Buchanan Testimony
Sub. On Substance Abuse Hearing: the New Freedom Comm. Report
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Witness:
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Testimony:
Chairman DeWine, Senator Kennedy and members of the Subcommittee, I am Ann Buchanan of Cockeysville, Maryland. I am proud to be here this morning to share with you the story of my son's struggle with mental illness and offer some perspectives on President Bush's New Freedom Commission on Mental Health. At the outset I would like to thank you for convening this important hearing and inviting the unique perspectives of individuals living with mental illness and their families.
Before commenting on the final report of the White House Commission on Mental Health, I would like to first tell you and members of this Subcommittee a little about myself and my family's experience with mental illness – a saga that continues to this very day. My son is Rusty is now 22 years-old. When Rusty was age 16, he and I suffered catastrophic event when his father, my husband, lost his battle with cancer. Shortly thereafter, Rusty was diagnosed with depression – probably not uncommon for a teenage boy coping with the trauma of the loss of a father. In 1997, Rusty was hospitalized twice at Shepperd-Pratt. During this period, Rusty was growing increasingly agitated and angry and he physically attacked me twice. Shortly thereafter, he was forced to withdraw from Towson High School at age 17 and was enrolled at Hannah Moore – a school for troubled adolescents.
After only three months at Hannah Moore, he was sent to the Regional Institute for Children and Adolescents (RICA) in Baltimore. RICA is a treatment facility that is part of the Maryland Department of Health and Mental Hygene. It includes both residential programs and day treatment for adolescents with serious emotional disturbances and other mental illnesses. It offers a range of services including psychiatric treatment, crisis intervention, behavior modification, special education and rehabilitative services.
After arriving at RICA, Rusty stayed for over a year, and with the help of the staff and a supportive environment, graduated high school in 1999. While this would normally be an occasion for celebration and accomplishment for most families, it was a source of enormous stress for Rusty, myself and many of the staff at RICA. Tragically for us the spring and summer of 1999 were filled with anxiety and uncertainty as Rusty approached his 18th birthday and high school graduation. The sad reality is that as he approached what would normally be a period of great optimism and promise for most adolescents and their families, Rusty and I were dealing with the fact that he was "aging out" of the child and adolescent mental health system with very little planning and stability about the adult system of care he would be entering.
While the staff at RICA were very caring and responsive, the sad reality is that it was rare for them to deal with a young person such as Rusty who was receiving a high school diploma. We all knew that a date certain was coming when Rusty would no longer be eligible to receive services at RICA – again, because of he was rapidly approaching the

point at which he had "aged out" of Maryland's child and adolescent system. The stress this placed on Rusty was enormous and in the summer of 1999 he attempted suicide.
I want to reiterate that the staff at RICA were helpful. However, I was forced to do most of the work to find a residential placement for Rusty. Waiting lists were long and finding a residential placement was enormously difficult. All across Maryland, psychiatric hospitals and residential programs have been cutting beds and shrinking programs. I made applications to 3-4 residential programs. Each had either a long waiting list or were unwilling to take him because of his history of abusive behavior – the result of his mental illness.
This period was filled with tremendous anxiety for Rusty and myself. RICA said that he had to leave and I felt strongly that it was not safe for him to return to my home. He was being denied placement in residential programs that could meet his needs or was going to be placed on a waiting list that could take months if not years. Eventually, he began receiving services from the adult system only after the suicide attempt in July 1999 and an involuntary admission to Spring Grove Hospital. In other words, only after his symptoms and condition had deteriorated to the point that he was a threat to himself (and most certainly others) was he able to get the treatment he needed from the adult system.

While our story may be unique, I doubt it is. The sad reality is that thousands of families every year face the enormous challenge of having their child "age out" of adolescent treatment and service programs. It should not come as no surprise to anyone that the course of mental illness does not magically shift once a child turns 18, 19 or 20. The symptoms they experience – be it anxiety, depression, mania, psychosis or paranoia – do not change to fit our mental health system's pre-existing definitions about what are children and adolescent services v. what are adult services. In my view, it is disturbing that the separate child-adolescent and adult systems struggle so mightily to help adolescents make the transition in to adulthood. This is especially the case with children and adolescents with more severe mental illnesses who are much more likely to see their diagnosis and illness stay with them into adulthood.
What must be done to ensure that meaningful transitional services become a reality? First, we need to recognize the shift in legal relationships that occurs when the law deems an adolescent to be an adult with full legal rights in our society. Rusty acquired specific rights once he became an adult. This included certain rights relative to his mental illness treatment that did not exist when he was an adolescent. At the same time, the genesis of these legal rights should in no way obscure the obligation of child-adolescent programs to be assertive in ensuring that young people are fully able to access to mental illness treatment and services. More importantly, they should have an affirmative obligation to ensure that the adult system – whether a public mental health authority or a CMHC – is aware of, and is prepared to meet the treatment needs of adolescents reaching adult age. The child-adolescent and adult mental health systems are necessarily separate – on the basis of clinical and legal rationale. However, this separation should not extinguish the obligation for both to develop a cooperative and collaborative relationship that can foster a seamless transition.
One major challenge for us – and for providers such as RICA – is the shift in eligibility for income support and health care entitlements that can occur as adolescent becomes a legal adult. In our case, Rusty qualified for certain Social Security survivor benefits from

