APPENDIX C: DRAFT STRATEGIC IMPERATIVE and POLICY DIRECTIONS

DRAFT DSAC POLICY DIRECTIONS Version 2.1

Community Services Strategic Imperative

The number of people with a disability and elders and who currently or will need long term care to live in the community is expected to grow rapidly over the next three decades. Despite improvements made over the past years, the current long term care system in Illinois is fragmented, unnecessarily weighted toward medical model programs, and biased toward institutional care. This results in many people in this state who are living in – or who will have to be placed in – nursing homes or other institutions when they would prefer to receive the services and supports they need in their home or in their community.

Current public policy throughout our nation supports that persons who are appropriate and would benefit from community settings should be served there rather than in institutions. The Governor has stated a similar policy in his personal letter to the DSAC. Federal legislation, policy and litigation, including the Americans with Disability Act and the Olmstead vs. LC & EW Supreme Court decision, have clarified that people have the right to services in the most integrated setting possible. They have also clarified a state’s responsibility to make community services available, with qualifications, to those who choose them over institutional care.

The Implementation Plan of the Disabilities Services Act presents Illinois’ blueprint for transitioning its long-term care system to one that reflects the public policy above. Developed in collaboration with the disability/older communities, involved state agencies and other stakeholders, this Implementation Plan demonstrates the State’s commitment to leverage the strengths of its existing long-term care system as it is transformed to one which embraces the following outcomes for people with a disability and elders:

Long-term care policy which appropriately emphasizes access to community care and which is developed in partnership with people with a disability and elders,

Access to adequate, effective and stable services in the community that allow them opportunities to remain in their home or in a community setting of their choice, or to move to one if they choose to leave their current placement in a nursing home or institution,

Support for choices they make regarding meaningful opportunities to be integrated and engaged in their community,

- A Quality Management System that offers effective service planning and performance information to people with a disability and elders and offers opportunities for their involvement in the assessment of performance,
- A state-level data base that identifies, among other things, people who prefer community services and which is used to better align available resources with expressed demand for
services in the community and to support quantifiable objectives regarding the successful transition of people who choose to leave institutional settings for the community, and

- Fiscal, programmatic and administrative policies that support a person’s choice of community services, are customer-friendly, eliminate bias toward institutional care, and provide the fiscal flexibility to support a person’s ability to change services, providers, and communities.

The Policy Direction Statements presented below demonstrate the priorities that the State will use to effect these changes. Along with those policy statements, a list of recent, current or future action steps are presented to describe how the involved agencies, in partnership with the disability/older communities, will redirect the existing long-term care system to reflect existing state policy and the direction outlined in federal legislation, regulation and court decisions.

**Policy Direction #1: Emphasize Choice in the Community: Enable individuals to choose from a range of appropriate community services.**

People with a disability and elders should have the ability to live and work in the location they prefer, with appropriate supports, services and housing alternatives that enable them to do so. Every effort will be made to maximize opportunities for people to choose living arrangements, supports and services that maximize their independence and their involvement in community living.

**Recommendations:**

- Reduce the need for people with a disability and elders to remain in or choose institutional care by developing adequate community capacity for supports, services, and housing alternatives.
- Identify barriers or obstacles to community services and community life and systematically resolve them.
- Make a full range of effective traditional and non-traditional community options and supports available to people with a disability and elders.
- Ensure that existing service entitlements result in people with a disability and elders accessing quality services.
- Cultivate best or promising practices to offer new and creative options for people with a disability and elders as they select community-based services and supports.
- Leverage certain SODC services and clinical capacities and make them available and accessible to community residents.
- Examine other states’ efforts to improve a person’s access to – and selection of - supports and services in the community.
- Leverage all available non-GRF funding to maximize the opportunities for people to choose community supports and services appropriate to their situation, while preserving the broadest possible access to services.
- Create mechanisms that allow people with a disability and elders appropriate choice among qualified providers and the ability to change providers through
planned transition while supporting a high quality and fiscally vibrant provider community

- Create appropriate administrative vehicles that offer people-directed service planning and service delivery to those who prefer that level of decision-making
- Create appropriate business opportunities to generate adequate and effective community services and to support the transition away from unnecessary reliance on institutional care through expansion of other support and service opportunities, reduction in institutional capacity, or through other business decisions that provide appropriate, demand-driven capacity in the community

(ACTION STEPS – See Appendix D)

Policy Direction #2: Support Effective, Informed Choice: Ensure that people with a disability and elders have timely access to adequate and effective information, assistance in navigating the administrative systems, and effective support for decision-making, to the extent that they request or require it.

Information on services and funding should be easily available to all people with a disability and elders. A user-friendly administrative structure should be available to them, to family and friends involved in their lives, and to those acting on their behalf if they are not capable or if they choose the assistance of others. Access to these services needs to be strengthened and provided in culturally appropriate ways for all people with a disability and elders in Illinois navigating long term care systems.

