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mental hope
... a little bit of hope is a powerful thing℠

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Note: The following is the original text of North Carolina Mental Hope's March 10 presentation to the LOC, but does not include extraneous remarks made during the actual presentation. During that presentation, two factual errors were made. A report on local CFACs was attributed to a state employee rather than a State CFAC member and provider organizations were incorrectly attributed as appointing some State CFAC members instead of Local Management Entities.

My name is David Cornwell. I'm executive director of North Carolina Mental Hope, a consumer-driven advocacy organization. I also serve on the board of Disability Rights North Carolina, chairing its Protection and Advocacy for the Mentally Ill Committee, better known as PAIMI. While I'm honored to serve on Disability Rights and PAIMI, I speak only for North Carolina Mental Hope today.

First, I thank the committee for this opportunity to update it on the first small steps toward inclusion of the largest contingency of stakeholders in the state's Mental Health, Developmental Disability, and Substance Abuse services into the actual planning of those services. I thank Secretary Cansler and Assistant Secretary Watson for their comments acknowledging the need for more consumer input. I thank Sen. Nesbitt for his remarks acknowledging not enough has been heard from consumers.

The small steps of which I speak are meetings that have begun between the Division and a growing collaborative of independent consumer-driven organizations representing a cross-section of the disability community. While time constrains me from acknowledging each of those groups, their directors and contact information are listed on the handout provided.

In January, we sat down with Mr. Watson, Leza Wainwright and Stuart Berde, from the division, to discuss, among other things, better communication, increased inclusion, and avenues for consumer empowerment. Some of the points we hope to discuss are also on your handouts.

The meetings in no way imply the journey toward inclusion has moved far down the path nor does it assure it will be completed. The Division, however, has committed to these meetings through October, for which we are grateful. And it's a dialogue in which we would also hope to engage the Division of Medical Assistance.

What is inclusion? First of all, as I discovered at dictionary.com last night while putting these comments together, it's not a very good word for what the grassroots advocacy collaborative or consumers are seeking. Inclusion can simply mean containing. The word that might better be used is "equality." Or "democracy."

In the present context, I see inclusion as representation of individuals from independent consumer driven organizations or unaffiliated individuals on all planning bodies at all levels dealing with decisions that affect services, representation on at least equal footing with other parties.

To be more specific, it’s just common sense that you don’t ask the waiter if a customer’s food is satisfactory. You ask the customer.

What other contingency is going to be more interested in providing the best services, with the best outcomes, most efficiently, and within the given budget? NAMI’s “Grading the States” report and President Bush’s “New Freedom Commission” each reached the same conclusion with regard to mental health systems, that systems that work the best are those that are consumer and family driven. New ideas, new perspectives. Inclusion saves money with better outcomes. The Colorado system is a case in point. It and other examples will soon be listed at ncmentalhope.org/inclusion.

I need to clarify that stakeholder inclusion is not necessarily synonymous with consumer inclusion. Providers, psychiatrists, employees of DHHS and its divisions are all stakeholders. But there has been very little independent consumer input. And that’s from the Division’s own documentation of meetings, such as the one from which CABHA sprang. Documented inclusion at those committee meetings, as far as I’ve been able to determine, was 1.5%.

Trust is the bedrock upon which any enduring system will be built. And trust needs to be built on truth. But I’ve listened to meeting after meeting this year, where truth has taken a beating. It has been stated and implied that stakeholder inclusion has been synonymous with consumer inclusion. Truth is one of the easiest things that can be done to heal our system. Truth costs no money and can be instituted immediately.

Another reason for inclusion was given more than 200 years ago in the Bill of Rights: “equality.” Recognizing those with disabilities as equals is morally right. Democracy is the foundation upon which our country was built. And there is nothing democratic about mental health planning as it now stands, despite the spin some try to give it.

My own advocacy began with the conviction that my child wasn’t going to grow up as a second class citizen with a second class illness. But when you advocate for one, you advocate for all.

What does exclusion say to my child? What does it say to him when only one individual with a mental health diagnosis serves on an Outpatient Commitment Work Group, a committee whose work goes to the heart of democracy, the stripping of a citizen’s civil rights. What does it say to the state’s consumers to have the state’s mandated committee that serves as the voice for consumers and family members be one that is politically and LME appointed? What equality do this and other rules and statutes that entrench exclusion convey? Again, these are issues of civil rights and democracy. And they don’t set standards for a world I want my child to grow up in.

So much money has been spent on so many studies on services and outcomes, but none that I know on the actual process of developing the definitions, policies and rules that guide our system. Could the process from which the product comes not be a part of the problem? To me, undoubtedly yes. For many, a side effect of mental illness is brilliance. Why not incorporate that brilliance into product development?

I respect the sincerity of this committee’s efforts and as a citizen appreciate your public service, a role that carries few rewards. Just as respectfully, however, I need to point out that the consumer voice has been rarely asked for or heard in these proceedings. Agendas since last September have included an update on CFACs and today’s presentation on Clubhouses. And while I can’t say enough good things about Clubhouses, the security and warmth felt just stepping through their doors and the need to preserve them, the voice of the general grassroots consumer community has not been sought nor heard at any significant level by any level of government.

From the public, stigma grows from the ground up. But it also filters down from public officials. And the present process only entrenches that stigma. I urge this committee to take a stand against stigma and for equality by adding the consumer voice to each of its meetings. Again, it's common sense to ask the diner how his service was and how it could be improved rather than always asking the waiter.

I understand there's no magic wand that can be waved to fix things. Now's not the time, some might say. We're in crisis. But we're always going to be in a crisis. And I would suggest that crisis is a time you most want everyone on the same page, working together.

I'll end with Einstein's three rules of work: "Out of clutter find simplicity, from discord find harmony; in the middle of difficulty lies opportunity." All are apropos, but perhaps none more so than the opportunity the state has, the opportunity to recognize the equality of all citizens, the opportunity to work together for a better system. I pray it is an opportunity that is seized.

David Cornwell
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