

The Arc of Illinois

November 29, 2010

Testimony to Senate Special Committee on Medicaid Reform

Thank you Chairperson's Righter, Steans and members of the committee for the invitation to present testimony on the need for Medicaid reform in the Illinois Developmental Disability System.

Our system is ripe and ready for real reform.

In my opinion, the single most important recommendation for reform to the Developmental Disabilities System is to plan for and close/downsize state and community institutions. In the past ten years, this has been a major recommendation of eight reports from national experts, the most recent being the "Illinois Blueprint for System Redesign" and the Chicago Community Trust's Whitepaper, "A Quest for Equality: Breaking the Barriers for People with Disabilities, A Call to Action for Illinois Leaders," and the Division of Developmental Disabilities Strategic Plan.

If you do nothing else, it is time to close down and downsize the institutional system in Illinois. It is a wiser investment for public spending and people will live happier, healthier and safer lives because of that decision.

Now on to your questions:

What is your role in the Medicaid System?

The Arc is a statewide public policy advocacy organization representing 220,000 infants, children and adults with developmental disabilities. We have 10,000 individual members and 60 local chapters throughout Illinois. We believe in inclusive community supports for everyone with a developmental disability. Medicaid reform is important to our individual members and local chapters. Most of our local chapters provide direct services funded by Medicaid.

1. From your viewpoint, what is the best way to reduce Medicaid costs without severely impacting services?

Rebalancing the system from costly, ineffective institutional services to supporting individuals in more effective, less costly person centered community services. This has been a success transition in many states including our

neighboring states of Indiana and Michigan. There are now 11 states without any state institutions.

My research also indicates that many of our state institutions are on the verge of losing their Medicaid match because of their failure to protect and support the individuals in those institutions. Choate, the state institution in Anna has been cited by the Department of Justice for numerous health and safety violations and Equip for Equality has called for its closing. I firmly believe that most of those institutions should be phased out as recommended in the "Blueprint for System Redesign."

Consider the costs. Our state institutions cost about \$170,000 per person per year. We spend about \$350 million to support 2,000 individuals in state institutions. In the community, we spend a similar amount of revenue to support 45,000 children and adults. Think about that. If we had begun deinstitutionalization 10 years ago, we might not have a waiting list for community services of 21,000 children and adults today.

Just as important, according to the University of Minnesota study, there have been 27 studies of state institutional closing over the past 30 years, all of those studies finding that the quality of life of individuals moving from institutional services to community services has been dramatically improved. According to that study, the persons who benefited the most from the transition to community living were the individuals labeled as having the most severe developmental disabilities. Smaller community services/supports are safer and more effective than institutional services.

2. What are you doing to maximize federal funding/ what else can the state do to capture these funds?

The Division of Developmental Disabilities has done just about all it can over the past 5 years to maximize federal funding through Medicaid. This was one of the first initiatives when the former Governor was first elected. Quite wisely the administration followed most of the recommendations of the Getting's Report except for the rebalancing of our system away from ineffective institutional services. The Arc was very much involved in supporting the policy to increase federal Medicaid match and disappointed that the rebalancing away from institutional services was not initiated.

One other recommendation would be submission of a new Home and Community Based Waiver that would reform our community system to fully embrace self-directed services and more flexible generic options in the community.

3. Can you identify any inefficiencies within our State's Medicaid system? How can these inefficiencies be corrected?

I believe that Phase 3, of the Managed Care Pilot will be inefficient in the provision of community services to adults with developmental disabilities.

I do not understand how we can put direct care services/supports like CILA, employment, self-directed services and day services under a Managed Care Organization, MCO. I do not know how an underfunded community system can become more efficient with the insurance companies taking their profits and having little or no knowledge of those services.

The managed care of health services may benefit adults with developmental disabilities in community services, if the MCO's can recruit more medical providers into their networks.

The Arc recommends that Phase 3 of the Managed Care Pilot which puts developmental disability services under a MCO be eliminated from the Pilot.

Another action you can take to support reform is to become a Co-Sponsor of Senate Joint Resolution 131. Senators Pankau and Steans are the Chief Co-Sponsors of this important resolution.

Lastly, if we do not take the leadership to reform the Developmental Disability System, the courts will do it for us. We have two Olmstead lawsuits, Ligas and Williams moving us away from the current institutional system. More are likely.

The decision is ours to make.

The following is a fact sheet on where we rank in community services and testimony to the House Committee on Medicaid Reform.

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