

PUBLIC COMMENTS  
SUBMITTED VIA E-MAIL  
May 8-14, 2008

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**COMMENTS ARE ORGANIZED BY BUDGET THEME.**

Comments that addressed more than one theme were placed under the theme that seemed most closely related. Comments are listed in the order they were received.

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**1. VULNERABLE OREGONIANS HAVE ACCESS TO HEALTH CARE.**

None.

**2. OREGONIANS HAVE ACCESS IN THEIR COMMUNITIES TO THE MENTAL HEALTH CARE AND ADDICTIONS TREATMENT THEY NEED.**

I am a Eugene citizen living with a mental illness in my community. I am also an advocate for the empowerment of those individuals also living and recovering from a mental illness in Lane County and in the nation. I have spent a lot of time writing letters to Governors, Senators, Representatives and even the President of the United States in reference to mental health issues and concerns.

My biggest concern to be brought to the attention of my mental health community is that the state of Oregon has decided to cancel out any funding for all support for mental health client, participant, consumer and survivor voice *for the next five years*. How does this help those who are struggling to recover from mental illness? Should not their voices be heard when the issue of mental illness recovery and support is discussed?

It is a proven fact that psychiatric hospitals, which Oregon has decided to invest \$500,000,000 (*half a billion*) into, are not as influential to mental health recovery as peer-advocacy and consumer run programs. Without funding for consumer coalitions and committees, the voices and ideas of these very important recovery facets will be unheard by the very human

service agencies created to support them.

Please understand the importance of funding the voice, empowerment and self determination of Oregon's mental health consumers and psychiatric survivors statewide. The lack of this funding means that those who are the MOST affected by any mental health system of recovery or support have no voice and no say in what type of mental health support will be utilized. This means that those people who have walked the long road and struggle of recovery from mental illness in this state are now being deemed unworthy of input about how this state works to support the ongoing recovery of mental health consumers.

I am asking that you please work to make sure that this lack of funding for mental health clients' statewide voice is reversed. I find it to be a very unproductive means of supporting those living with mental illness and a shame when so many individuals in this state are willing and able to lend strong and empowering voices to strengthen the recovery process.

Thank you for your time and consideration.

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I urge you to add funding to establish a statewide office to represent and organize the concerns of people who use mental health services in this state.

Part of this state's problem in mental health service delivery is the rejection and devaluation of the personal experience of former service users who have recovered from a disabling illness. In the addictions field, experience as a recovering addict is respected, valued and rewarded. But in mental health, the emphasis is on "a master's degree in behavioral health care," an irrelevant and inappropriate standard (because it does not qualify staff in working with seriously mentally ill people). We lose out on a source of effective treatment by relegating these true experts to the lower levels of caregivers. Oregon used to have more flexibility when the rules focused on a person's actual ability to do the job, rather than having purchased a diploma. We had it more correct then, and the trend toward "professionalism" has led to a workforce of green recent college graduates doing jobs they are untrained to do with people they don't understand. A state office to represent and encourage this sort of workforce development is worthy of state support. It wouldn't take a lot of money, and it would be a

very useful resource to reshape our service delivery toward competence and effectiveness.

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I am appalled that Oregon is planning zero funding for the voice of mental health consumers at a time when such expertise about psychiatric disabilities is more essential than ever. I urge you to fully fund statewide voice, empowerment and self-determination of Oregon's mental health consumers and psychiatric survivors. The National Council on Disability has stated that it is a violation of the Americans with Disabilities Act to negate choice and empowerment for people with psychiatric and other disabilities. The report on psychiatric disability stresses client voice, expertise and states "nothing about us without us." The State of Oregon must fund consumer/client input.

Although I will not be attending the hearing, I will follow this issue.

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There urgently needs to be a significant funding package for the statewide voice of mental health consumers and psychiatric survivors!

Unfortunately, the Governor's budget has zeroed out that item for five years now!

The main argument used against funding statewide voice is that there are so many other competing needs.

But what other whole categories have been ZEROED OUT?

Also, during a time of cutbacks, when building a new institution, this is exactly WHEN you need to take all possible measures to support the empowerment, self-determination and advocacy of mental health clients.

A few quick points as background:

- 1) Most U.S. states now have some kind of support for mental health client voice, such as an office of mental health consumer affairs, a conference, a newsletter, training, something. Oregon is in the minority of states with zero support.

