underwood+lee
CLINIC

January 18, 2011

Dear Rulemaking Committee:

My name is Dr. Matthew Holder, I am a developmental medicine physician. I manage the Underwood and Lee Clinic, a medical, dental and behavioral services clinic in Louisville, KY that is devoted only to caring for adults with neurodevelopmental disorders and intellectual disability (ND/ID) that is, the medical syndromes which result in developmental disability, such as cerebral palsy, autism, Down syndrome, and fetal alcohol syndrome.

If you close your eyes and try to imagine somebody with autism or Down syndrome, chances are you picture a young child. Our society, in general, has been conditioned to think of these individuals as children primarily because, for most of human history, very few of these individuals lived far into adulthood. Consequently our entire system of healthcare has been designed to accommodate our concept of people with these syndromes, that is, a system for children. Today, however, the majority of these roughly 8 million individuals are adults- in fact, we are facing the first generation of elderly people with significant intellectual and developmental disabilities in the history of the world - and their health needs have been neglected and ignored for far too long.

The patients that we see at my clinic are the most underserved group that I have ever come into contact with. I have cared for inner city ethnic minorities, I have cared for patients on Indian reservations, I have cared for economically disadvantaged children, I have cared for abused women, I have cared for people with physical disabilities, I have cared for patients from the LGBT community, I have cared for people with severe and persistent mental illness and I have cared for the urban homeless – all in the healthcare setting. Though I do not wish to discount the disparities experienced by the aforementioned groups, nothing in my professional training prepared me for the level of unmet need or the sociologic complexity that surrounds the patients I see now.

My clinic serves over 1000 people with neurodevelopmental disorders and intellectual disability from over 45 counties within the state of Kentucky. Many of these patients are have such significant disabilities that the average person who has never come into contact with individuals like them is uncomfortable just being in the same room. These are the kind of individuals that most people try to put out of their mind. These are the kind of patients that I routinely hear our volunteers say “I just pray that I don’t have a child like that”.

These adults are marginalized and underserved in every sense. They are so marginalized, that they are not directly represented on your committee. They are so underserved, in fact, that the very formula the government has created to determine “medical underservice” discriminates against them. The factor that uses ‘percent of population over the age of 65’ discriminates against my patients because they are so underserved that they are much less likely to live into their sixties – and yet the outcome of their health neglect is more horrific than anything I have ever seen in the geriatric population. The factor that uses ‘number of primary care physicians per 1000’ creates a false sense of service when studies have shown that 98% of primary care physicians haven’t received the most basic training in caring for this population.

The lack of attention paid to this population by society is reflected in our system education for healthcare providers and in the healthcare providers themselves. Many of our patients drive as much as five hours each way to come to our clinic. Imagine all of the physician and dentist offices they pass along the way. Consider the fact that there are 19 federally qualified health centers, three medical

schools and two dental schools within the state, yet my patients are routinely turned away from all of these entities and most other providers in the state.

Even if they do finally access care in our state, there is a very good chance that the care they are accessing is of poor quality. In a recent case involving one of our non-verbal patients, he had been misdiagnosed with a psychiatric illness that caused him to be kept under psychiatric observation at an inpatient facility for over three weeks. When he was discharged he was taking thousands of dollars of medication per month. Ultimately, we found that his behaviors were a direct result of an uncomfortable deformity of his stomach - a birth defect that had been undetected by his previous doctors for over 30 years! Once the condition was corrected surgically, his behaviors improved and he required no psychiatric medication, but tens of thousands of dollars worth of inappropriate care had been given before his true health issues could be addressed.

I think it is crucial for the committee to recognize that the ND/ID population is a terribly underserved population. In 2006, following a 2002 report from the Surgeon General on this population, HRSAs own primary care education advisory committee recommended that this population be designated as medically underserved – yet ironically, this underserved and under-represented group was ignored by the very office within HRSA whose task it is to designate underserved groups.

These individuals live in every zip code and they are underserved in every zip code. Rules which are meant to define "underservice" that are rigidly constrained by geographical boundaries will only serve to further undermine the quest for health parity that advocates and doctors like me are seeking for this population. The very mandate for deinstitutionalization and community inclusion seeks to disburse people with ND/ID so that there is no significant concentration of these individual in any locale. Simply put, geographic considerations when determining underservice are nothing but a barrier to health parity for people with ND/ID. This group has the highest infant mortality rate of any group in the country, nearly one third live in poverty and despite the issues with the other factors this group still meets the mathematical definition of a medically underserved population. However, in preliminary conversations with HRSA, geography is used as a convenient excuse to exclude these individuals from properly being recognized as underserved.

I understand that there are significant challenges determining who in this country is underserved. I understand that there are a number complex factors and ramifications that must be considered. My hope is that the committee, through the course of its deliberations, will consider the impact that its new policies will have on patients like mine - people who, through no fault of their own, are pushed out of common consciousness and consistently find themselves at the bottom of every ethnic classification, gender-relationship category and socioeconomic class.

I would like to thank the committee for the important work that it is undertaking. I hope that I have made my concerns clear, especially those regarding the potentially harmful limitations of utilizing geographical factors in determining underservice. If the committee would like any further information from me regarding this particular patient population or clarification regarding my experiences, I would be more than happy to communicate further with the committee. I wish you all the best in your endeavor to improve our system of care.

Sincerely,

Matthew Holder, MD, MBA
Director, Underwood and Lee Clinic