuses treatment unless the person is compliant with all parts of the treatment plan, that decision will guarantee that the person will fail in the community and have to be hospitalized. Agencies must work with the consumer to develop a treatment plan they agree with, and if that does not happen, help them with the areas in which they are compliant, and monitor the person's status so that crisis intervention can occur if it becomes necessary.

Standard: Adults with severe mental illnesses may not be excluded from treatment because they have a history of being dangerous to others. Adjustments must be made to accommodate the treatment of the person in ways that provide for the safety of the person, the staff, and other consumers. The treating agency may not refuse to accept, or discharge, a person with a history of dangerous behavior unless the agency can demonstrate an imminent risk that cannot be compensated for. If that risk is present, the agency must arrange for alternate placement. Discharge of an adult with a severe mental illness, or failure to accept one for treatment, if the adult has a history of dangerousness toward others will be a QA exception, unless the imminent risk is established and the agency has assumed responsibility for, and has arranged alternate placement.

Discussion: While relatively rare, adults with a severe mental illness may present with a history of violence, and may currently have some violence propensity. Such a person maintains a right to treatment that cannot be ignored by grant-funded agencies. The agency must plan to treat the person in ways that provide for the least risk, while meeting the treatment needs of the person. The person may be seen at a police station, or other setting that provides safety. The person may be excluded from group treatment activities, but seen individually. If the treating agency refuses treatment because the person presents with some violence risk, that decision will put the community at risk and guarantee that the person will fail in the community and have to be hospitalized, possibly after hurting someone. Agencies must work with the consumer and help them with the areas in which treatment can be safely delivered, and monitor the person's status so that crisis intervention can occur if it becomes necessary.

Standard: Centers must make an active effort to involve families of adults with severe mental illness in the treatment and support of the adult. The consumer should be encouraged to sign a release permitting communication with family (including unmarried significant others), and the clinical record should indicate that the discussion took place and what the consumer's decision was. The adult must be allowed to choose personal representatives from his/her natural support/family system that will be involved in the treatment process. The clinical record must also show active involvement of the family in the treatment process, unless the consumer chose to not have them involved, or the family member(s) declined the offer to be involved. Not attempting to involve the family, as above, will lead to a QA exception.

Discussion: Over half of all adults with a severe mental illness live with there families and/or receive the majority of their personal support from their families. At the same time, most families are not included in the treatment process. It is necessary to have families included in the treatment process to link treatment with the natural support system.

Standard: Adults with severe mental illness who live in Assisted Living Facilities must have the assisted living facility involved in the treatment and support of the adult to the extent permissible by law and practicality. There must be a release permitting communication with facility in each clinical record, or a statement that the adult refused after being actively encouraged to sign one. The treatment plan at the treating agency must include a description of the services to be provided at the assisted living facility and the expected outcomes. If the release is signed, the assisted living facility must be made a part of the treatment team, and a copy of the treatment plan must be located in the assisted living facility. The clinical record must also show active involvement of the facility in the treatment process, and communication between the treating agency and the facility, unless there is documentation the assisted living facility refused after being actively encouraged to be involved. Not attempting to involve the facility, as above, will lead to a QA exception.

Discussion: Many adults with a severe mental illness live in assisted living facilities, because they are unable to live independently. Most of their support comes from these facilities. At the same time, most of these facilities are not included in the treatment process. The lack of involvement and communication often leads to consumer problems that could have been prevented. It is necessary to have these facilities included in the treatment process to link treatment with this vital support system.

Standard: A grantee may not, as a matter of policy, exclude an adult with a severe mental illness from treatment because that adult has chosen that part of that treatment is to be provided by one or more other agencies. Grantee agencies must allow for this choice, and coordinate treatment planing with all involved providers. The collective treating agencies must develop a common treatment plan which is shared by all agencies, and be present in the clinical record(s) at the grantee agency(s). Not allowing this choice will lead to a QA exception.

Discussion: Adults with severe mental illnesses sometimes choose a physician or case manager that is not employed by the agency providing most of the rehabilitation services. These consumers must be allowed to choose providers of services, even if those decisions result in treatment being shared by more than one agency, with resultant communication and billing complications. This issue is a matter of consumer rights.

Standard: The treatment plan of an adult with a severe mental illness must include those individualized outreach services that are necessary to help maintain the adult in the community. The agency providing treatment to an adult with a severe mental illness must provide outreach services on an individualized basis to the extent necessary to meet the basic support needs of the adult. At a minimum, the outreach must occur under the following circumstances:

1. As an emergency measure to handle crises occurring with current consumers or others in the community that are eligible for CSP services but have not yet chosen to accept active treatment.
2. As a way to monitor high-need consumers, or consumers who are not following their treatment plan, whether current consumers, or those eligible who have not yet chosen to become consumers.
3. As a way to do rehab work with consumers in their natural environment.
4. As a tool for case-finding - locating eligible consumers who are in need of treatment and rehabilitation, but have not been referred, or have been reluctant to seek care.
5. As a way of providing training and support to families and other care givers

Discussion: Outreach is a vital part of services for this population, and must be within the repertoire of agency services. Needed outreach often makes the difference between staying in the community and hospitalization.

Standard: Adults with a severe mental illness must be provided with the opportunity to change therapists, case managers, or doctors if the adult cannot work effectively with the therapist, case manager, or doctor. It is recognized that a request to change workers can mean that the consumer has become frustrated with the treatment process, and the treating agency may request that the consumer try to work through the problems with the worker. However, a consumer has a basic right to change workers, even if that change is not necessarily in his or her best interest. To the extent practical due to staff availability, the agency must allow the requested change. The consumer request and the agency's response must be documented in the consumer's clinical record.

Discussion: This is a very controversial area. Consumers want the right to choose those with whom they trust their private lives. That choice may sometimes be made due to genuine inability to work together, sometimes due to frustration over temporary disagreements, and sometimes for other non-clinical reasons. Providers sometimes see the desire to change workers as "manipulation", "splitting", etc. The bottom line is that the consumer has a right to choose, even if the choice is not made with the best of perceived motivation.

Standard: Adults with severe mental illnesses who leave treatment for an extended period of time, and who return to treatment with the former treating agency, must be allowed, to the extent possible, to have access to the same therapist, case manager, doctor, etc. to ensure continuity of care. Efforts must be documented in the clinical record.

Discussion: If staff have left employment, there is obviously no way to provide the consumer choice. If the staff are still employed, but have full case loads, the agency could possibly re-arrange case loads to move the consumer in, or have the former worker meet with the consumer and new worker to "bridge". The continuity is important, and should always be considered.

Standard: Adults with severe mental illnesses who present with dual diagnoses, whether substance abuse or developmental disability must be given access to mental health services for their legitimate mental disorder. These consumers may not be excluded from treatment pending resolution of the co-occurring disorder, but must receive mental health treatment concurrent with any treatment for the other disorder. In addition, mental health treatment must be provided even if the consumer refuses treatment for the co-occurring disorder, unless the mental health provider can clearly document that the untreated co-occurring disorder has created a situation in which the mental health treatment cannot be delivered. That decision must be made on a case-by-case basis; the decision must be made clinically; and the decision cannot be made on the basis of a blanket exclusion policy.

Discussion: Fortunately, the exclusion of persons from treatment who have co-occurring disorders is becoming less frequent, but it does still happen. Consumers with co-occurring mental disorders and substance abuse disorders can still find themselves unable to access mental health care "until the substance abuse is under control" and simultaneously cannot access substance abuse treatment "until the mental illness has stabilized". This is not acceptable, and will not be permitted in grant-supported programs for adults with severe mental illnesses.

