

Rep. Dave Camp, Chairman of the Committee on Ways and Means
Rep. Geoff Davis, Chairman of the Subcommittee on Human Resources
Members of the Subcommittee on Human Resources
Ways and Means Committee Office
1102 Longworth House Office Building
Washington D.C. 20515

November 10, 2011

Dear Chairman Camp, Chairman Davis, and Members of the Subcommittee on Human Resources:

During the October 27th hearings, your Subcommittee heard accounts of fraud and misuse by SSI beneficiaries and their families, and poor policy implementation by the Social Security Administration (SSA). What was not emphasized was the critical need for comprehensive and integrated services vital to children who have profound and severe disabilities. In this context, I am writing to highlight the distinction between children who have moderate disabilities, such as those described in the *Boston Globe* series, compared to children who have profound intellectual disabilities and severe and persistent mental illnesses. While the *Boston Globe* articles and the October 27th testimony provided to your Subcommittee emphasized the need for accountability and reform, these suggestions were painted with a broad brush. They did not address the importance of developing policy and practice reforms effective at encompassing the diverse levels of services and support needed by a diverse society.

I am the Co-chair of the Clients Rights Committee for FACT Specialized Services, a residential program in North Carolina providing intensive treatment for children dually diagnosed with severe and persistent mental illness and cognitive impairments. As part of its work, the Client Rights Committee regularly interviews parents and guardians of FACT clients to monitor the effectiveness of FACT's client rights policies and practices for those it serves. Repeatedly, the Committee has been presented with horror stories of what these complicated children experienced when they did not receive the intensive therapy and treatment they required, as well as the dramatic positive changes their families observed once these same children were finally provided appropriate treatment.

There are many success stories – Here are two: Once intensive and appropriate care was provided, “John” stopped bouncing through multiple psychiatric hospitalizations and is now successfully living at home, has a part-time job, and is on track for high school graduation. “Pamela,” a child dually diagnosed with autism and severe psychiatric illnesses was able to return home and has made the honor roll at school. The success of these children and others is not accidental. Success was possible because of access to appropriate intensive treatment available via SSI funding and Medicaid services.

Unlike the misguided parents of children who have relatively manageable disabilities, and who seek financial stability via their children's SSI payments, most parents who have children with complex cognitive disabilities and mental illnesses would be completely unable to provide the array of services needed by their children without SSI funding and Medicaid services. This is doubly true for parents of children dually diagnosed with both profound intellectual disabilities, and severe and persistent mental illness. In North Carolina, for example, the Day Treatment Program, a Medicaid service used by children whose psychiatric illnesses are so severe as to preclude inclusion in public school classroom, is funded at \$31.41/hour. That's over \$180 per 6-hour school day; a fee unreachable by the vast majority of parents, poor or otherwise. While this intensive service is costly, the success of many FACT clients is due, in part, to its efficacy. In the long run, the Day Treatment Program pays off financially, as its graduates gain psychiatric stability, as well as the necessary behavioral skills to live successful, more independent lives. This clearly is a better outcome for everyone than having children with severe psychiatric illnesses veer from place to place on an expensive and ineffective psychiatric hospital treadmill. This thoughtful approach to Medicaid services can be seen in a variety of effective and evidence-based programs across the country. In fact, SAMHSA has defined specific evidence-based practices, which can aid states in the development of meaningful Medicaid services.

The statistics and incidents reported by the U.S. Government Accountability Office and the experts testifying before this Subcommittee show that misuse of SSI funds, along with decreasing oversight by the Social Security Administration, has generated consequences unintended by those who designed SSI and Medicaid programs. And, while a categorical discontinuance of these funds and services would be catastrophic for children with severe and profound disabilities, it may be less obvious that a one-size-fits-all reform plan could be just as disastrous.

When Dr. Burkhauser testified to this Subcommittee, he pointed out that adolescents receiving SSI sometimes identify these funds as "income maintenance," so lose incentive to remain in school or obtain employment. According to the reported accounts, some parents encourage this SSI "income maintenance" approach, as SSI funding avoids the limitations of AFDC/TANF funds. One solution suggested to the Subcommittee is that SSI funding be tied to school attendance or employment. While such an incentive program might prove beneficial for adolescents with diagnoses of ADHD or language delays, who are capable of functioning in school or on the job, this "incentive" becomes the door to disaster for adolescents who have profound intellectual disabilities and severe psychiatric disorders. It is hard to imagine that a rational response to an actively psychotic adolescent with an IQ of 65 (some persons do not respond to currently available psychotropic medications) would be to remove all services because that teen is unable to attend public school or participate in full-time employment.

My recommendation to this Subcommittee is that it consider the proposed reform measures thoughtfully and carefully. Members of the disability community have strengths and challenges as varied as do members of the larger community. To be

effective, federally funded infrastructure and treatment must be tailored to meet this diversity of need. We know from experience that one size does not fit all, and when this poor approach is taken to develop public policy, the results are anemic programs that bleed shattered lives and wasted funds. Children with severe and profound disabilities can participate as productive members of the community, and often require significant infrastructure and treatment to do so. Those with less complex disabilities may be better served by a completely different approach. And while the percentage of children with dual diagnoses or profound disabilities may be small, lack of meaningful treatment and infrastructure for them results in dismal outcomes for themselves and their families, and expensive “fixes.” This Subcommittee has seen the negative result of unintended consequences forged by a one-size-fits-all approach used with prior reform measures. Thoughtful reform will carefully identify children with complex severe disabilities. Effective and meaningful reform will take their needs into consideration when designing solutions to the current SSI and Medicaid policy and practice failures, which will result in a better solution for us all.

Sincerely,

Kathleen Herr, Esq.
Co-chair of the Client Rights/Interventions Advisory Committee for FACT Specialized Services, LLC.
1704 Ferrell Road
Chapel Hill, NC 27517
kathleen.herr@gmail.com