# The Arc of Illinois
# Phase Three of Managed Care in Illinois:
# *Position Statement*

June 18, 2013

The Arc of Illinois stands in determined opposition of the implementation of Phase Three of the Illinois Integrated Care Program (ICP). We do not believe that for-profit Managed Care Organizations (MCOs) can, or will, adequately respond to the unique and fluid needs of individuals with intellectual and other developmental disabilities (IDD) in a community-based, person-centered, and self-directed manner focusing on individual choice and family involvement. **We call on the Administration to exempt individuals with IDD immediately from the implementation of Phase III.** Instead, we ask for a continued commitment to offering choices to these individuals, beyond managed care, as our long-term supports and services (LTSS) further evolves.

Not only does The Arc of Illinois have serious trepidation about the ability of MCOs to provide LTSS to people with IDD, we are concerned that their role will contradict the duties of the Illinois Department of Human Services/Division of Developmental Disabilities by:

1. Undermining the Division's role, which is to provide "… *leadership for the effective management of the design and delivery of quality outcome-based, person-centered services and supports for individuals who have developmental disabilities. These services and supports will be appropriate to their needs, gifts, talents and strengths; accessible; life-spanning; based on informed choice; and monitored to ensure individual progress, quality of life, and safety*"[1];
2. Decelerating compliance with the Supreme Court's *Olmstead* Decision in which the United States Supreme Court held that "unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act."[2]
3. Impeding implementation of the US District Court *Ligas* Consent Decree[3] which provides class members with the option of community-based supports and services.

In addition to the threat of disrupting the current momentum toward system transformation, we believe that cost-cutting measures, such as those used by managed care organizations (MCOs), will not increase the quality of services/supports; in fact we believe the contrary. Not only will the use of MCOs fail to increase quality of services, it will fail to result in cost-savings above and beyond what we will see as a result of the

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[1] Division of Developmental Disabilities, Mission Statement: http://www.dhs.state.il.us/page.aspx?item=29761.
[2] About *Olmstead* http://www.ada.gov/olmstead/olmstead_about.htm
[3] *Ligas* Consent Decree http://www.dhs.state.il.us/OneNetLibrary/4/documents/Ligas/LigasConsentDecree061511.pdf

Money Follows the Person grants used in Governor Quinn's Rebalancing Initiative[4]. We believe the Governor's leadership addresses necessary reforms to the Illinois IDD service system which will aid in its transformation from one reliant on costly, archaic and institutionally-based services into one dedicated to the provision of community-based services and supports and reduction of the PUNS waiting list. The Arc contends that the current system transformation through the Governor's Rebalancing Initiative and the existing template for system redesign, *Illinois at the Tipping Point – Blueprint for Redesign in Illinois*[5], requires adequate time to evolve before its outcome can be determined; these are the plans that will provide necessary reform for the disability service system in Illinois. **To introduce an additional moving part to this Initiative before it has run its course is near-sighted and irresponsible**.

The Arc of Illinois is not alone in its critique and opposition to managed care long-term supports and services (MLTSS). In an analysis of managed care in four states, Robert Gettings reported that stakeholders in those states expressed "***deep disappointment with the failure of the program to promote community integration, individualization and enhanced self-direction and independence***[6] (p.8, 2009)".

A more recent study[7] from the University of Illinois at Chicago, evaluating Phase I of the ICP which included health care, revealed that consumers with physical disabilities surveyed "*…expressed* ***significantly lower satisfaction with their healthcare in general …with their primary care provider …and …medical services***" as compared to baseline. However, data from consumers with IDD and mental health needs did not show any significant differences. In addition, consumers voiced the transition into ICP as "inconvenient" and "rushed"; this was intensified for caregivers of individuals with complex medical needs.

Phase II, which began in February of 2013, addresses LTSS but excludes people with IDD. Phase III, set to begin in 2014, will involve moving all direct services for individuals with IDD, including community-based and institutional residential services/supports, into one of two for-profit MCOs; Aetna and Centene-IlliniCare.

Not only do we believe that implementation is unnecessary, **we believe that the medical model used in the delivery of managed care is an inappropriate service delivery model for persons with IDD**. The Arc of Illinois subscribes to the more contemporary social model of disability in which disability is seen as a byproduct of environmental context. Through the use of a variety of individualized supports and

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[4] Office of the Governor (2011, November). Governor Quinn's Rebalancing Initiative – November 2011. http://www.ilga.gov/commission/cgfa2006/upload/GovernorsDDandMHCRebalancingInitiative.pdf.

