

To: House Social Services Budget Committee
From: Trip Frizell, CLO Board President and Parent
Date: March 18, 2009
RE: Special Tier Funding Provided to CLO

Chairperson Mast and members of the committee, thank you for the opportunity to provide information today regarding the specialized funding that SRS approved for Community Living Opportunities (CLO). I am Trip Frizell, the President of the Board for CLO and also father of Tom Frizell, a young man for whom CLO has provided services for over 15 years. My wife, Allison, and I started the Early Childhood Autism project in 1990. In 1994, in order to expand that project to provide assistance to more children with autism, we merged the program into CLO. As my son, Tom, has grown, this program within CLO has grown not only to cover children with autism but adults with this severe disability. CLO has provided innovative and essential services to our family during Tom's development that have made much easier our family's ability to deal with his disability.

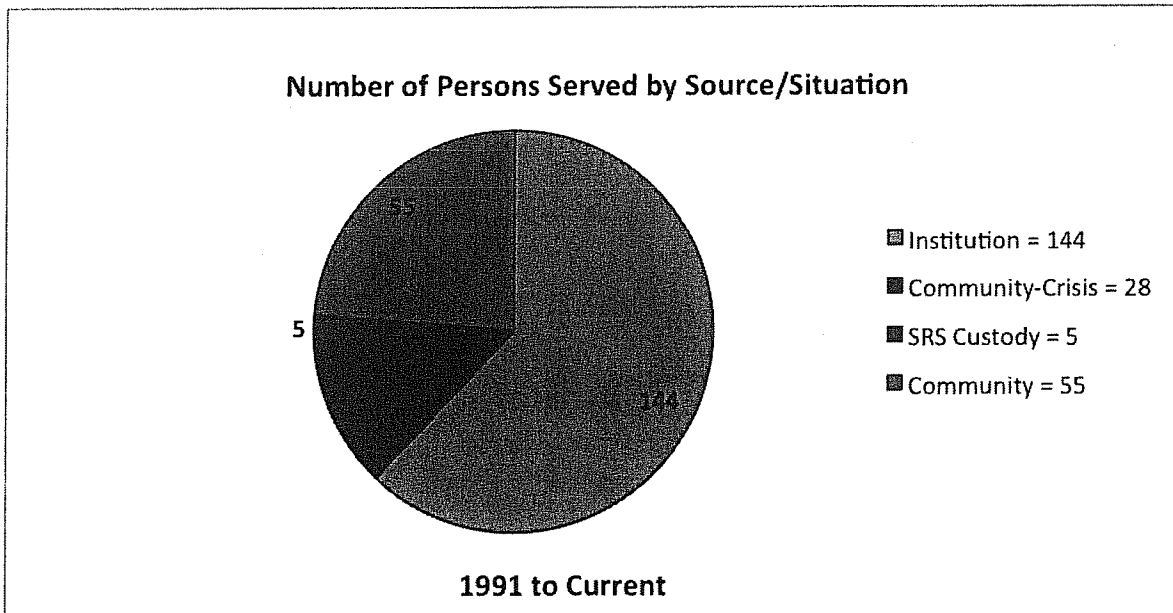
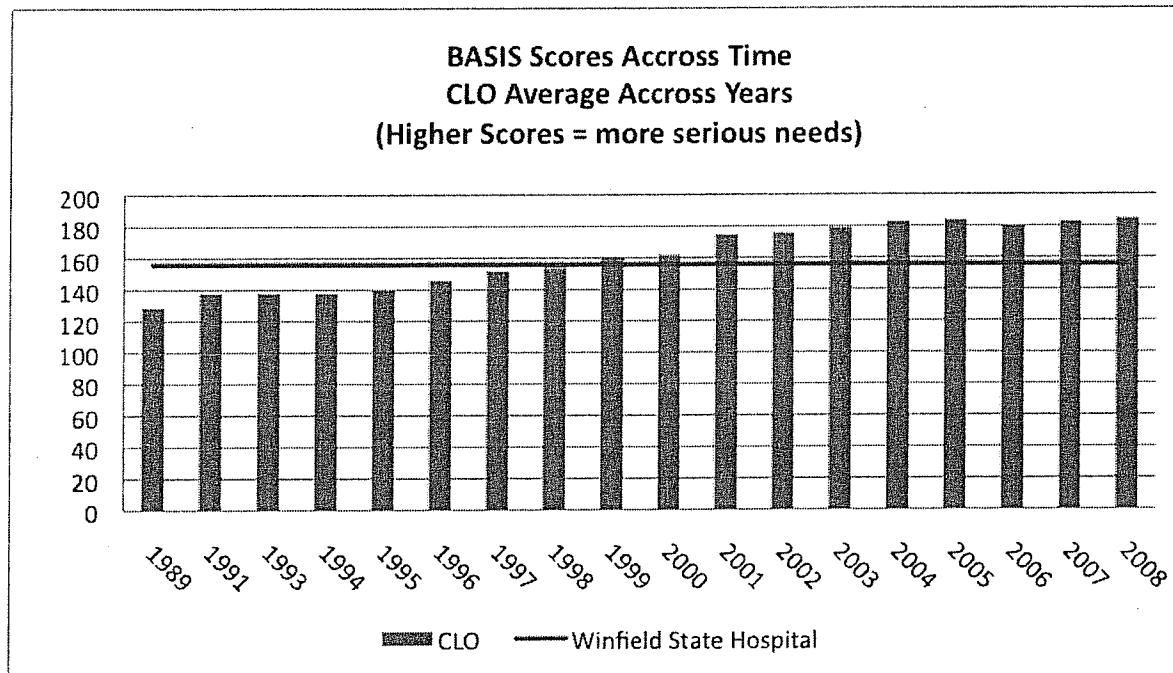
Based on that involvement, I have served on CLO's Board of Directors for 13 years, and became the President of the Board 3 years ago. My primary interest in serving on CLO's Board is to ensure that quality services and life opportunities are offered to Tom and other persons like Tom who have significant developmental disabilities. CLO has been in operation for over 30 years and currently serves approximately 350 persons with developmental disabilities in Northeast and Southeast Kansas.

