

Wednesday, April 9th, 2014 – OGR Subcommittee hearing:
“Examining Ways the SSA Can Improve the Disability Review Process”
Ms. Jennifer Lockhart, State Director, Sooner SUCCESS,
The University of Oklahoma Health Sciences Center
Note: All times EST

On behalf of Sooner SUCCESS and every individual with disabilities I am here today. I am here today to speak with you about the state of our existing system. I am here to tell you it does not work. I am here to tell you why. You might ask what positions me to speak out so strongly about what I believe to be one of the most undignified supports we have in our great country. I have seen it first hand, I have lived it. From the moment my family adopted four children with special needs over 30 years ago to the moment I stand here today. I have witnessed it up close and personal.

First let me tell you about Sooner SUCCESS. Sooner SUCCESS was piloted over ten years ago by Dr. Mark Wolraich. At that time, Dr. Wolraich left Vanderbilt University for the University of Oklahoma, to fill the chief of developmental behavioral pediatrics Shaun Walters Endowed Chair, also known as the University of Oklahoma Child Study Center. Dr. Wolraich realizing the same struggles existed in Oklahoma for families he treated at Vanderbilt created Sooner SUCCESS. Sooner SUCCESS was developed on a complex adaptive systems (CAS) approach allowing local coalitions to address their unique needs. We believe Sooner SUCCESS does exactly this through advancing an inclusive comprehensive unified, system of health, social, and educational services for Oklahoma children with special healthcare needs or chronic illnesses within their community, Sooner SUCCESS embeds multiple levels of service delivery seamlessly

so families can address both immediate and long term goals through an adaptive approach. Through this approach, we are not only able to analyze the multiple systems (educational, health, social) families struggle to navigate, but also, mobilize the system as warranted within the community when needed through adaptive change agents. This is where our local coalitions and county coordinators are tremendous assets. Change is inevitable, so we must organize the system in a way adapting to change but also educate providers, caregivers, self-advocates, and patients to understand an ever evolving system instead of multiple independent static structures or agencies. Anecdotally speaking we believe this model works. We see this in observation in articles such as the recently published Newsweek article titled The Health Gap: The Worst Place in America for Mental Health, Child Poverty and College Attendance Mapped: The article ranked counties in each state. Of the Top ten counties in Oklahoma five are Sooner SUCCESS Counties and part of the original pilot program ten years ago. Last year alone, in 2013 Sooner SUCCESS made over 31,537 community linkages in our 13 pilot counties. Our 13 counties consist of Tulsa and Oklahoma City, Oklahoma's two most populated cities and 11 rural communities. Within these demographics we are able to serve close to half of Oklahoma's children with disabilities ages newborn to 21. We often serve transitional years between 18-24 as well. With that said, you could say we have a pulse on the grass root level, the view from the balcony as to what our communities look like, each very different with very unique needs. We are your eyes and ears on the ground. What does the view from the balcony look like? A victim of unintended consequences our system designed to assist individuals with disabilities is paralyzed by multiple levels of dysfunction.

For the sake of understanding why, we will understand Sooner SUCCESS. Sooner SUCCESS based on CAS, a complex adaptive system model facilitates adaptation on the local level. Unlike typical service delivery programs, Sooner SUCCESS challenges the current system and integration process as well as the complex systems within which integrated care is enacted. In regard to disability services, integrated, comprehensive care has not developed widely nor as quickly as we hoped. We believe this is because integrated care is not a **program but a process**. Why is this important you might ask? Let me explain further. "...findings indicate that integration is challenged by:

- system complexity,
- weak ties and poor alignment among professionals and organizations
- a lack of funding incentives to support collaborative work
- a bureaucratic environment based on a command and control approach to management

Further, and I quote from a recent publication in the International Journal of Integrated Care "lack of systems change towards integration is that we have failed to treat...the system as complex-adaptive system. The data suggest that future integration initiatives must be anchored in a CAS perspective, and focus on building the system's capacity to self-organize. **We conclude that integrating care requires policies and management practices that promote system awareness, relationship-building and information-sharing, and that recognize change as an evolving learning process rather than a series of programmatic steps**". What does this mean on the system level and what does it have to do with our

issues here today? It means that unless the system is fluid and adaptive we leave it vulnerable. Those vulnerabilities expose themselves through certain outcomes, mostly gaps in service, system exploitation, duplicative services, and fragmentation or dissonance in services. Those vulnerabilities also tell us what often numbers cannot, what the system looks like from real life application. So in real world terms what does that look like?