[5] Illinois At the Tipping Point - Blueprint for Redesign in Illinois Update
http://www.state.il.us/agency/icdd/pdf/Blueprint%20Refresh%20-%20May%201%20(FINAL)-Rev.doc

[6] Reassessing the Impact of Managed Care in the Developmental Disabilities Sector
http://www.nlcdd.org/insights/policy-bulletin-short030509.pdf.

[7] An Independent Evaluation of the Integrated Care Program: Results from the First Year:
http://www.idhd.org/downloads/An%20Independent%20Evaluation%20of%20the%20Integrated%20Care%20Program%20(full).pdf

services, barriers that may limit an individual's ability to fully access and participate in the activities of day-to-day life can be eliminated. Independence, through the lens of the social model, becomes a function of societal and environmental support responses.

MCOs, on the other hand, typically operate under a "one size fits all" treatment approach and have little or no expertise in the delivery of direct services to individuals with IDD, many of which are specialized (e.g., person-centered planning, individual budgets, community living, employment, home-based services and day services, etc.). The daily support needs for an individual with IDD vary from day to day and from individual to individual. There is no such thing as a "silver bullet" which enables an individual to live independently in the community; however, services provided under the social model provide opportunities for individuals to become employed, attend day programs, receive respite and other non-facility based support services. These services do not attempt to "fix" the individual in a medical sense, but provide supportive service environments which adjust to one's ever-changing needs, therefore enabling individuals to flourish in their communities of choice.

Managed care is primarily a cost-containment approach to managing health care expenditures. Individual choice, community living and person-centered planning are critical components of the developmental disability system and cannot be achieved with the traditional capitated (capped) managed care model implemented by for profit health insurance companies. We are concerned about the availability and quality of supports to individuals with complex healthcare needs requiring an array of specialists and intense services, often requiring technology, within the MLTSS system. **We fear that a move to an MLTSS system will reverse the system transformation Illinois is currently experiencing and lead to further service inequities as providers struggle to stay within their established capitated rate systems.**

Further, we are concerned that introduction of MLTSS to Illinois will lead to the addition of another layer of oversight, regulation and monitoring and will fail to address the ever-growing PUNS waiting list of nearly 23,000[8] Illinois residents. Community-based providers already receive sufficient monitoring from Bureaus within the Division (e.g., BALC and BQM), the Department of Public Health, service coordination agencies and accreditation bodies. The added cost of yet another administrative level will lead to further cuts to an already lean system. This is unacceptable. Provider agencies already receive an average of only 74-79% of agency costs from the state and have to underwrite the remaining percentage[9]. **MCOs simply replicate, to a lesser extent, many of these same processes and waste scarce resources in an already financially strapped system.**

[8] PUNS Overall Summary of Support Needed: http://www.dhs.state.il.us/page.aspx?item=56036
[9] State Funding of Community Agencies for Services to Illinois Residents with Mental Illness and/or Developmental Disabilities: http://igpa.uillinois.edu/system/files/MentalHealthFundingStudy.pdf

The Illinois IDD service system is at a tipping point[10]. At this critical time in the evolution of the LTSS system, anything done to weaken the Division's ability to implement its changes would be a grave mistake. Phase I of ICP has failed to show an increase in treatment satisfaction. Phase II, which began in February of 2013, addresses LTSS but excludes people with IDD. Phase II has not yet been evaluated to determine its effectiveness in the Illinois LTSS system. Phase III is scheduled to begin in 2014. It is irresponsible to proceed with the implementation of Phase III without having the results of an evaluation of the impact on the non-IDD population in Phase II.

The Arc of Illinois applauds Governor Quinn's Rebalancing Initiative. We believe his leadership addresses necessary reforms to the Illinois developmental disability service system which will aid in the transformation of Illinois' system from one reliant on costly and archaic institutionally-based services into one dedicated to the provision of community-based services and supports and reduction of the PUNS waiting list. The necessary reforms to the Illinois IDD service system are being implemented. Illinois is undertaking a tremendous transformation through Money Follows the Person. **Not only is managed care inappropriate for individuals with intellectual and other developmental disabilities because of its philosophical underpinnings, it's unnecessary and ill-timed**. We already have a template for system redesign in Illinois; the Illinois Blueprint for System Redesign is what Illinois residents with disabilities and their families need, not managed care. We believe the Blueprint, in addition to the Governor's Rebalancing Initiative, should be allowed to run their course and be adequately evaluated prior to making rash decisions about conversion to a MLTSS.

We strongly recommend that LTSS for people with IDD be carved out of Phase III of Integrated Care Program.

The Arc of Illinois

[10] Illinois At the Tipping Point - Blueprint for Redesign in Illinois Update
http://www.state.il.us/agency/icdd/pdf/Blueprint%20Refresh%20-%20May%201%20(FINAL)-Rev.doc