- 2) Since January 2003 -- more than five years ago -- Oregon has zeroed out all funding for the statewide voice of mental health clients. This was not just a cutback, this was zeroing out.
- 3) Countless studies show that those diagnosed with serious psychiatric disabilities are among the most marginalized, powerless, discriminated against citizens. Especially at a time when there have been U.S. Department of Justice investigations, foster care investigations, and plans for new institutions, it's absolutely crucial to do what we can to address this extreme disempowerment.
- 4) In the last round of budgets, Oregon's own mental health system had a proposal to the Governor for some funding for statewide mental health consumer voice. Somewhere above the Oregon mental health system, that item was removed, over the advice of Bob Nikkel.
- 5) In the last few legislative sessions, I've seen about three great bills that have had lots of support, but that were killed ONLY because they did not make it into the Governor's budget. Yes, of course, the Legislature can overturn the Governor's budget. But as I said, this is a disenfranchised group. In my experience, in several sessions, with several proposals, the Governor's budget is essentially acting as a veto on these proposals.
- 6) As a specific example, you may know that Senator Morrisette passionately championed two bills for our community in the last session -- SB 363 and SB 364. One would have required a small budget, the other one was free. The free one passed, but the Senate committee basically said that because the Governor's budget had not included the item in SB 363, it couldn't get through. For more info see <http://www.mindfreedom.org/as/act/us/or/sb363-364>. Please note that because our bill last session for empowerment as a principle in Oregon's mental health system passed, BY LAW DHS ought to take action to support the self-determination of mental health consumers!
- 7) I have some very good news to report: Although Oregon did not fund the statewide voice of mental health clients, the McKenzie River Gathering Foundation did. The result is that on April 22, 2008, 14 groups run by mental health clients in Oregon united to form the

Oregon Consumer/Survivor Coalition, OCSC. I am on their board, and although I'm writing this on behalf of our group MindFreedom, and not OCSC at this time, I can say that as never before Oregon has a chance to start again, anew, to support the voice of consumer/survivors throughout Oregon, and to become a leader.

- 8) I conclude on a sobering note: Due to our research based on a law student researched article, we discovered that Oregon is still giving out the occasional FORCED -- as in, involuntary -- electroshock to this day. That is, last year an Oregonian in the state mental health system had electroconvulsive therapy over and against their expressed wishes. This was confirmed by the office of Bob Nikkel. Now, wherever people may stand on a controversy like forced electroshock, isn't it absolutely crucial to have an organized voice for clients at the table on such a matter, and speaking out.
- 9) It is with great sadness that I know the Oregon legislative session found half a billion for new institutions without finding a dime for the statewide voice of mental health clients. Whatever one's position is on the bricks and mortar of new institutions, we all know the inherent risk of disempowerment in these large institutions! As never before, there needs to be a concerted effort to support the empowerment, self-determination and voice of some of Oregon's most excluded citizens.
- 10) I've found, in my 32 years as a human rights activist in this field, to be cautious of mild reform. Mild reform can result in "more of the same." We need deeper change. This is a complicated subject. But a simple, commonsense step is to LISTEN TO THE CUSTOMER, hear the diverse perspectives of mental health clients, especially their often fragile and under-funded organizations.

After talking with many leaders in Oregon's own mental health system, and after talking with many legislators, I have to conclude that there must be some kind of obstacle in the Governor's office itself that I am not aware of. It's probably just lack of information, and so it would be good to begin a dialogue.

I would like to submit to you the following letter to the editor that was published May 6, 2008, in our daily newspaper in Eugene, Oregon, The Register-Guard:

LETTER TO EDITOR:

The Register-Guard's recent guest viewpoints and letters about humane alternatives in mental health are appreciated. This community dialogue is healing and necessary.

I've studied the history of the mental health system over the centuries. Minor reform is not enough. Reform often results in more money for more of the same. One step to deeper change is to start to listen to the diverse perspectives of mental health consumers, psychiatric survivors and their organizations.

Most of the states support the statewide voice of mental health clients in some way, even if small. Most states fund an office of mental health consumer affairs, a statewide conference or a newsletter to support the empowerment of our citizens who are diagnosed with psychiatric disabilities. Many leaders in Oregon's mental health system and Legislature endorse this common sense idea.

Our advocacy group concludes that a top obstacle to real change in Oregon's mental health system is in the office of Gov. Ted Kulongoski.

Since Kulongoski took office, his budget item for the statewide voice of mental health clients has been eliminated. The Governor has continued to recommend that this funding stay at zero, even while he raised about half a billion dollars to build huge new psychiatric institutions.

Now I hear Kulongoski say that as a superdelegate he may override the majority of Democratic voters in Oregon's May 20 presidential primary. Is there a pattern here of the Governor squelching the voices of Oregonians? Let's all ask him.

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Please consider reviving funding for the voice, empowerment and self-determination of Oregon's mental health consumers and psychiatric survivors. We need the funding to be heard. Please help.

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Sometimes not spending money is more wasteful than spending it, and I believe that is true when it comes to the decision made by the Governor's office when it zeroed out funding for the mental health consumer voice at the statewide level. Mental health care systems for decades, even centuries, have been plagued by their tendency to become systems of oppression rather than assistance. A primary reason for this is lack of accountability: these systems declare that they don't have to please the recipients of the treatment (who after all, are "mad") and so they quickly become accountable to no one. One responsible and relatively cheap solution to this problem is to allow mental health consumers to have a strong voice, so they can influence the direction of systems of care toward what is actually experienced as helpful rather than oppressive.