Standard: Adults with severe mental illnesses must be given flexible access to the treatment, rehabilitation, and support services offered at the treating agency. Consumer "level of functioning" may vary widely over the course of a few months, from very "high-functioning" to very much in need of intensive support, and back again. One way of assisting consumers in maintaining relative stability is to allow some self-selection of service elements they want to use. For example, a consumer who is "high-functioning" may want to drop-in periodically at clubhouses, day activities, etc., that are primarily intended for less stabile consumers. This type of contact assures the consumers that the services "are still there" and should be permitted, unless a specific service is very highly structured around a specific group of consumers, and the drop-in would be disruptive. That situation should be rare. Some of this contact may be in the treatment plan, and billed as it occurs. Other contact may be a courtesy service to the consumer, and as such not billed. This contact can help the consumer cope, and must be permitted. In addition, some types of support given high-need consumers, like transportation, use of agency facilities, etc. must also be reasonably available to all adult consumers with severe mental illness while more natural supports are being developed.

Discussion: Some agencies tend do provide an "all or nothing" approach to care - the consumer either gets a full array of services, or is designated "high-functioning" and is excluded from most elements of service, especially if there is an expectation that all contact must be billable and billed. This jump is too much for some consumers, and does not allow for flexible services and supportive contact to meet individual needs.

Standard: All agencies with grant funds to treat adults with severe mental illness must submit a plan indicating how they will handle any aggressive acing out on the part of consumers. The plan must show a distinction between acting out due to fear and confusion, and deliberate, intentional acting out, and indicate how each will be handled. The plan must include staff training in the appropriate handling of aggressive behavior, and indicate the circumstances under which the agency, or an agency staff person, will initiate police involvement. The plan must be approved by the division. Any time an agency, or an agency staff person, has a consumer arrested, a complete description of the incident and the stated reason for arrest must be included in the clinical record. That report may be part of a quality assurance review.

Discussion: There is an unfortunate tendency in some agencies to over-react to any threat of "violence" and quickly take the most drastic step and have the consumer arrested. Most of the time this action is not necessary, and may cause serious harm to the emotional state of the consumer. Common sense and an understanding of the consumer's emotional state and level of confusion should dictate the response. If a person is actively psychotic - currently displaying positive symptoms of psychosis such as delusions, hallucinations, confused thinking, emotional instability - and strikes out at someone they fear is trying to harm them, the response should be very different from that taken when a person who is currently showing none of those symptoms acts out aggressively. It should be very rare that an actively psychotic consumer would be arrested. Commitment might be appropriate in some of these siuations.

Consumer Involvement Standards

1. The grantee has a clear, written mission or philosophy that focuses on the services it provides and how it empowers consumers and their families and recognizes cultural and ethnic diversity.

2. Grantee education and orientation about mission, philosophy, and values promote understanding and commitment to consumer-centered services in daily operation.

3. Grantee governing body membership, or advisory board membership, must include primary and secondary consumers in sufficient numbers to ensure meaningful consumer and family input into the planning, design, implementation, management, and review of the agency's treatment and rehabilitation services. Governing body or advisory board membership must also reflect community ethnic and cultural diversity. If currently unable to meet these criteria, a grantee must provide DMHDD with a plan as to how it will reach compliance, such as adding consumers, family members, or representatives of underrepresented ethnic or cultural groups to the governing body or advisory board as openings occur.

4. The grantee actively solicits and carefully utilizes consumer and family input in grantee policy setting and program delivery. The grantee must be able to demonstrate regular and active solicitation of such input and its use in policy and program delivery decisions.

5. The grantee systematically and meaningfully involves consumers, staff and community in annual grantee planning and evaluation of programs, including feedback from its current and past users about their satisfaction with the planning and delivery of services. A preferred means of involvement is a committee or other group of consumers and family members utilizing a grantee's services. Unless impractical, those participating in a program should choose membership on the committee or group. Absent a compelling reason for denial, grantees should honor consumer policy and program choices.

6. The grantee develops annual plans, goals, and objectives in response to consumer, community, and self-evaluation activities.

7. All grantee publications, advertisements, brochures and articles reflect the grantee’s philosophy of a consumer-driven system, support the service principles, and foster a positive and respectful portrayal of people who experience disabilities.

8. All grantee events and trainings are open to consumers and family members, except those the grantee can justify as inappropriate. Adequate notification will be given to allow consumers and family members to participate.

9. The grantee shall, subject to its governance and charter, incorporate meaningful consumer participation into the interviewing, hiring, and evaluation of direct service providers.

10. The grantee shall endeavor to hire consumer practitioners.

Consumer Grievance Redress Standards

1. Each grantee must have a written consumer grievance redress policy. The grantee will clearly explain the policy to all consumers (and family members in the case of minors) upon entry to services. Each consum and family member will be given a simple language document (DMHDD approved) that outlines procedu rights, and responsibilities under the policy. A signed form confirming that the consumer and family rece this document and understands the policy will be part of the consumer's file and copies given to the consu and family. DMHDD approved notices outlining grievance redress policy, procedures, and resources wil prominently displayed in all grantee facilities.

2. Grantee consumer grievance policies and procedures should be developed with meaningful consumer and family participation and must be stated in plain language. The grievance process must be available to all grantee clients, without regard to services used or funding source, and to all consumers denied access to services.

3. Grantee consumer grievance procedures must, at a minimum, meet the following criteria:

- The grantee must treat all grievances as genuine and pursue resolution accordingly.
- The grantee will provide a simple form with which consumers and family members may file grievances. The form will include an optional waiver of confidentiality. The grantee shall accept grievances submitted in other formats, including grievances submitted orally in person or over the telephone.
- Consumers or family members may designate a representative (see advocate below) to assist them during grievance proceedings.
- The grantee must respond in writing within 5 days of receiving a grievance or moving a grievance to the next level. If unable to respond within 5 days, the grantee must explain why in writing.
- Grantees should develop, or have available, alternative dispute resolution techniques or resources.

4. Consumers and family members may have advocates present during all steps of a grievance. Upon request, grantees shall provide assistance to those who wish to file grievances. Grantees may identify staff to provide assistance, but consumers and family members may choose their own advocate (whether from grantee staff or elsewhere). Grantees must inform in writing those filing grievances or expressing interest in filing grievances that advocates such as the Disability Law Center, the Alaska Mental Health Consumer Web and NAMI-Alaska may be available to assist them in the grievance process.

5. Grantees will maintain separate grievance files, which contain all documents related to grievances and record all actions resulting from grievances. All grievances will be reported to the grantee governing body and consumer advisory body. These reports will maintain consumer confidentiality.

6. A grantee grievance process may not include more than three separate steps, which may include

- Direct dialogue with the staff member involved (with staff supervisor present if party filing the grievance desires) or that staff member's supervisor;
- Elevation to the executive director;
- Elevation to the Governing or Advisory Board.

Grievances unresolved to the consumers satisfaction within 30 days shall be reported to the DMHDD Regional Coordinator pursuant to AS 47.30.660(b)(12).

7. Grievances involving abuse or neglect of any description, or unnecessary seclusion or restraint will be investigated and reported immediately to the governing body and DMHDD.

8. The grievance procedure must include provisions to ensure the right of consumers to grieve without intimidation to prevent the filing of a grievance or retaliation if they do. Intimidation or retaliation will not be tolerated, and may result in sanctions by DMHDD, up to, and including, loss of grant funds.

ADD LC1003 - 6

ALASKA MENTAL HEALTH BOARD

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July 2, 2002

Jay Livey
Commissioner
Department of Health and Social Services
P.O. Box 110601
Juneau, Alaska 99811

Dear Commissioner Livey:

At its June 16, 2002 meeting, the Alaska Mental Health Board (AMHB) adopted a motion requesting that the Department of Health and Social Services translate into regulation several standards now established as community mental health grant conditions. The standards in question are:

- ✓ Emergency services;
- ✓ Community support services;
- ✓ Consumer involvement; and
- ✓ Grievance and redress procedures.

These standards are key criteria defining the scope and conditions of services that grantees must provide to eligible Alaskans. Given the critical nature of these standards, the AMHB believes that it is both appropriate and necessary that these be codified as regulation. This action will underscore the significance and authority of the standards.

The AMHB understands that the regulation drafting and adoption process entails a significant allocation of resources. The Board stands ready to shoulder part of this burden by producing an initial draft of the regulations.

We appreciate your giving this request serious consideration. Please let us know if you have any questions. The AMHB looks forward to working with you on this project.

