RE: MHLG Supports the Inclusion of Schizophrenia in National Neurological Conditions Surveillance System (NNCSS)

Dear Chairman Blunt & Ranking Member Murray,

The Mental Health Liaison Group (MHLG) is writing to express our support for the inclusion of committee report language in the House Labor, Health and Human Services, Education and related agencies FY2020 Appropriations bill directing schizophrenia as a condition in the National Neurological Conditions Surveillance System (NNCSS), as authorized under the 21st Century Cures Act (P.L. 114–255). Schizophrenia is strikingly similar to other neurological diseases because it is brain-based, has biological underpinnings, and shares common symptomology – most notably, psychosis – with neurological conditions like Parkinson’s disease and Alzheimer’s disease.

There are published studies suggesting that patients with schizophrenia die on average 28.5 years sooner than other Americans.1 Sadly, 40% of this is due to suicide,2 with 5% lifetime completed suicide rates in schizophrenia.3 Whether patients receive timely, appropriate treatment has great consequence to positive outcomes. Unfortunately, up to 40% of individuals with schizophrenia are untreated (Treatment Advocacy Center).4 At least eleven percent of the homeless population have a diagnosis of schizophrenia, with higher rates in younger persons (13% for 18–30 years old; 21% for 31–40 years old), women (twice the rate of men) and the chronically homeless (18%), with slightly less than half not receiving treatment.5 In regard to tobacco use, individuals with a mental illness are twice as likely to smoke cigarettes than the regular population.6 For people with

schizophrenia, the incidence is strikingly high, with more than 60% of schizophrenic patients being current smokers – heavily contributing to excessive mortality.  

Moreover, the NNCSS is designed to establish prevalence estimates for neurological conditions, and there is a specific controversy about the number of people with schizophrenia in the United States. Recently the National Institute of Mental Health (NIMH) released drastically reduced prevalence estimates for schizophrenia – dropping from 2.8 million to a mere 750,000. This figure is strikingly lower than the 1.1% estimate of the adult population that had been accepted for many years. These findings come from a National Comorbidity Survey from the early 2000s that include only individuals who live at home and acknowledge symptoms of schizophrenia. It excludes all who are in hospitals, nursing homes, group homes, jails, prisons, homeless shelters and on the stress – or those with schizophrenia among the almost 30% who refused to participate in the survey. In our view, it is clear that the CDC generally and the NNCSS statutorily are specifically responsible for providing accurate data documenting the prevalence of schizophrenia in the United States.

In closing, the MHLG strong urges the Senate Labor, Health and Human Services, Education and related agencies Appropriations Subcommittee to include committee report language in the FY2020 Appropriations bill directing schizophrenia’s inclusion within the NNCSS, which is as an important first step to understanding schizophrenia better and reducing stigma.

Sincerely,

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