

Illinois League of Advocates for the Developmentally Disabled

IL-ADD

October 17, 2011

Senator Jeffrey Schoenberg, Co-Chair
Representative Patricia Bellock, Co-Chair
Commission on Government Forecasting and Accountability
703 Stratton Office Building
Springfield, IL 62706

Dear Senator Schoenberg and Representative Bellock:

High-needs individuals with developmental disabilities are and will continue to be expensive to serve. This is true whether they are to be served in State Operated Developmental Centers (SODCs) or in community settings.

Some community advocates claim that people can be served in the community for “on average \$55,000.” It is certainly not true that high-needs individuals with severe medical and/or behavioral challenges, like those currently served in the SODCs, can be appropriately, adequately and safely served in the community for \$55,000 or for significantly less than in the SODCs.

In the attached document, an actual high-needs SODC resident, BRB, is evaluated for CILA services and rates with the assistance of one of the largest and most reputable community providers in the state. The cost in each scenario is in multiples of \$55,000.

In scenario #1, Provider is realistically evaluating BRB for services and rates for which BRB would likely qualify in a one-person CILA. A one-person CILA was chosen due to BRB’s extreme behaviors and low ICAP score. The estimate is \$183,016 at current wage rates, or \$192,592 with a modest \$1 per hour raise for low-wage direct care staff. Even in this expensive “best case scenario,” guardians, as well as many professionals in the field, would judge these services to be inadequate and dangerous. These concerns are footnoted in the attached document and include: isolation, periods of time with unsafe staffing levels (e.g., 1:1 with no back-up staff), inability of community to use mechanical restraints, likely use of emergency “911” to summon police due to lack of immediately available professional help, behavior intervention and psychotropic medication administration by low-wage staff, and greatly reduced professional support (compared to SODCs).

In scenario #2, Provider is again realistically assessing what BRB would likely be provided in a four-person CILA with the assumption that BRB has improved during scenario #1. That cost is \$146,701 at current wage rates, or \$153,550 with \$1 per hour raise. Guardians and other professionals would have the same concerns as in scenario #1. Additionally, the assumption that BRB would improve in scenario #1 (rather than deteriorate or place other house mates at risk, which is much more likely) is not realistic because BRB depends on a high level of structure and his behavior deteriorates with less.

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In scenario #3, we have evaluated BRB's needs and attempted to provide professional and staffing supports minimally comparable to SODC services. The cost for scenario #3 exceeds \$270,000. Even at that cost, some of the same concerns persist, namely, isolation, lack of structure, and high risk of "911" police intervention due to diminished availability of sufficient professional staff trained to intervene, and inability of community service providers to employ mechanical restraints.

While very challenging, BRB is not the most challenging and cannot be dismissed as a uniquely expensive case. He does not present severe medical conditions, seizure activity, sexual aggression, fire-starting, or PICA (his PICA behavior has been extinguished at the SODC) as do some SODC residents.

While this document emphasizes cost issues, there are programmatic, human, and even legal issues which are at least as important as the issue of cost and must be weighed in deciding whether or not to close SODCs. Closures will both disrupt and risk the lives of the most fragile people with developmental disabilities, those who are served in SODCs. As their families and guardians, we implore you to seriously weigh these consequences.

Sincerely,

Rita Burke, President