Sincerely,

William H. Hogan

William H. Hogan
Chair

Cc: Walter Majoros, Director
Division of Mental Health and Developmental Disabilities

Proposed Amendments to Alaska Administrative Code to Implement the Community Support Services, Consumer Involvement in Grantee Agencies, and Grievance Redress Standards

Additions are bolded and underlined

[DELETIONS ARE IN CAPS AND WITHIN BRACKETS]

7 AAC 71.030(a) is amended to read:

07 AAC 71.030. Governing Boards and Advisory Boards

(a) A community mental health center receiving financial assistance under AS 47.30.520 - 47.30.620 must be governed by a board selected in accordance with the following criteria, except as provided for in (b) of this section:

(1) A governing board must be composed of at least five members who reside in the area served by the mental health center.

(2) A majority of the board members may not be providers of direct health care services or have been providers of direct health care services for the 12 months before appointment. No more than two members or 40 percent of the membership, whichever is greater, may be providers of direct health care services.

(3) As much as practicable, a governing board must be representative of the geographic planning area, including representatives of the

(A) major racial and linguistic groups; and

(B) various economic groups.

(4) Governing body membership must include existing and former clients and family members of clients of mental health services for serious mental illness from the center or some other mental health provider in sufficient numbers to ensure meaningful input into the planning, design, implementation, management, and review of the center's treatment and rehabilitation services. A governing body whose membership equals 51% or more of existing and former clients and family members of clients of mental health services for serious mental illness satisfies this requirement.

[(4)] (5) A representative of a particular subgroup or class of members need not be an actual member of the subgroup or class if the representative is designated by an organization composed primarily of members of the subgroup or class.

Attachment 5

[(5)] (6) No employee of a grantee may be a member of the grantee's governing board.

7 AAC 71.105 is amended by adding a new subsection to read:

07 AAC 71.105. Policy and Procedures Manual

(d) The center's policies and procedures manual must include:

(1) a clear, written mission or philosophy statement that focuses on the services it provides and how it empowers clients and their families and recognizes cultural and ethnic diversity;

(2) that all of its publications, advertisements, brochures and articles reflect the center's philosophy of a client-driven system support the service principles, and foster a positive and respectful portrayal of people who experience disabilities; and

(3) that all of its events and trainings be open to clients and family members, except those that are inappropriate and that adequate notification be given to allow clients and family members to participate.

7 AAC 71.130 is amended to read:

07 AAC 71.130. Plan of Services

(a) A center must have a written plan of services which

(1) [THE CENTER STAFF REVIEWS] it reviews annually and revises as necessary to reflect clients' and family members' input and changing community needs;

(2) includes the center's annual goals, the steps and resources necessary to implement the goals;

(3) includes a review of compliance with or reasons for exceptions to relevant regional and state planning documents; [AND]

(4) includes a five-year plan for development and delivery of mental health services to the service area[.];

(5) provides, to the maximum extent possible, for the hiring of mental health consumers, survivors and ex-patients as practitioners and other staff;

(6) must, subject to its governance requirements, incorporate meaningful and direct client participation into the interviewing, hiring, and evaluation of direct service providers: and

(7) provides on-going education and orientation about its mission, philosophy, and values to promote understanding and commitment to client-centered services in daily operation.

(b) The plan review and revision process must systematically and meaningfully involves clients and their family members, including feedback from its current and past clients about their satisfaction with the planning and delivery of services. A center satisfies this requirement of meaningful involvement if it takes the form of a committee or other group of current and past clients and their family members chosen by a mechanism in which all existing clients are entitled to participate as voting members, and the committee or group's policy and program choices are incorporated into the plan.

(c) The center's plan must also be the result of active solicitation and careful utilization of client and family input gathered throughout the year.

7 AAC 71.210 is amended to read:

07 AAC 71.210. [BILL OF] Client Rights

(a) Clients have, without limiting any other rights, the rights set forth in this section. A center must prepare a "bill of client's rights," including all rights in this section, which must be prominently posted in places of treatment.

(b) Clients' rights include, and [T]the "bill of client's rights" must [CONTAIN THE FOLLOWING INFORMATION] state, that:

(1) a client is entitled to participate in formulating, evaluating, and periodically reviewing his or her individualized written treatment plan, including requesting specific forms of therapy, being informed why requested forms of therapy are not made available, refusing specific forms of therapy that are offered, and being informed of treatment prognosis;

(2) a client has the right to review with or without a staff member as the client may desire, at a reasonable time, the client's treatment record; however, information confidential to other individuals may not be reviewed by the client;

(3) a client must be informed by the prescribing physician of the name, purpose, short and long term prognosis with and without, and possible side effects of medication prescribed as part of the client's treatment plan at the center;

(4) a client may request a copy of the treatment summary which should include follow-up plans;

(5) a client has a right to confidential treatment of all information pertaining to the client and the right of prior written approval for the release of identifiable information[.];

(6) a client with severe mental illnesses may not be excluded from treatment because the client does not agree with, or does not follow, one or more parts of the client's treatment plan;

(7) a client has the right to have adjustments made to accommodate the client if the client does not agree with, or does not follow, one or more parts of the client's treatment plan in the areas of the treatment plan the client does follow;

(8) a client with a severe mental illness may not be discharged from a center's program for failure to accept a treatment plan;

(9) a center may not refuse to accept a client with a severe mental illness for treatment, if the client refuses to accept one or more parts of the treatment plan proposed by the center;

(10) a person with severe mental illnesses may not be excluded from treatment because the client has a history of being dangerous to others and the person the right to have adjustments made to accommodate the treatment of the person in ways that provide for the safety of the person, staff, and other clients;

(11) a center may not refuse to accept, or discharge, a person with a history of dangerous behavior unless the center can demonstrate an imminent risk that cannot be compensated for and, if that risk is present, the agency must arrange for alternate placement;

(12) a client with severe mental illness has the right to have a center make an active effort to involve the client's family in the treatment and support of the client;

(13) a client has the right to choose personal representatives who will be involved in the treatment process, including development of the client's treatment plan, including from the client's natural support/family system;

(14) a client with severe mental illness who lives in an assisted living facility has the right to have the assisted living facility involved in the treatment and support of the client to the extent permissible by law and practicality, including having the assisted living facility participate in the client's treatment planning and services to be provided at the assisted living facility being part of the treatment plan;

(15) if a client signs a request for an assisted living facility to participate in the client's treatment planning, the assisted living facility must be made a part of the treatment team, and a copy of the treatment plan must be located at the assisted living facility;

(16) a center may not exclude an adult with a severe mental illness from treatment at the center because that adult has chosen part of the treatment be provided by one or more other agencies;

(17) to the maximum extent possible, a client with a severe mental illness has the right to change therapists, case managers, doctors or other similar staff;

(18) a client with severe mental illness who leaves treatment for a period of time, which includes an extended period of time, and who returns to treatment with the same center has the right, to the maximum extent possible and consistent with the client's desires, to have access to the same therapist, case manager, doctor, etc., and if not possible, approve replacements;

(19) a client with severe mental illness who presents to a center for services with a co-occurring substance abuse or developmental disability disorder has the right to access mental health services for the mental disorder, including if the client refuses treatment for the co-occurring disorder, unless the untreated co-occurring disorder has created a situation in which the mental health treatment cannot be delivered; and

(20) a client with severe mental illness has the right to flexible access to the treatment, rehabilitation, and support services offered at the center based on the client's desires, including (a) socializing opportunities, (b) use of center facilities, and (c) transportation services available to other clients, regardless of the client's current "level of functioning," and regardless of whether the services are billable.

7 AAC 71.220 is amended to read:

07 AAC 71.220. Grievance Procedures.

[A CENTER MUST ESTABLISH A GRIEVANCE PROCEDURE BY WHICH A CLIENT MAY SEEK REDRESS OF GRIEVANCES. A COPY OF THE GRIEVANCE PROCEDURE MUST BE FILED WITH THE DEPARTMENT AND POSTED AT THE CENTER.]

(a) A center must have a written client grievance redress policy. The center must clearly explain the policy to all clients upon entry to services. Each client and family member must be given a simple language document approved by the department that outlines procedures, rights, and responsibilities under the policy.