Recent concerns have been raised regarding Special Tier rates that SRS approved for 43 individuals for whom CLO serves. The issue of adequate funding for persons with developmental disabilities having more significant needs has been a discussion between CLO and SRS for many years. The State's HCBS waiver funding system was developed to meet the average cost of serving persons with developmental disabilities, but I believe it has been documented across four independent rate studies and two Legislative Post Audits that funding across the tiers is not fair. In fact, I believe all four independent rate studies and Legislative Post audits since DD Reform show that tier 1 and 2 clients generally lose money and that tier 4 and 5 clients have produced significantly more gains. Stephanie Wilson will further explain the details of this in her testimony.

CLO was founded in 1977, before the HCBS tier funding system was developed. Our original mission was to serve persons with severe to profound developmental disabilities, including persons with significant health and behavioral challenges. Over the years we have developed a positive reputation for serving these persons and have been asked repeatedly by our CDDOs and SRS to serve persons with greater needs. Thus, CLO's mission does not fit the average funding methodology used in Kansas. CLO's position is that funding should be fair across tiers. If not, it presents the real possibility that providers will cherry pick persons based upon profit motives, which is exactly what post audits and rate studies have confirmed.

To demonstrate the level of need of persons we serve, I am providing below a graph of the average BASIS score of persons CLO has served from 1989 to 2008. BASIS is the assessment tool approved by SRS to determine level of need. The higher an individual's BASIS score is, the higher the need is for that individual. The average BASIS score for persons served

by CLO as of December 2008 was 184. In comparison, the average BASIS score for persons residing at Winfield State Hospital during its closure was 156. The second chart provided shows that since 1991, 76% of the persons CLO has served have been placed from State Mental Retardation Hospitals or private ICFs/MR, from community crisis cases, or from SRS custody.



The CLO Board approached Secretary Don Jordan after losing almost \$1 million on our Kansas Medicaid operations in 2006. We requested that SRS review the value of the services we provide and address the adequacy of funding for the persons we serve. Secretary Jordan visited CLO's homes, talked with our staff, reviewed our financials and met with our

Board of Directors. He is the first SRS Secretary to visit CLO since the implementation of the Developmental Disability Reform Act in 1996. CLO presented Secretary Jordan with several ideas for how the funding issue could be resolved. After SRS staff reviewed the needs of persons served by CLO, SRS determined that an additional 43 people would qualify for Special Tier rates. SRS also compared the level of need of persons served by CLO to the other two Kansas agencies which serve a similar population and determined that CLO received a lower percent of Special Tier rates, even though the assessed needs were similar.