his late father. Many other adolescents with severe mental illnesses qualify for SSI before their 18th birthday. In either case, their access to certain programs may often be driven by what Medicare and Medicaid will pay for.

More importantly, for most families, this transition is rarely smooth and can involve months, and even years, of uncertainty as to which programs they qualify for – this is especially the case with respect to state Medicaid "spend down" requirements. Moreover, in many states eligibility for Medicaid can be tied to participation in a specific program. For example, Rusty's eligibility for Medicaid currently depends on his continuing to be served in the residential program where he lives. If he were to leave (or were forced out), he would almost certainly lose eligibility for Medicaid and be left with no coverage for prescription medications and only limited coverage for outpatient therapy. Note – he would still be able eligible for Medicare; however, Medicare does not cover prescription medications and has a 50% co-payment requirement for outpatient mental health services. Clearly more needs to be done to address the fragmentation in both funding streams and eligibility standards for these very complicated programs.

Our struggle with mental illness continues. Rusty has been diagnosed with schizophrenia. Since 1999, he has been in several different programs in Maryland, including Alliance in Essex. Currently, he resides at Keypoint in Dundalk, in a 3-bedrrom apartment he shares with two other consumers. He slowly gaining more independence and has begun to ride the MTA on his own. He has also been participating in a day treatment program. As part of this, he has begin working in the greenhouse at Keypoint in hopes of acquiring skills that will allow him to participate in a work program at the local Home Depot.

The White House Mental Health Commission Report

I would like to make a few brief observations about President Bush's New Freedom Mental Health Commission Report as it relates to my own family's experience with mental illness. First, it is important to note this report does not contain any specific findings or recommendations with respect to services designed to address the transition from the child-adolescent system to the adult system. At the same time, this report does document the enormous fragmentation that remains a serious problem in our public mental health system.

The report also calls for development of an individualized plan of care for both children and adults with mental illness (Recommendation 2.1). Specifically, the report recommends that such plans should be designed to improve service coordination, allow for informed choices and help achieve and sustain recovery. I have little doubt that had such a plan been in place, Rusty would have been able to make a more productive transition into adulthood.

On a more macro-level, Recommendation 2.2 calls for greater involvement of consumers and families in fully orienting the mental health system toward recovery. This includes a plea for greater engagement of consumers and families in the planning and evaluation of services. This is certainly a laudable goal and would certainly help make providers (and more importantly) public officials more aware of the struggles that adolescents and their families experience when children become adults.

The report also contains a heavy focus on the need for more comprehensive state planning (Recommendation 2.4). This is a very positive step toward making the transition between the child-adolescent and adult system more seamless. As the report notes, such

comprehensive state planning should allow for more creativity and flexibility with respect to eligibility requirements for federal programs, insist on more accountability at the state and local level (especially to consumers and families) and expand the array of available services. Among the requirements that could be an integral part of this new era of comprehensive state planning is accountability for ensuring that adolescents aging into the adult system (and their families) receive assistance in making this often difficult transition. Such transition services should include intensive case management and benefit planning.

Finally, I also want to comment on findings and recommendations in the report calling for consumes and families to have a greater control over their own care. While this goal is laudable, it will never be achieved without expansion of family education and peer support programs to help consumers and families learn more about mental illness, treatment system and how to advocate for themselves. I am a graduate of the NAMI "Family-to-Family" Education program. I found it to be enormously helpful in preparing me to cope with my son's illness and become an advocate both for his recovery and for improvements in the service system in our community.

Likewise, numerous peer support and psycho-education programs for both consumers and families have a proven track record of effectiveness in promoting recovery real change at the community level. As you and your colleagues on this Subcommittee move forward in implementing this report, I would urge you to consider the enormous value of programs such as "Family-to-Family" in moving toward the goals articulated by the White House Commission.

Conclusion

Chairman DeWine and members of the Subcommittee that you for the opportunity to offer this testimony on behalf of myself and millions of families living everyday with mental illness.