A signed form confirming that the client and family received this document and understands the policy must be part of the client’s file and copies given to the client and family. The department approved notices outlining grievance redress policy, procedures, and resources must be prominently displayed in all center facilities.

(b) A center's client grievance policies and procedures must be developed with meaningful client and family participation and must be stated in plain language. The grievance process must be available to all center clients, without regard to services used or funding source, and to all persons denied access to services.

(c) A center's client grievance procedures must, at a minimum, meet the following criteria:

(1) The center must treat all grievances as genuine and pursue resolution accordingly.

(2) The center must provide a simple form with which clients and family members may file grievances. The form must include an optional waiver of confidentiality. The center must accept grievances submitted in other formats, including grievances submitted orally in person or over the telephone.

(3) A client may designate an advocate to assist the client during grievance proceedings.

(4) A center must to respond in writing within 5 days of receiving a grievance or moving a grievance to the next level. If unable to respond within 5 days, the center must to explain why in writing.

(5) A center must develop, or have available, alternative dispute resolution techniques or resources.

(d) A client may have advocates present during all steps of a grievance. Upon request, centers must provide assistance to those who wish to file grievances. A center may identify staff to provide assistance, and a client may choose an advocate or advocates , whether from center staff or elsewhere. The department must maintain a list of agencies and persons who are potentially available as advocates. A center must inform in writing those filing grievances or expressing interest in filing grievances of the existence of this list of potential advocates and provide information on where to obtain the list from the department.

(e) A centers must maintain separate grievance files which contain all documents related to grievances, and record all actions resulting from grievances. All grievances must be reported to the center governing body and client advisory body. These reports must maintain client confidentiality unless specifically waived in writing by the client.

(f) A center grievance process may not include more than three separate steps, which may include

(1) Direct dialogue with the staff member involved with the client having the option of having the staff member's supervisor present.

(2) Elevation to the executive director.

(3) Elevation to the Governing or Advisory Board.

(4) Grievances unresolved to the client's satisfaction within 30 days of filing must be reported to the department by the end of the business week in which the 30th day falls.

(g) Grievances involving abuse, neglect or intimidation of any description, or unnecessary seclusion or restraint must be investigated and reported immediately to the governing body and the department.

(h) The grievance procedure must include provisions to ensure the right of clients to grieve without intimidation. Intimidation or retaliation will not be tolerated. Any employee of a center intimidating or retaliating against a client or family member for filing a grievance or contemplating filing a grievance must be immediately terminated.

ALASKA MENTAL HEALTH BOARD

MEMORANDUM

To: Legislation Committee Date: October 9, 2003

From: Jim Gottstein

Subject: Voluntary Admissions to API from Other Communities

Background

During the January 2000 Program Evaluation and Review Committee (PERC) review of Alaska Psychiatric Institute (API), the committee heard from a rural provider that API did not allow voluntary admissions from outlying communities. PERC formally expressed its concerns about this in its AMHB 2000 API Review:

> Another issue emerging from the rural provider dialogue is the difficulty in winning admission of voluntary patients from outside Anchorage. Some of the components of this matter include liability for transport of patients and possible inconsistency on the part of the API admissions office. PERC is concerned that patients are denied the right to voluntary admission to API on the basis of residence.

(Page 27)

There was a series of written communications and meetings about this issue. AS 47.30.655 states that the "the purpose of the 1981 major revision of Alaska civil commitment statutes . . . is to more adequately protect the legal rights of persons suffering from mental illness," including "(1) that persons be given every reasonable opportunity to accept voluntary treatment before involvement with the judicial system." The Department believes a person does not have that right until after being transported to a mental health facility for evaluation and an involuntary commitment petition applied for. The Division says it is not opposed to the concept of allowing a person to come voluntarily, but is concerned about liability and safety issues, particularly if the person were to change his or her mind en route and rescind the agreement to present voluntarily.[1]

Our response was that a person who agrees to present voluntarily in lieu of being involuntarily transported to a mental health facility for evaluation should have to sign an enforceable agreement to that effect. The Department of Law has stated that no such binding commitment can constitutionally be given.[2] That position made no sense to me,[3] but nevertheless might have been true, so the Department

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[1] However, because it's position does not stand up under scrutiny one wonders if the Division just finds it easier to bring people in involuntarily.

[2] For example, that is precisely what happens at API under AS 47.30.685.

[3] It is hard for me to see how it is any different than waiving one's constitutional right to a jury trial by pleading guilty. See, eg U.S. v. Ruiz 122 S.Ct. 2450 U.S.(2002) ("This Court has found that the Constitution [permits] waiver of various constitutional rights."); and In re Roger S., 569 P.2d 1286, 1296 (Cal. 1977) ("A minor may, of course, waive any of these

of Law was asked to provide legal authority for its position. It has declined to do so. While the Department of Law's conclusion that a person can not sign an enforceable agreement to be admitted in lieu of being taken in involuntarily is dubious at best, it was felt that it might be easier to obtain a statute change that sidesteps the issue. Therefore the issue was referred to this Committee.

At the December, 2002 Mental Health Board Meeting, Dr. Leonard Abel indicated that he finally understood my position and was going to go back and see if it could be worked out. Therefore the issue was deferred to see if it could be resolved internally. However, Dr. Abel subsequently reported back that it could not so the issue is back before the Legislation Committee.

Importance of Issue

It is a matter of simple dignity, as well as much more therapeutic, to allow people the option of accepting voluntary treatment rather than having them hauled off to a mental institution without any notice or even an opportunity to accept such treatment voluntarily. This is an important issue for consumers.

Statutory Provisions

Relevant statutes are:

> AS 47.30.655. Purpose of Major Revision.
>
> The purpose of the 1981 major revision of Alaska civil commitment statutes (AS 47.30.660 and 47.30.670 - 47.30.915) is to more adequately protect the legal rights of persons suffering from mental illness. The legislature has attempted to balance the individual's constitutional right to physical liberty and the state's interest in protecting society from persons who are dangerous to others and protecting persons who are dangerous to themselves by providing due process safeguards at all stages of commitment proceedings. In addition, the following principles of modern mental health care have guided this revision:
>
> (1) <u>that persons be given every reasonable opportunity to accept voluntary treatment before involvement with the judicial system</u>;

(emphasis added)

> AS 47.30.700. Initiation of Involuntary Commitment Procedures [Ex Parte].
>
> (a) Upon petition of any adult, a judge shall immediately conduct a screening investigation or direct a local mental health professional employed by the department or by a local mental health program that receives money from the department under AS 47.30.520 - 47.30.620 or another mental health professional designated by the judge, to

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rights and acquiesce in the parent's decision to place him in a state hospital for treatment, thus achieving what is in practical effect a "voluntary" admission.")

conduct a screening investigation of the person alleged to be mentally ill and, as a result of that condition, alleged to be gravely disabled or to present a likelihood of serious harm to self or others. Within 48 hours after the completion of the screening investigation, a judge may issue an ex parte order orally or in writing, stating that there is probable cause to believe the respondent is mentally ill and that condition causes the respondent to be gravely disabled or to present a likelihood of serious harm to self or others. The court shall provide findings on which the conclusion is based, appoint an attorney to represent the respondent, and may direct that a peace officer take the respondent into custody and deliver the respondent to the nearest appropriate facility for emergency examination or treatment. The ex parte order shall be provided to the respondent and made a part of the respondent's clinical record. The court shall confirm an oral order in writing within 24 hours after it is issued.

(b) The petition required in (a) of this section must allege that the respondent is reasonably believed to present a likelihood of serious harm to self or others or is gravely disabled as a result of mental illness and must specify the factual information on which that belief is based including the names and addresses of all persons known to the petitioner who have knowledge of those facts through personal observation.

AS 47.30.705. Emergency Detention For Evaluation [POA].