In the words of our Oklahoma County Coordinator, Lori Wathen proud democrat and mother of a child with Down syndrome:

"I am tired of seeing those who need help unable to get it, because people who don't need it are using the system...we see it every day"

From Donald Baily of S.C.

"I am testifying at a hearing next week in DC presenting testimony regarding disability reform and Social Security. In my testimony I will be discussing the higher Ed piece and referencing your work with the CTC and the S.C. model. I just wanted to be sure this was OK?"

Donald's reply: Good for you! Of course you can... tell all, thanks!

Donald is a former trustee with the University of South Carolina, father of a son with Autism, and founder of the South Carolina College Transition Connection, a consortium of five universities in S.C. providing Higher Ed options for individuals with intellectual/developmental disabilities. Donald and his wife, along with other parents created the CTC because they wanted something more for his son than sitting at home after he aged out of the system.

I have chosen Donald and Lori and could provide you with many more parent and provider statements as to barriers in the system. The bottom line is due to the many gaps we have created a pervasive problem in which we have left not only the system vulnerable but the individuals we are to be helping. We see children with impairments labeled disabled, we see parents and adolescents remain under employed so they may sustain their benefits. We see thousands on a wait-list in Oklahoma who receive no services because they are “waiting” for “assistance”. Aside from service gaps, we see something more concerning. Deeply concerning. We see people with disabilities unknowing segregated from their communities because the transition from the school support service stops often when the individual ages out of the system. Services stop, the support system is gone instantly and because transition services are programs rather than processes we see individuals who should be out in their communities go from an active community life, that being their school, to nothing. Almost overnight. In observation we are able to see a gap where most young adults with disabilities should be transitioning into the community. Why weren't they in their community all along? Like you and me? People with disabilities deserve to be a part of our community, a natural part, not guests. And those programs while intended to be helpful...turn people away rather than towards each other. The "turning towards each other" ...is our instinctive way of facilitating integration one with another. When we impede this fundamental human transaction...we unknowingly stop the natural process of inclusion-to some extent. The family and the individual can become dependent on the services if they are not gradually removed over time preparing the person for more independent living. This is not an agency problem as much as it is a systems problem and reform is essential to change. Most agencies are merely trying to implement the parameters

placed before them. However, this change includes better definitions of disabilities, understanding the differences between disability and impairment, and instigating a convergence between the two parallels of commerce, community and independent living with government support services. This will require fundamental change not only in how we perceive disability but how we support individuals, specifically children, with disabilities.

Lastly, as we move forward in the spirit of transformation understanding this is not a partisan issue. It is not a bi-partisan issue. It is a non-partisan issue, a civil rights issue, a human rights issue and lastly a dignity of life issue. It is our responsibility to prepare all individuals for independent living, to be productive contributing citizens of society. This is the root goal of education and individuals with disabilities deserve more than what we have in place now.

Change will require efforts of both the public and private sectors working in tandem. Through a sound joint process we can create a system equally welcoming to all. In closing I want to share a quote with you from one of our Successforlife Foundation Trustees:

Sooner Success is filling a significant need, to support Oklahoma Families secure the resources needed to access and achieve the American Dream, of enjoying a life that fulfills one's aspirations. Children with disabilities deserve the opportunity to grow up to be productive adults in society and secure gainful employment. Employers who recognize the value of all types of diversity in the workplace, will be the ones who enjoy a win/win experience, in achieving their corporate goals. I am proud to be associated with the U.S. Chamber of Commerce, who recently stated that, "greater access and opportunity for individuals with disabilities, will also be beneficial to business."

---Charles H. Van Rysselberge, President, CVR Consulting, LLC, in Charleston, SC (former President & CEO of the Oklahoma City and Charleston, SC Chambers of Commerce).

Former Greater Oklahoma City Chamber President Charles Van Rysselberge, one of the founding minds of Oklahoma City's Cinderella story. Charles returns to Oklahoma City after a decade of absence as a trustee of the SUCCESSforlife Foundation. Charles was recently honored by the National Chamber of Commerce Executives, with a lifetime membership award for his innovativeness and ingenuity essential to thriving communities. Through his work with the Atlanta Chamber, Oklahoma City Chamber and Charleston, SC Chamber, he has brought revitalization to systems and infrastructure, the life blood of communities. Charles understands the business of business. He also understands to attract businesses, you first must attract families. Charles teaches at the US Chamber-Institute for Organizational Management and is a graduate of the "Diversity Leadership Academy" sponsored by the Riley Institute at Furman University. A key focus of the Diversity Leadership Academy is to educate individuals on the value of diversity in the workplace...in solving workplace and corporate problems through the benefits of a diverse workforce.