The state is planning to spend half a billion dollars on more mental hospitals. But new buildings alone cannot improve care, when the bureaucracy is not getting feedback from the people it treats or, too often, mistreats. Please restore full funding to support the statewide voice of mental health consumers. I and many others will be following this issue to see what you decide.

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I am a Lane County Commissioner. I am writing in support of funding, in your budget, for the voice for Oregon's mental health consumers.

This funding isn't just a good idea, it's a way to lower the costs of providing services.

I think it's a bad decision to zero out all support for mental health clients.

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Please fund the voice, empowerment and self-determination of Oregon's mental health consumers and psychiatric survivors, statewide, INCLUDING children's mental health.

PLEASE also budget funding for TBI-specific services for children who do not have ""emotional"" disorders but who have neuro needs and need competent specialized care in the areas of 1) cognitive rehabilitation services

and 2) CBT by certified trained professionals. Right now, OMHAS is very deficient in the area of neurological disorder treatments for TBI and other neurologically based “mental health” needs. FAMILY VOICE needs to be greatly increased to get a system that works.

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I am someone who spent years in mental hospitals diagnosed as a paranoid schizophrenic. I left to spend 5.5 years in a Rescue Mission, figuring I had no hope to make it in the world.

It was with the help of fellow mental health consumer/survivors that I learned to live again, to gain my own self-respect and to move back out in the community.

I urge you to consider funding an office of mental health consumers for those in Oregon who have had mental and emotional difficulties. We, the consumer, know how to help our fellow suffering Oregonians, and we know how to do it without violating their human rights in the process.

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A couple of months ago, I attended the “public forum” in Salem regarding the Oregon State Hospital, and heard the Salem mayor mourn the lack of public input throughout the process. The “discussion” was all about the building, with nothing said about improving the treatment of the poor souls within. With over 6,000,000 children on some type of psych drug right NOW, I suspect that OSH will be full if not bursting at the seams in a few years. The Americans with Disabilities Act states that it is a violation to negate choice and empowerment for people with psychiatric and other disabilities. People who have been tagged as having mental health problems need both a CHOICE in their "treatment" and a VOICE (an advocate/ombudsman).

I have become a mental health advocate because I saw how easily doctors prescribed psych drugs instead of ordering real lab tests to determine the cause of illness. My 9-year-old son was suffering from constant nausea for over 2 years; during that time, we saw 22 doctors, many of whom recommended “anti-anxiety” psych drugs instead of ordering real lab tests to determine what was wrong (the good doctors found mercury and lead

poisoning, no digestive enzymes (per the Mayo Clinic in Minnesota), the H. pylori bacterium in his stomach, “leaky gut” caused by gluten, and an almost nonexistent immune system per the immunoglobulin panel). I know a man in Salem whose son was “diagnosed” with ADHD and prescribed Ritalin within 5 minutes, with not one real lab test done to determine whether the 5-year-old child had nutritional deficiencies or other common health problems that could affect his behavior. I have read the menus of meals served at OSH, and am shocked to see that they are heavy in gluten and casein, two proteins known to cause intestinal permeability. Check out <http://www.nutritionj.com/content/7/1/2>, [www.gutandmentalillness.com](http://www.gutandmentalillness.com) and [www.tacanow.org](http://www.tacanow.org) for some eye-opening information. Also check the research of Dr. Kalle Reichelt in Norway, Dr. Marios Hadjivassiliou in the U.K., and Dr. Alessio Fasano in the U.S.

Oregon can lead the nation in solving the mental health crisis! Instead of drugged misery behind sparkling new walls, we can use real lab tests to determine what is really wrong and get these poor souls back on the road to good physical AND mental health. I urge you to fully fund statewide voice, empowerment and self-determination of Oregon’s mental health consumers and psychiatric survivors.

### **3. SENIORS AND PEOPLE WITH DISABILITIES LIVE SAFELY AND INDEPENDENTLY IN THEIR COMMUNITIES.**

I am writing on behalf of Centers for Independent Living of Oregon.

I am an employee of an Independent Living Center: proud of the work we do with disabled and senior citizens, and especially proud of the honor system we enjoy while working with our consumers and community partners.

At this time, CILs are enduring traumatic funding cuts, which in the end spiral to our partner organizations and the state and federal government. Please work to reinstate the CIL funding back to the 2001 level.

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Considering that Independent Living Centers provide services that empower individuals to live independently and rely on themselves, then adequate funding for the centers would benefit the state.

I applaud the state for taking the time to gather input from the communities.