A peace officer, a psychiatrist or physician who is licensed to practice in this state or employed by the federal government, or a clinical psychologist licensed by the state Board of Psychologist and Psychological Associate Examiners who has probable cause to believe that a person is gravely disabled or is suffering from mental illness and is likely to cause serious harm to self or others of such immediate nature that considerations of safety do not allow initiation of involuntary commitment procedures set out in AS 47.30.700 , may cause the person to be taken into custody and delivered to the nearest evaluation facility. A person taken into custody for emergency evaluation may not be placed in a jail or other correctional facility except for protective custody purposes and only while awaiting transportation to a treatment facility. The peace officer or mental health professional shall complete an application for examination of the person in custody and be interviewed by a mental health professional at the facility.

Sec. 47.30.730. Procedure for 30-day commitment; petition for commitment.

(a) In the course of the 72-hour evaluation period, a petition for commitment to a treatment facility may be filed in court. The petition must be signed by two mental health professionals who have examined the respondent, one of whom is a physician. The petition must

* * *

(5) <u>allege that the respondent has been advised of the need for, but has not accepted, voluntary treatment</u>, and request that the court commit the respondent to the specified treatment facility or less restrictive alternative for a period not to exceed 30 days;

(emphasis added)

Basically, while AS 47.30.655(1) states that a major purpose of the statute is to allow people "be given every reasonable opportunity to accept voluntary treatment before involvement with the judicial system," in practice and the way it is interpreted, this only arises after people have been taken into custody, either through (1) a "POA" (Peace Officer Application) under AS 47.30.705, which allows police as well as specified mental health workers to have people pulled in for evaluation without a court order and (2) through an Ex Parte Order under AS 47.30.700 in which the court orders the person to be picked up and brought in without the person even knowing it is going on.[4]

Some Ideas

You suggested that Legislative Counsel might disagree with the Attorney General's Office that an enforceable agreement to come in voluntarily is not possible. This is one avenue to pursue although I'm not sure where that leads. The other is to make a couple of statutory amendments:

> AS 47.30.700. Initiation of Involuntary Commitment Procedures [Ex Parte].
>
> (a) Upon petition of any adult, a judge shall immediately conduct a screening investigation or direct a local mental health professional employed by the department or by a local mental health program that receives money from the department under AS 47.30.520 - 47.30.620 or another mental health professional designated by the judge, to conduct a screening investigation of the person alleged to be mentally ill and, as a result of that condition, alleged to be gravely disabled or to present a likelihood of serious harm to self or others. Within 48 hours after the completion of the screening investigation, if the screening investigation, which must include a genuine attempt to interview the person being screened, determines that the person is mentally ill and presents a likelihood of imminent serious harm to self or others,[5] and if the person has been advised of the need for, but has not accepted, voluntary treatment under AS 47.30.670,[6] a judge may issue an ex parte order orally or in writing, stating that there is probable cause to believe the respondent is mentally ill and that condition causes the respondent to be gravely disabled or to present a likelihood of serious harm to self or others. The court shall provide findings on which the conclusion is based, appoint an attorney to represent the respondent, and may direct that a peace officer take the respondent into custody and

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[4] It is also worth noting that while the POA statute requires that "considerations of safety do not allow initiation of involuntary commitment," which does provide for the person to be given the voluntary admission option, the practice seems to be to ignore this requirement through an assumption that the required exigency always exists.

[5] "Gravely disabled" is omitted here just because unless it means a serious danger to self it isn't constitutional under Doe v. Gallinot, 486 F. Supp. 983 (C.D. California 1979). See, also, Stamus v. Leonhardt, 494 F. Supp. 439, 451 ((S.D. Iowa 1976), citing Doremus v. Farrell, 407 F.Supp. 509 (D. Neb. 1975). In other words, I can't bring myself to put in something that I believe is unconstitutional. However, to make it consistent with the rest of the statute, "gravely disabled or" would be inserted here.

[6] AS 47.30.685 (set forth above), which gives the hospital 48 hours to seek a court order if the person wants to sign out is intended to automatically apply through this addition, but it might be made explicit.

> deliver the respondent to the nearest appropriate facility for emergency examination or treatment. The ex parte order shall be provided to the respondent and made a part of the respondent's clinical record. The court shall confirm an oral order in writing within 24 hours after it is issued.
>
> AS 47.30.705. Emergency Detention For Evaluation [POA].
>
> A peace officer, a psychiatrist or physician who is licensed to practice in this state or employed by the federal government, or a clinical psychologist licensed by the state Board of Psychologist and Psychological Associate Examiners who has probable cause to believe that a person is gravely disabled or is suffering from mental illness and is likely to cause serious harm to self or others of such immediate nature that considerations of safety do not allow initiation of involuntary commitment procedures set out in AS 47.30.700, and the person has been advised of the need for, but has not accepted, voluntary treatment under AS 47.30.670, may cause the person to be taken into custody and delivered to the nearest evaluation facility. A person taken into custody for emergency evaluation may not be placed in a jail or other correctional facility except for protective custody purposes and only while awaiting transportation to a treatment facility. The peace officer or mental health professional shall complete an application for examination of the person in custody and be interviewed by a mental health professional at the facility.

There are no doubt many ways to accomplish what the board wants and the proposed amendments are just suggestions as to an approach. The main point is that unless the Department changes its position that people don't have the right to come in voluntarily from outside Anchorage, appropriate legislation changes should be sought. The state may also be vulnerable to a lawsuit the way it is doing it now, particularly with the Attorney General's Office taking a position without being able to cite to anything that supports its position..

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The case against antipsychotic drugs: a 50-year record of doing more harm than good☆

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Summary Although the standard of care in developed countries is to maintain schizophrenia patients on neuroleptics, this practice is not supported by the 50-year research record for the drugs. A critical review reveals that this paradigm of care worsens long-term outcomes, at least in the aggregate, and that 40% or more of all schizophrenia patients would fare better if they were not so medicated. Evidence-based care would require the selective use of antipsychotics, based on two principles: (a) no immediate neuroleptisation of first-episode patients; (b) every patient stabilized on neuroleptics should be given an opportunity to gradually withdraw from them. This model would dramatically increase recovery rates and decrease the percentage of patients who become chronically ill.

Introduction

The standard of care for schizophrenia calls for patients to be maintained indefinitely on antipsychotic drugs. The evidence for this practice comes from research showing the drugs are effective in treating acute psychotic symptoms and in preventing relapse [1,2]. Historians also argue that the introduction of neuroleptics in the 1950s made it possible to empty the mental hospitals, and that this is further proof of the drugs' merits [3]. Yet, long-term outcomes with schizophrenia remain poor, and may be no better than they were 100 years ago, when water therapies and fresh air were the treatment of the day [4–7].

There is an evident paradox in the research record. The efficacy of neuroleptics appears to be well established, yet there is a lack of evidence showing that these drugs have improved patients' lives over the long-term. That paradox recently stirred an unusual editorial in *Eur. Psychiatry*, which posed this question: "After fifty years of neuroleptic drugs, are we able to answer the following simple question: Are neuroleptics effective in treating schizophrenia?" [8] A close review of the research literature provides a surprising answer. The preponderance of evidence shows that the current standard of care – continual medication therapy for all patients so diagnosed – does more harm than good.

Did neuroleptics enable deinstutionalization?

The belief that the introduction of chlorpromazine, marketed in the US as Thorazine, made it possible to empty state hospitals stems from research by Brill and Patton. In the early 1960s, they reported that the patient census at state mental hospitals in the US declined from 558,600 in 1955 to 528,800 in 1961. Although they did not compare discharge rates for drug-treated versus placebo-treated patients, they nevertheless concluded that neuroleptics must have played a role in the decline since it coincided with their introduction. The fact that the two occurred at the same time was seen as the proof [9,10].

☆ Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill (Perseus Publishing, 2002).

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However, there were obvious confounding factors. In the early 1950s, the Council of State Governments in the US urged the federal government to share the fiscal burden of caring for the mentally ill, and proposed that "out-patient clinics should be extended and other community resources developed to care for persons in need of help, but not of hospitalization" [11,12]. As part of this agenda, states began developing community care initiatives, funneling the mentally ill into nursing homes and halfway houses. This change in social policy could easily have been responsible for the slight drop in patient numbers observed by Brill and Patton.

