



## **Written Testimony of Access Living to the Illinois Human Services Commission**

September 8, 2011

Access Living is the nationally recognized Center for Independent Living (CIL) for metropolitan Chicago. Our work primarily consists of our independent living services, policy and grassroots organizing advocacy, and civil rights legal services, all focused on furthering disability rights and quality of life for people with disabilities. Access Living is co-counsel in the *Ligas* and *Williams Olmstead* statewide class action cases, and lead counsel in the *Colbert* class action case that will affect Cook County. We are also a member of Illinois Partners in Human Services and the Illinois Network of Centers for Independent Living (INCIL).

This testimony concerns both the impact of state budget cuts on CILs and people with disabilities, and our thoughts on the Budgeting for Results process.

### **Impact of Budget Cuts on State CIL System**

State GRF funding has primarily come to Access Living through the state's DHS/DRS line item allocation for CILs, and through the DHS/DRS allocation for the Community Reintegration Program (CRP), which funds the work of coordinators who actively support people leaving nursing facilities and moving into their own apartments. Due to the enormous time and effort spent on advocacy by our grassroots advocates and allies in the spring of 2011, the Governor's proposed FY 12 budget cuts to these programs were largely restored by the final budget passed by the General Assembly, resulting in minimal reductions in Access Living's FY 12 state CIL-related funding. Because Access Living exceeded our goals in moving people out of nursing homes under CRP, we actually saw a slight increase in our FY 12 CRP funding.

Access Living has been very concerned about funding for the DHS Home Services Program and the Department of Aging Community Care Program, because while those programs saw funding increases in FY 12, much of the increase reflects a labor agreement to raise the hourly wages of personal attendants, rather than reflecting an increase in enrollment investment in these two increasingly popular and necessary programs. Both HSP and CCP are key pieces in helping Illinois meet its *Olmstead* obligations. We are currently advocating against proposed across-the-board limits to HSP service hours because we believe the long-term success of HSP lies in its flexibility to serve the individual needs of HSP participants.

We have also been very concerned about budget damage to sister CILs statewide, many of whom do not have the same financial cushion of diversified funding that we have at Access Living. Some Centers have already experienced layoffs or diminished hours of operation. Forcing a CIL to reduce operations or close can greatly reduce the peer-driven supports available to people with disabilities in resource-poor areas of our state. We believe that it is critical to

invest in technical assistance to CILs to first work to improve outcomes, rather than simply whittling away at services.

Our broader concern about cuts to CILs and the CRP has to do with the underfunding of the State's stated policy to empower as many people with disabilities to live in the community as possible, and its goal to re-balance Medicaid long-term care spending away from large institutional settings and towards home and community based services. Like HSP, CILs provide supports that can and do help the State meet its *Olmstead* obligations to ensure that people with disabilities can live in the community rather than institutional settings. Those supports include peer support, independent living skills development, information and referral, advocacy and community reintegration, all of which services are needed statewide.

In the broadest sense of the disability social safety net, we all well know that many of our fellow disability service providers have experienced delayed state contract payments, layoffs and cuts that ultimately hurt not only providers but most importantly, the people with disabilities that we serve. As a cross-disability organization, Access Living serves people with many kinds of disabilities, and often people have more than one type of disability. Our consumers rely not only on us but on a wide array of programs funded by DHS and its divisions, the Department of Aging, the Department of Health and Family Services, and others. When state funding is limited to human service programs under any of these agencies, it directly affects other human services agencies trying to pick up the slack, resulting first in overload and then denial of services.

### **Impact of Budget Cuts on People with Disabilities in Illinois**

While the State's budget crisis presents us with a potential recipe for human rights disaster, it also presents us with a unique opportunity to create meaningful systems change reform that will benefit people with disabilities. People with disabilities have a civil right to inclusion, as well as home and community based services. These rights are protected under a variety of federal laws and court decisions. The difficulty for Illinois has been in creating the legal, policy and programmatic infrastructure that supports and enforces these rights, and in prioritizing funding for that infrastructure. The urgency to enforce these rights is now higher than ever before, given the high number of low-income people with disabilities who lack both housing and supports, in addition to the high cost of warehousing our community in institutional settings as a default solution.