I work for Eastern Oregon Center for Independent Living in Ontario. I attended the teleconference on May 8 and would appreciate more information on the Wrap-Around Initiative.

**4. CHILDREN ARE SAFE AND HEALTHY.**

None.

**5. FAMILIES ARE SAFE AND STABLE.**

None.

**6. DHS PROMOTES PREVENTION, PROTECTION AND PUBLIC HEALTH.**

I would like to address DHS's role in prevention, protection and public health. Tobacco use continues to be the leading cause of death in Oregon. We have made great strides since the tobacco prevention and education program began, reducing adult smoking rates by 22% and 8<sup>th</sup> grade smoking rates by 60%. We still have a long ways to go, however. In Umatilla County alone, tobacco costs us \$45 million dollars every single year in medical care for tobacco-related illness and lost productivity due to tobacco-related deaths.

The Centers for Disease Control recommends that Oregon make an annual investment of \$43 million a year to comprehensively address tobacco use in the state. Oregon's current funding amount is \$8 million annually, 19% of the CDC's recommended investment level. Funding the tobacco prevention and education program (TPEP) at the CDC-recommended level will allow Oregon to serve more people through comprehensive evidence-based targeted interventions outlined by the CDC. I urge DHS to fully commit to and provide full funding to both the TPEP program and other efforts to reduce chronic diseases and their impact on Oregon.

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I understand that the state has limited resources to address suicide prevention and that you are seeking input on how to wisely allocate these resources. I have been in the suicide prevention field for 10 years and have witnessed the tragic repetition of a youth suicide in towns across Oregon. Schools that have not experienced a suicide in recent memory don't see a need for prevention, or delay implementation. "Out of nowhere a student dies by suicide in one of these schools and administrators scramble for assistance and programming; or, even more tragically, the administrator denies that a suicide could ever strike again, and it does. Anyone with experience in this field sees this happen over and over again. It's heartbreaking.

A very recent example is the April 18th suicide of a 17-year-old in Butte Falls Oregon. With a population of 480, Butte Falls is a small town in southern Oregon. The local high school was offered a suicide prevention program, and administration intended on implementing it, but there was a change in leadership that put suicide prevention on the back burner. After the suicide on the 18th, teens came forward with information that they knew this teen had a plan for suicide and that he had been talking about it. These teens, however, did not know who to talk with about it. If they had implemented the school-based suicide prevention program, the contact would have been clear.

I would love to see a portion of this funding allocated to increasing awareness among schools about the need for prevention programs. I just got out of delivering a presentation to schools for this very purpose, and convinced most participants to implement a program called RESPONSE that is endorsed by the state of Oregon's Injury and Epidemiology Department.

Please support work that increases awareness and opportunities to implement school-based suicide prevention programming.

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I am a resident of Milton Freewater, a retired Registered Nurse and mother of three children, ages 26, 24 and 16.

I am very concerned that the state of Oregon continues to be one of only four states in the nation without a Birth Defects Surveillance System in place. To stress to you how very important this issue is, let me share my friend's story.

My friend's first baby died shortly after birth and although an autopsy was performed, the pathologist never passed the information (the report sat in his desk drawer) on to the obstetrician, who a couple of months later told my friend: "Oh, it was probably the flu bug...go ahead and try again." Naturally, my friend was so excited to have the doctor's approval. She loved being pregnant and eagerly anticipated the arrival of their second baby. However, several hours after the delivery of the baby, the pediatrician, walked into my friend's room in the middle of the night and announced: "I think this baby has what your first baby died of." My friend responded, "Well, what was that?" and he replied: "Cystic Fibrosis". She responded, "What is that?" and with that the baby was airlifted to OHSU.

I can't begin to tell the long and difficult journey this family has been on since day one. But I do know that had a Birth Defects Surveillance System been in place, my friends would have received proper genetic counseling after the death of their first baby.

I write to you today to encourage each of you to think of the sacrifices this family has made. With your help and financial support for the Birth Defects Surveillance System the babies and families of Oregon will be much better off...and remember, the children ARE our future!

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It is my understanding that Oregon is one of only four states in our country that does not have a birth defects surveillance system in place to monitor the need to help improve the health status of infants and children. I have also heard that this system was part of a Policy Option Package in our state's last budget, but that it did not make it into the Governor's budget.

In a state that prides itself in putting the care and education of its people in front of all else, I found this information very surprising, to say the least. Please be sure to put the surveillance system on the top of your budget list for this term. Organizations like the March of Dimes need this data to identify any environmental hazards we may have, and to determine where they need to provide more programs and increase prevention activities.

Our children and future children need this system in place. Our future needs this system in place.

**7. SERVICES ARE SAFE AND AVAILABLE IN COMMUNITIES WHEN THEY ARE NEEDED.**

None.

**8. DHS HAS THE CAPACITY TO MEET CLIENTS' NEEDS.**

None.

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