Moreover, there was one state that did compare discharge rates for schizophrenia patients treated with and without drugs, and its results do not support the historical claim made for neuroleptics. In a study of 1413 first-episode male schizophrenics admitted to California hospitals in 1956 and 1957, researchers found that "drug-treated patients tend to have longer periods of hospitalization... furthermore, the hospitals wherein a higher percentage of first-admission schizophrenic patients are treated with these drugs tend to have somewhat higher retention rates for this group as a whole". In short, the California investigators determined that neuroleptics, rather than speed patients' return to the community, apparently *hindered* recovery [13].

The true period of deinstitutionalization in the US was from 1963 to the late 1970s, the exodus of patients driven by social and fiscal policies. In 1963, federal government began picking up some of the costs of care for the mentally ill not in state institutions, and two years later, Medicare and Medicaid legislation increased federal funding for care of mental patients provided they were not housed in state hospitals. Naturally, states responded by discharging their hospital patients to private nursing homes and shelters. In 1972, an amendment to the Social Security act authorized disability payments to the mentally ill, which accelerated the transfer of hospitalized patients into private facilities. As a result of these changes in *fiscal* policies, the number of patients in state mental hospitals dropped from 504,600 to 153,544 over a 15-year period (1963—1978) [14].

Establishing efficacy: the pivotal NIMH trial

The study that is still cited today as proving the efficacy of neuroleptics for curbing acute episodes of schizophrenia was a nine-hospital trial of 344 patients conducted by the National Institute of Mental Health in the early 1960s. At the end of six weeks, 75% of the drug-treated patients were "much improved" or "very much improved" compared to 23% of the placebo patients. The researchers concluded that neuroleptics should no longer be considered mere "tranquilizers" but "antischizophrenic" agents. A magic bullet had apparently been found for this devastating disorder [1].

However, three years later, the NIMH researchers reported on one-year outcomes for the patients. Much to their surprise, they found that "patients who received placebo treatment were less likely to be rehospitalized than those who received any of the three active phenothiazines" [15]. This result raised an unsettling possibility: While the drugs were effective over the short-term, perhaps they made people more biologically vulnerable to psychosis over the long run, and thus the higher rehospitalization rates at the end of one year.

The NIMH withdrawal studies

In the wake of that disturbing report, the NIMH conducted two medication-withdrawal studies. In each one, relapse rates *rose* in correlation with neuroleptic dosage before withdrawal. In the two trials, only 7% of patients who were on placebo relapsed during the following six months. Twenty-three percent of the patients on less than 300 mg of chlorpromazine daily relapsed following drug withdrawal; this rate climbed to 54% for those receiving 300—500 mg and to 65% for patients taking more than 500 mg. The researchers concluded: "Relapse was found to be significantly related to the dose of the tranquilizing medication the patient was receiving before he was put on placebo — the higher the dose, the greater the probability of relapse" [16].

Once more, the results suggested that neuroleptics increased the patients' biological vulnerability to psychosis. Other reports soon deepened this suspicion. Even when patients reliably took their medications, relapse was common, and researchers reported in 1976 that it appeared that "relapse during drug administration is greater in severity than when no drugs are given" [17]. A retrospective study by Bockoven also indicated that the drugs were making patients chronically ill. He reported that 45% of patients treated at Boston Psychopathic Hospital in 1947 with a progressive model of care did not relapse in the five years following discharge, and that 76% were successfully living in the community at the end of that follow-up period. In contrast, only 31% of patients treated in 1967 with neuroleptics at a community health center remained relapse-free over the next five years, and as a group they were much more "socially dependent" — on welfare and needing other forms of support — than those in the 1947 cohort [18].

Drug treatment versus experimental forms of care

With debate over the merits of neuroleptics rising, the NIMH revisited the question of whether newly admitted schizophrenia patients could be successfully treated without drugs. There were three NIMH-funded studies conducted during the 1970s that examined this possibility, and in each instance, the newly admitted patients treated without drugs did better than those treated in a conventional manner.[1]

In 1977, Carpenter reported that only 35% of the nonmedicated patients in his study relapsed within a year after discharge, compared to 45% of those treated with neuroleptics. The non-medicated patients also suffered less from depression, blunted emotions, and retarded movements [20]. A year later, Rappaport et al. [21] reported that in a trial of 80 young male schizophrenics admitted to a state hospital, only 27% of patients treated without neuroleptics relapsed in the three years following discharge, compared to 62% of the medicated group. The final study came from Mosher, head of schizophrenia research at the NIMH. In 1979, he reported that patients who were treated without neuroleptics in an experimental home staffed by nonprofessionals had lower relapse rates over a two-year period than a control group treated with drugs in a hospital. As in the other studies, Mosher reported that the patients treated without drugs were the better functioning group as well [22,23].

The three studies all pointed to the same conclusion: Exposure to neuroleptics increased the long-term incidence of relapse. Carpenter's group defined the conundrum

> There is no question that, once patients are placed on medication, they are less vulnerable to relapse if maintained on neuroleptics. But what if these patients had never been treated with drugs to begin with?... We raise the possibility that antipsychotic medication may make some schizophrenic patients more vulnerable to future relapse than would be the case in the natural course of the illness [20].

In the late 1970s, two physicians at McGill University in Montreal, Guy Chouinard and Barry Jones, offered a biological explanation for why this was so. The brain responds to neuroleptics — which block 70—90% of all D_2 dopamine receptors in the brain — as though they are a pathological insult. To compensate, dopaminergic brain cells increase the density of their D_2 receptors by 30% or more. The brain is now "supersensitive" to dopamine, and this neurotransmitter is thought to be a mediator of psychosis. The person has become more biologically vulnerable to psychosis and is at particularly high risk of severe relapse should he or she abruptly quit taking the drugs. The two Canadian researchers concluded:

> Neuroleptics can produce a dopamine supersensitivity that leads to both dyskinetic and psychotic symptoms. An implication is that the tendency toward psychotic relapse in a patient who has developed such a supersensitivity is determined by more than just the normal course of the illness... the need for continued neuroleptic treatment may itself be drug induced [24,25].

Together, the various studies painted a compelling picture of how neuroleptics shifted outcomes away from recovery. Bockoven's retrospective and the other experiments all suggested that with minimal or no exposure to neuroleptics, at least 40% of people who suffered a psychotic break and were diagnosed with schizophrenia would not relapse after leaving the hospital, and perhaps as many as 65% would function fairly well over the long-term. However, once first-episode patients were treated with neuroleptics, a different fate awaited them. Their brains would undergo drug-induced changes that would increase their biological vulnerability to psychosis, and this would increase the likelihood that they would become chronically ill.

The world health organization studies

In 1969, the World Health Organization initiated a study to compare outcomes for schizophrenia in "developed" countries with outcomes in "undevdeveloped" countries. Once again, the results were surprising. Patients in the three poor countries —

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[1] In the early 1960s, May conducted a study that compared five forms of treatment: drug, ECT, psychotherapy, psychotherapy plus drug, and mileu therapy. Over the short-term, the drug-treated patients did best. As a result, it came to be cited as proof that schizophrenia patients could not be treated with psychotherapy. However, the long-term results told a more nuanced story. Fifty-nine percent of patients initially treated with mileu therapy but no drugs were successfully discharged in the initial study period, and this group "functioned over the follow-up (period) at least as well, if not better, than the successes from the other treatments". Thus, the May study suggested that a majority of first-episode patients would fare best over the long-term if initially treated with "mileu therapy" rather than drugs [19].

India, Nigeria and Colombia — were doing dramatically better at two-year and five-year follow-ups than patients in the US and four other developed countries. They were more likely to be fully recovered and faring well in society — "an exceptionally good social outcome characterized these patients", the WHO researchers wrote — and only a small minority had become chronically sick. At five years, about 64% of the patients in the poor countries were asymptomatic and functioning well. In contrast only 18% of patients in the rich countries were in this best-outcomes category. The difference in outcomes was such that the WHO researchers concluded living in a developed nation was a "strong predictor" that a schizophrenic patient would never fully recover [26].