The U.S. Supreme Court's *Olmstead* decision in 1999 fundamentally stated that people with disabilities living in institutions have the right to live in the community if that is their choice. This decision is based on Title II of the Americans with Disabilities Act, which provides that people with disabilities have a right to receive federally funded services in integrated settings. This means any provider providing Medicaid long term care services is subject to *Olmstead*, since Medicaid is a federally funded program. *Olmstead* is often referred to as on par with *Brown vs. the Board of Education* due to its civil rights implications. It is also, along with the

federal Individuals with Disabilities Education Act (IDEA), a part of the disability civil rights legal infrastructure most impacted by the Illinois budget cuts.

Ensuring that the State upholds its legal obligations in the three *Olmstead* class action cases—*Ligas*, *Williams*, and *Colbert*—is a starting point for reform. Throughout the FY 12 budget legislative process, lawmakers repeatedly referred to the need to meet the State’s legal obligations under *Williams*, since that consent decree had been made public at that point. Essentially, the *Williams* implementation plan calls for the State to transition residents of Institutes for Mental Diseases (IMDs) to community-based settings and supports if they so choose. As of today, there is no clear indication that the State has allocated FY 12 funds that will meet this obligation. Under the recently approved consent decree for *Ligas*, the State must also transition out residents of Intermediate Care Facilities for the Developmentally Disabled (ICF-DDs) who have indicated a desire to live in community-based settings with community supports as needed. Again, we have no clear indication yet what funds the State intends to put aside for this effort. During the next year, the State must also consider how it will fund the implementation of *Colbert*, which will assist those who choose to do so to move out of Cook County nursing facilities and back into the community. A preliminary settlement agreement has been reached in *Colbert* and the fairness hearing is currently scheduled for December 2011.

Meeting the legal obligations will demand that the business of institutionalization implement some fundamental changes—changes that will need to be folded into Budgeting for Results. If done correctly, we could see some important opportunities for disability civil rights enforcement in Illinois.

### **Budgeting for Results**

As we understand it, the promise of Budgeting for Results lies in improving outcomes and promoting efficiency in budgeting spending. We are also firm in our opinion that we don’t want to throw the baby out with the bathwater by making cuts while failing to efficiently invest in Illinois’ infrastructure of community supports.

Access Living wants to stress that we know from firsthand service delivery, and from research, that human service providers save the state money by empowering people with disabilities to live in the community. The state loses millions of dollars each year in unnecessary hospitalizations and institutionalizations, particularly in the case of people with complex disability-related needs. Needless to say, community living supports also help the state comply with *Olmstead*. None of us can afford to see cuts that eliminate programs with total disregard to the infrastructure of cost-saving community supports. Thus, we believe that reforming the delivery of long term care supports to people with disabilities is part and parcel of sustainable economic development, civil rights enforcement AND savings.

We believe there are several core components of this needed reform that should be implemented within the Budgeting for Results process. We know that some of this will be addressed by DHS. They are as follows:

1. **Bind agency performance measurements to providers' success in supporting people with disabilities' self-direction and community integration.** For those who may be less familiar with what we mean by this, consider an example. A traditional state measurement of success for a long term care facility provider might be the number of people who lower their Determination of Need (DON) scores in the first two months of their stay in that facility. In our view, that success measurement is incomplete. Lowering the DON score should be tied to whether or not the facility has determined if the individual wants to stay in the facility or move out, and whether steps to ensure that the individual is supported to move out are being taken. The traditional measurement considers the success of the facility alone. Our version considers the success of the facility in supporting the resident's self-direction, and it also demonstrates that the facility has made an effort to lower state costs.
2. **Support interagency cooperation/flexibility in ensuring civil rights, self-direction and community integration for people with disabilities.** In particular, we would like to see interagency coordination between DHS, HFS, IDPH, DoA and to some extent, the Department of Insurance, with the goal of ensuring community living and support networks for people with disabilities who wish to live in the community. It is reported at this point in time that the Budgeting for Results process may involve the state agencies bidding against each other for funds. We fear that a competitive process will discourage interagency collaboration. The Budgeting for Results Commission must be careful to weigh the real strengths of each agency as a team player in the whole government system. We face too many complex challenges in solving the puzzle of community living supports; we cannot afford to be hamstrung by an overly rigid allocation of state resources. The current status of Money Follows the Person reflects this problem.
3. **Ensure open community dialogue on the potential termination of programs mandates.** At the Budgeting for Results Commission meeting on September 7, GOMB announced that it will present a lot of almost 150 program mandates they recommend for termination due to insufficient data or insufficient costs. The community at large must have ample opportunity to comment on this effort and to provide feedback on whether mandates should be terminated. We understand that the Commission intends to hold hearings where the public can provide feedback and we feel this could potentially be one of the burning issues.
4. **Meet *Olmstead* legal obligations, and prioritize funding for programs that support those obligations.** At this point in time, we have not heard that this topic has been directly addressed by the Budgeting for Results Commission or by the state agencies. In light of the possibility that the Budgeting for Results process contains competitive