Questions have been raised about why CLO did not apply for these Special Tiers through our CDDOs. There are three primary concerns we have addressed with SRS about the CDDO approval system.

- The first is that there is inconsistency between CDDO regions regarding approval of Special Tiers. Individuals who receive services from CLO have qualified for a Special Tier in one CDDO area and have lost their Special Tier when moving to a different CDDO area.
- The second concern is that the Special Tier approval process requires that a provider lose a significant amount of funding on services for an individual to qualify for special rates. This process, however, cannot work for agencies like CLO that serve so many people with high needs because the losses to qualify for funding would be too great.
- The third reason the CDDO approval system hasn't worked is that our CDDOs have historically not supported the existence of Special Tier funding and as post audits and funding studies confirm, CDDOs have not supported fair increases for Special Tiers. This is because all of the CDDOs with which CLO affiliates are also providers of services in direct competition with CLO for limited funding. CDDOs serve persons with fewer needs in their residential and day programs and they support (and benefit from) the "averaged" funding system. CLO has had to fight for Special Tier funding outside the contracting process because it is not allowed to participate in this process. Our efforts and those efforts of a few similar agencies have included working with the legislature to impose moratoriums upon removing Special Tier rates in order to protect persons with special needs from losing their funding through a CDDO review.

I would also like to note that one of our CDDOs, Johnson County Developmental Supports, receives \$6.9 million in discretionary county mill levy funds and does not share this funding with any of its affiliate providers, including CLO, even though this funding is levied to benefit persons with developmental disabilities in our county. Unfortunately, these funds are not tied to persons served. Likewise, Cottonwood CDDO in Lawrence and the other six CDDOs with which CLO affiliates, do not share their county funds. We have made repeated requests for access to these funds and this has caused considerable friction between CLO and the Johnson County CDDO, in particular.

There have also been concerns raised about the Midnight Farm, a project CLO is developing. First, let me make one thing completely clear. Midnight Farm is not solely a

therapeutic riding facility. In approximately 1998, my wife found out about a rural living environment outside of Toledo, Ohio named Bittersweet Farms. Bernard Rimland of the Autism Research Center had sent his autistic son to Bittersweet Farms and his son loved the pastoral rural environment. Knowing Tom and his likes and dislikes, my wife and I believe that a similar rural living environment would be a perfect long-term solution to Tom's residential needs. Accordingly, Midnight Farm has been in the development stages and was studied by CLO for nearly seven years before CLO acquired the Midnight Farm property. It was always to involve, as an integral part, a rural living environment for people with developmental disabilities who would benefit from that type of life style. Accordingly, the primary purpose of this project, as with Bittersweet Farms, is to provide valuable day and residential services that can be easily accessed by persons with severe to profound developmental disabilities, and activities in which our local communities can become involved. Midnight Farm has offered residential living options since 2005. It will soon also offer opportunities for employment including horticultural and greenhouse businesses such as plant leasing and plant sales; valued day activities such as gardening, crafts, exercise trails, planned events with community members, and therapeutic riding programs primarily for children with significant developmental disabilities. There will also be intensive behavioral intervention services for children with autism and fee-for service summer camps for children with disabilities, including specialized training classes for their parents. It should also be noted that this program, in various forms, has existed at CLO for over two decades beginning as "CLO's Green Thumb Project" which offered horticultural activities, plant leasing and many valued day activities in Johnson County. The kind of activities provided by Midnight Farm are ones that families want for adults and children with very challenging needs and command large waiting lists locally and nationally. As you can see, Midnight Farm is much, much more than has been portrayed in recent news articles. It is what my wife and I hope will be the rural living environment in which our son, Tom, will prosper for the rest of his life.

As a Board member, I have reviewed the business plan for Midnight Farm's operations, and the funds that have been raised. Our plan is that the initial development of the project be supported through private contributions and non-DD revenue and funds and that the ongoing cost be supported by funding for persons who receive day and/or residential services at the farm, augmented by private fee-based funding from persons from the community who participate in various classes offered, as well as continued fundraising and grants. Further, many horticultural activities on Midnight Farm offer opportunities for producing income and the cost of day or residential services to persons who choose Midnight Farm will not be more than those who choose other day or residential services at CLO, or with other providers.

Again, I appreciate the opportunity to address these issues with you. I would be happy to address any questions you have. CLO's CEO, Mike Strouse, is also present to respond to any questions.