These findings naturally stung psychiatrists in the US and other rich countries. Faced with such dismal results, many argued the WHO study was flawed and that a number of the patients in the poor countries must not have been schizophrenic but ill with a milder form of psychosis. With that criticism in mind, the WHO conducted a study that compared two-year outcomes in 10 countries, and it focused on first-episode schizophrenics all diagnosed by Western criteria. The results were the same. "The findings of a better outcome of patients in developing countries was confirmed", the WHO investigators wrote. In the poor countries, 63% of schizophrenics had good outcomes. Only slightly more than one-third became chronically ill. In the rich countries, the ratio of good-to-bad outcomes was almost precisely the reverse. Only 37% had good outcomes, and the remaining patients did not fare so well [27].

The WHO investigators did not identify a cause for the stark disparity in outcomes. However, they did note there was a difference in the medical care that was provided. Doctors in the poor countries generally did not keep their patients on neuroleptics, while doctors in the rich countries did. In the poor countries, only 16% of the patients were maintained on neuroleptics. In the developed countries, 61% of the patients were kept on such drugs.

Once again, the research record told the same story. In the WHO studies, there was a correlation between use of the medications on a continual basis and poor long-term outcomes.

MRI studies

While most researchers have used MRIs to investigate possible causes of schizophrenia, a small number have employed this technology to study the effects of neuroleptics on the brain. These investigators have found that the drugs cause atrophy of the cerebral cortex and an enlargement of the basal ganglia [28—30]. Moreover, researchers at the University of Pennsylvania reported in 1998 that the drug-induced enlargement of the basal ganglia is "associated with greater severity of both negative and positive symptoms" [31]. In other words, they found that the drugs cause changes in the brain associated with a *worsening* of the very symptoms the drugs are supposed to alleviate.

Relapse studies

As discussed earlier, evidence for the efficacy of neuroleptics is stated to be two-fold. First, the NIMH trial in the 1960s found that neuroleptics are more effective than placebo in curbing acute episodes of psychosis. Second, the drugs have been shown to prevent relapse. In 1995, Gilbert reviewed 66 relapse studies, involving 4365 patients, and summed up the collective evidence: Fifty-three percent of patients withdrawn from neuroleptics relapsed within 10 months, versus 16% of those maintained on the drugs. "The efficacy of these medications in reducing the risk of psychotic relapse has been well documented," she wrote [2].

At first glance, this conclusion seems to contradict the research showing that the drugs made patients chronically ill. There is an answer to this puzzle however, and it is a revealing one. The studies by Rappaport, Mosher and Carpenter involved patients who, at the start of the experiment, were not on neuroleptics but were then treated either with placebo or a neuroleptic. And in those studies, relapse rates were lower for the placebo group. In contrast, the 66 studies reviewed by Gilbert were *drug-withdrawal* studies. In the studies she analyzed, patients who had been stabilized on neuroleptics were divided into two cohorts: One would keep on taking the drugs and the other would not, and the studies reliably found that people withdrawn from their neuroleptics were more likely to become sick again.

Thus, the literature suggests that relapse rates fall into three groups: lowest for those not placed on neuroleptics in the first place, higher for those who take the drugs continuously, and highest of all for those withdrawn from the drugs. Yet even that picture is misleading.

First, for the most part, the drug-withdrawal studies were conducted in a select group of "good responders" to neuroleptics, rather than in the general patient population. In the real world, up to 30% of hospitalized patients do not respond to neuroleptics. Among those who do and are discharged, more than one-third relapse within the next 12 months and need to be rehospitalized, even though they reliably take their medications. Thus, fewer than 50% of people who suffer a schizophrenic break respond to standard neuroleptics and remain relapse-free for as long as a year, but the relapse studies, to a large degree, were conducted in this group of good responders. In 1998, Hogarty pointed out how this study design led to a mistaken understanding of true relapse rates with antipsychotics: "A reappraisal of the literature suggests a one-year, post-hospital, relapse rate of 40% on medication, and a substantially higher rate among patients who live in stressful environments, rather than earlier estimates of 16%" [32].

At the same time, the relapse studies were designed in ways that exaggerated the risk of relapse in the drug-withdrawn groups. In response to Gilbert, Baldessarini reanalyzed the same 66 studies, only he divided the drug-withdrawn cohort into "abrupt-withdrawal" and "gradual-withdrawal" groups. He determined that the relapse rate in the abruptly withdrawn group was *three times higher* than in the gradual group [33]. In other words, it was the abrupt cessation that caused much of the excess relapse risk. Indeed, in a further review of the relapse literature, Baldessarini found that only one-third of schizophrenia patients gradually withdrawn from their drugs relapsed within six months and that those who reached this six-month point without become sick again had a good chance of remaining well indefinitely. "The later risk of relapsing was remarkably limited," he concluded [34].

The relapse studies are cited to support a paradigm of care that emphasizes continual drug therapy for schizophrenia patients. But upon closer examination, a new picture emerges. The real-world first-year relapse rate for patients maintained on neuroleptics is understood to be 40%, while the rate for patients gradually withdrawn from the drugs is 33%. Thus, once bad trial design is eliminated, the evidence for continual medication disappears. At the same time, evidence appears showing that a majority of patients — two-thirds in the gradual withdrawal studies — can do fairly well without the drugs.

Doing more harm than good

Although this review of neuroleptics may seem surprising, the research record actually is quite consistent. The pivotal NIMH study in the early 1960s found that the drugs had a short-term benefit, but that over the long-term the drug-treated patients had higher relapse rates. Similarly, in his retrospective study, Bockoven found that patients treated with neuroleptics were more likely to become chronically ill. The experiments by Carpenter, Mosher, and Rappaport all showed higher relapse rates for drug-treated patients, and in 1979, Canadian investigators put together a biological explanation for why this would be so. The World Health Organization reported higher recovery rates in poor countries where patients were not regularly maintained on the drugs. Finally, the MRI studies by investigators at the University of Pennsylvania confirmed the problem of drug-induced chronicity in a compelling way. The drug treatment caused a pathological change in the brain associated with a worsening of symptoms — that is a convincing example of cause and effect.

Thus, there is a preponderance of evidence showing that standard neuroleptics, over the long-term, increase the likelihood that a person will become chronically ill. This outcome is particularly problematic when one considers that the drugs also cause a wide range of troubling side effects, including neuroleptic malignant syndrome, Parkinsonian symptoms, and tardive dyskinesia. Patients maintained on standard neuroleptics also have to worry about blindness, fatal blood clots, heat stroke, swollen breasts, leaking breasts, impotence, obesity, sexual dysfunction, blood disorders, painful skin rashes, seizures, diabetes, and early death [35—40].

Once all these factors are considered, it is hard to conclude that standard neuroleptics are therapeutically neutral. Instead, the research record shows harm done, and the record is consistent across nearly 50 years of research. [See "Timeline to Failure" in Appendix A.]

A better model: the selective use of neuroleptics

At the very least, this history argues that the best model of care would involve selective use of neuroleptics. The goal would be to minimize their use. Several investigators in Europe have developed programs based on that goal, and in every instance they have reported good results. In Switzerland, Ciompi established a house modeled on Mosher's Soteria Project, and in 1992 he concluded that first-episode patients treated with no or very low doses of medication "demonstrated significantly better results" than patients treated conventionally [41]. In Sweden, Cullberg reported that 55% of first-episode patients treated in an experimental program were successfully off neuroleptics at the end of three years, and the others were being maintained on extremely low doses of chlorpromazine. Moreover, patients treated in this manner spent fewer days in the hospital than conventionally treated patients during the follow-up period [42,43]. Lehtinen and his colleagues in Finland now have five-year results from a study that involved treating first-episode patients without neuroleptics for the initial three weeks and then initiating drug treatment only when "absobsolutely necessary". At the end of five years, 37% of the experimental group had never been exposed to neuroleptics, and 88% had never been rehospitalized during the two-to-five-year follow-up period [44,45].

Those results are much better than any achieved in the US following the standard model of continual medication. Indeed, in his meta-analysis of such experimental studies, John Bola at the University of Southern California concluded that most "show better long-term outcomes for the unmedicated subjects" [23].