elements, we have to reiterate that the legal obligations we have discussed are not optional and should not be impacted by competitive bidding processes.

5. **Factor in opportunities for Federal matching funds for programs that ensure civil rights, self-direction and community integration for people with disabilities.** For example, the State is currently examining the feasibility of applying for the Community First Choice Option under the federal Affordable Care Act. Budget forecasts should consider both the inclusion and non-inclusion of these potential funds.
6. **Forecast the needs of disability-related projects and obligations under development.** Consider that Illinois is still in the process of rolling out its managed care pilot program, and that many people with complex support systems have found their networks disrupted. Both people in institutions and in the community face this problem. We have the challenge of potentially seeing this disruption happen on a large scale since the state has indicated wanting to move one million Medicaid recipients into managed care by 2015. The State must also evaluate and improve its resources for housing assistance for people with disabilities, both for those who need permanent supportive housing and those who want scattered site housing.
7. **Weigh seriously the risk of cutting disability-related programs that draw down Federal Medicaid matching dollars.** If under the outcomes and allocations, a certain program that receives matching funds is not deemed worth funding, we could lose millions of dollars.
8. **Ensure that disability civil rights, inclusion and community integration are core value in deciding the dollar allocations for State agencies and programs.** The Budgeting for Results process needs to ensure that performance measurements in every pertinent state agency are truly relevant to the everyday lives of people with disabilities, and that they measure success in self-determination. The state's six priority areas and their attached outcomes are too broad for us to meaningfully outline, here and now, what will work for the people we serve. What we need is for the Commission to direct state agencies to value self-determination and coordination in the human services supporting people with disabilities, and use these values as a framework to structure meaningful performance measurements. Interagency collaboration and flexibility will be a natural product of this effort, and by no means do we wish to see that dynamic nipped in the bud by an overly rigid Budgeting for Results process.
9. **Use the Budgeting for Results process as an opportunity to rebalance Medicaid long term care spending away from institutional settings and towards home and community based services.** We will not succeed in successful rebalancing without

adequately measuring successes in community transition, and ensuring that those successes are measured across state agencies.

In addition to our recommendations, we also have a number of unanswered questions about the Budgeting for Results Process at this time.

- Given that non-profits have little information as yet about how Budgeting for Results affects them, how can we be expected to effectively plan programs and strategies?
- How will competitive bidding between agencies for dollars allocated by outcome affect the state's many provider contracts? Will providers, in the end, be forced to bid for our own programs? What will this cost our consumers?
- How does the Budgeting for Results Commission realistically expect to address the issues we raise when no one on the committee, to our knowledge, has substantive experience in these highly complex issues?
- What mechanisms are in place to ensure that the Illinois legislature will honor the end product of the Budgeting for Results process? In Illinois, history has shown time and again that good intentions can be thwarted by politics.

In summary, we see in Budgeting for Results an opportunity to spend Illinois budget dollars in a way that makes sense to the everyday lives of people with disabilities in our state. In order to make the most of this opportunity, however, the State should engage in significant dialogue with stakeholders, both providers and consumers. Only through this dialogue can the State ensure that it is not only building a better budget, but supporting and enforcing our civil rights.

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