The atypicals: dawn of a new era?

Admittedly, the record of poor long-term results reviewed here was produced by standard neuroleptics. The poor outcomes may also reflect prescribing practices in the US that, until the late 1980s, involved putting patients on high dosages. The long-term research record for clozapine and other atypicals like risperidone and olanzapine has yet to be written.

One hopes that these newer drugs will lead to better outcomes, but there are reasons to be skeptical. As is now widely acknowledged, the clinical trials of the atypicals were biased by design against the old ones, and thus there is no compelling evidence that the new ones are truly better [46]. While the risk of tardive dyskinesia may be reduced with the atypicals, they bring their own set of new problems, such as an increased risk of obesity, hyperglycemia, diabetes, and pancreatitis [47—49]. Together, these side effects raise the concern that the atypicals regularly induce metabolic dysfunction of some kind, and thus their long-term use will lead to early death. The atypicals also have been shown to cause an increase in D2 receptors, just like the old ones do, and that is believed to be the mechanism that makes medicated patients more biologically vulnerable to psychosis [50].

Summary

The history of medicine is replete with examples of therapies that were eagerly embraced for a period and then later discarded as harmful. A scientific examination of the evidence is supposed to save us from such folly today. And science has in fact provided research data to guide prescribing practices. The evidence consistently reveals that maintaining all schizophrenia patients on antipsychotics produces poor long-term outcomes, and that there is a large group of patients — at least 40% of all people so diagnosed — who would do better if they were never exposed to neuroleptics, or, in the alternative, were encouraged to gradually withdraw from the drugs. (The percentage of patients diagnosed with schizoaffective disorder, or some milder form of psychosis, that could do well without the drugs is undoubtedly much higher.)

This conclusion is not a new one, either. Nearly 25 years ago, Jonathan Cole, one of the pioneering figures in psychopharmacology, published a paper provocatively titled "Maintenance Antipsychotic Therapy: Is the Cure Worse than the Disease?" After reviewing the research data, he concluded that "an attempt should be made to determine the feasibility of drug discontinuance in every patient" [17]. The evidence supported a standard of care that involved gradual withdrawal. The research record of neuroleptics since that time — most notably the WHO studies and the MRI study by investigators at the University of Pennsylvania — confirms the wisdom of his advice.

Indeed, Harding's long-term study shows that gradual withdrawal is an essential step on the path to full recovery. She found that one-third of the schizophrenia patients on the back wards of a Vermont state hospital in the 1950s were completely recovered thirty years later, and that this group shared one characteristic: all had long since stopped taking neuroleptics [51]. She concluded that it was a "myth" that patients must be on medication all their lives, and that in "reality it may be a small percentage who need medication indefinitely" [52].

Yet, in spite of all this evidence, today there is almost no discussion within psychiatry of adopting practices that would involve using neuroleptics in a selective manner, and that would integrate gradual withdrawal into the standard of care. Instead, psychiatry is moving in the opposite direction and prescribing antipsychotics to an ever larger patient population, including those said simply to be "at risk" of developing schizophrenia. While this expansion of the use of antipsychotics serves obvious financial interests, it is treatment that is certain to harm many.

Appendix A

A timeline for neuroleptics.

Preclinical	
1883	Phenothiazines developed as synthetic dyes.
1934	USDA develops phenothiazines as insecticide.
1949	Phenothiazines shown to hinder rope-climbing abilities in rats.
1950	Rhone Poulenc synthesizes chlorpromazine, a phenothiazine, for use as an anesthetic.
Clinical history/standard neuroleptics	
1954	Chlorpromazine, marketed in the US as Thorazine, found to induce symptoms of Parkinson's disease.
1955	Chlorpromazine said to induce symptoms similar to encephalitis lethargica.
1959	First reports of permanent motor dysfunction linked to neuroleptics, later named tardive dyskinesia.
1960	French physicians describe a potentially fatal toxic reaction to neuroleptics, later named neuroleptic malignant syndrome.
1962	California Mental Hygiene Department determines that chlorpromazine and other neuroleptics prolong hospitalization.
1963	Six-week NIMH collaborative study concludes that neuroleptics are safe and effective "antischizophrenic" drugs.
1964	Neuroleptics found to impair learning in animals and humans.
1965	One-year followup of NIMH collaborative study finds drug-treated patients more likely than placebo patients to be rehospitalized.
1968	In a drug withdrawal study, the NIMH finds that relapse rates rise in direct relation to dosage. The higher the dosage that patients are on before withdrawal, the higher the relapse rate.
1972	Tardive dyskinesia is said to resemble Huntington's disease, or "postencephalitic brain damage".
1974	Boston researchers report that relapse rates were lower in pre-neuroleptic era, and that drug-treated patients are more likely to be socially dependent.
1977	A NIMH study that randomizes schizophrenia patients into drug and non-drug arms reports that only 35% of the non-medicated patients relapsed within a year after discharge, compared to 45% of those treated with medication.
1978	California investigator Maurice Rappaport reports markedly superior three-year outcomes for patients treated without neuroleptics. Only 27% of the drug-free patients relapsed in the three years following discharge, compared to 62% of the medicated patients.
1978	Canadian researchers describe drug-induced changes in the brain that make a patient more vulnerable to relapse, which they dub "neuroleptic induced supersensitive psychosis".
1978	Neuroleptics found to cause 10% cellular loss in brains of rats.
1979	Prevalence of tardive dyskinesia in drug-treated patients is reported to range from 24% to 56%.
1979	Tardive dyskinesia found to be associated with cognitive impairment.
1979	Loren Mosher, chief of schizophrenia studies at the NIMH, reports superior one-year and two-year outcomes for Soteria patients treated without neuroleptics.
1980	NIMH researchers find an increase in "blunted effect" and "emotional withdrawal" in drug-treated patients who don't relapse, and that neuroleptics do not improve "social and role performance" in non-relapsers.
1982	Anticholinergic medications used to treat Parkinsonian symptoms induced by neuroleptics reported to cause cognitive impairment.
1985	Drug-induced akathisia is linked to suicide.
1985	Case reports link drug-induced akathisia to violent homicides.
1987	Tardive dyskinesia is linked to worsening of negative symptoms, gait difficulties, speech impairment, psychosocial deterioration, and memory deficits. They conclude it may be both a "motor and dementing disorder".
1992	World Health Organization reports that schizophrenia outcomes are much superior in poor countries, where only 16% of patients are kept continuously on neuroleptics. The WHO concludes that living in a developed nation is a "strong predictor" that a patient will never fully recover.

Appendix A (*continued*)

Clinical history/standard neuroleptics

1992	Researchers acknowledge that neuroleptics cause a recognizable pathology, which they name neuroleptic induced deficit syndrome. In addition to Parkinson's, akathisia, blunted emotions and tardive dyskinesia, patients treated with neuroleptics suffer from an increased incidence of blindness, fatal blood clots, arrhythmia, heat stroke, swollen breasts, leaking breasts, impotence, obesity, sexual dysfunction, blood disorders, skin rashes, seizures, and early death.
1994	Neuroleptics found to cause an increase in the volume of the caudate region in the brain.
1994	Harvard investigators report that schizophrenia outcomes in the US appear to have worsened over past 20 years, and are now no better than in first decades of 20th century.
1995	"Real world" relapse rates for schizophrenia patients treated with neuroleptics said to be above 80% in the two years following hospital discharge, which is much higher than in pre-neuroleptic era.
1995	"Quality of life" in drug-treated patients reported to be "very poor".
1998	MRI studies show that neuroleptics cause hypertrophy of the caudate, putamen and thalamus, with the increase "associated with *greater* severity of both negative and positive symptoms".
1998	Neuroleptic use is found to be associated with atrophy of cerebral cortex.
1998	Harvard researchers conclude that "oxidative stress" may be the process by which neuroleptics cause neuronal damage in the brain.
1998	Treatment with two or more neuroleptics is found to increase risk of early death.
2000	Neuroleptics linked to fatal blood clots.
2003	Atypicals linked to an increased risk of obesity, hyperglycemia, diabetes, and pancreatitis.

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