Recommendations:

- Create and implement culturally appropriate and geographically tailored outreach activities that ensure broad community knowledge of available supports, services and housing alternatives and how to connect with the system
- Expand the cross-disability database to include all disability populations and highlight those who choose to modify their services and living arrangements to better meet their needs
- Invest the staff and/or technology to provide information and referral to all individuals who seek assistance, through providers and staff with sufficient training and experience. Options need to be explained thoroughly to people with a disability, elders and their families, and all alternative sources of funding need to be explored.
- Develop user-friendly and value-added pre-admission assessments and evaluations to make eligibility and access simpler for people with a disability and elders.
- Make sure that intake and case management are effective and that each offers a level of people-directed activity for those who wish that level of decision-making. This would include effective cross-agency or cross-system coordination (no wrong door), clear roles, responsibilities and outcomes for case management and service coordination, and effective quality management practices.
• Ensure that assistance is adequate and available in all geographic areas.
• Centralize information about service quality and availability and make information widely available.

(ACTION STEPS – See Appendix D)

Policy Direction #3: Increase System Capacity for High Quality Care.

The state agencies responsible for long term care—in partnership with people with a disability, elders, advocates and the provider community—should provide the leadership to ensure high quality supports and services for people who receive them. This includes the capacity to identify and support effective programs and services and quality providers. It also needs to be adequate to recruit new providers and assist in development of new alternatives.

Recommendations:

• Create or enhance quality management tools and protocols that evaluate quality of care, identify provider strengths and opportunities for improvement, and offer effective technical assistance or support when appropriate
• Support investment in best or promising service practices
• Continuously support provider development of quality supports and services, including changing service elements or components to respond to changing demand and the development of sufficient provider agency capacity to offer legitimate choice
• Through the cross-disability database and industry-specific policy research, identify those quality supports or services that are critical for a person’s successful life in the community. These supports include, but are not limited to: the availability of affordable housing, access to affordable and geographically accessible health care, transportation, and employment opportunities (including supported employment and entrepreneurship).
• Create mechanisms that support people’s ability to move when provider performance is unacceptable and resistant to improvement
• Align system access points to support increased access to available, quality supports and services.
• Fiscal policy needs to support the provision of high quality services that respond to articulated need or demand by supporting a person’s choice of higher quality services, encouraging continuous quality improvement within the provider community, and providing timely and adequate compensation for services that are delivered.

(ACTION STEPS – See Appendix D)

Policy Direction #4: Strengthen Quality Management: Ensure effective supports and services and appropriate outcomes for people through enhanced quality and compliance monitoring systems and improved accountability.
People with a disability and elders deserve an effective system that offers informed choice, delivers effective, quality supports and services and which is responsive to articulated and changing needs. The public deserves a quality management system that effectively monitors and supports quality and cost-effective use of public monies. It should also provide appropriate opportunities for the involvement of people with a disability and elders in quality management activities and offer opportunities for direct communication with people with a disability and elders to determine need, assess the satisfaction of people with a disability and elders and record and resolve complaints and other issues of concern to people with a disability and elders.

Recommendations:

- Quality assurance and quality improvement activities across disabilities systems should be organized around a framework that reflects the components of the Quality Framework established by the Centers for Medicare and Medicaid Services (CMS)
- Quality assurance mechanisms and processes related to long term care should include a focus on individual choice, personal outcomes, and include the involvement of individuals with disabilities
- Oversight and accountability for all quality assurance activities for both institutional and community services should be properly organized, adequately resourced, effectively completed, and inform program and fiscal policy decisions
- Ensure that people with a disability and elders have user-friendly access to information about available supports and services and the relative levels of quality, as reflected in quality management tools and publications
- Quality management structures and activities should directly support the articulated vision(s) and mission(s) for long term care services and provide support for all strategic, tactical and political decisions
- Roles, responsibilities and performance expectations for each public and private component of the long term care system should be clearly articulated, measured and accountable
- Publicly articulated and industry-supported benchmarks should be used to track progress in matching the needs of people with a disability and elders with articulated outcomes, and appropriate service levels and settings
- Publicize existing tools on quality comparisons and/or complaint history (e.g., federal “Compare” websites).

(ACTION STEPS – See Appendix D)

Policy Direction #5: Support the Network of People with a Disability, Elders, their Families, Friends, Neighbors and Communities.

Family members often provide supportive services for people with a disability and elders that meet their needs. For a variety of reasons some people with a disability and elders choose these valuable “natural supports”, often reducing government’s role in providing care and allowing scarce resources to be redirected to others in need. With family size shrinking, more two-person
wage earners families and the population growing older, the ability of family members to sustain this level of effort is strained. Providing support to these caregivers becomes ever more important. Investing in these family supports has been proven to defer a person’s further involvement in the service system.

In addition, volunteer efforts should be recognized for the value they provide. Self-advocacy, support groups, and other creative ideas for enabling individuals within the community of persons with disabilities to provide mutual support and assistance should be fostered.

Recommendations:

- Strengthen programs and curricula that offer education, training and assistance to families that choose to provide care for their loved ones with disabilities
- Create mechanisms that allow people with a disability and elders who live with family members to receive supports in their home and in their community that augment the supports provided by family members and sustain their decision to live with their families
- Strengthen current opportunities and develop creative mechanisms that allow self-advocates and support groups to provide direction for state efforts to support people who choose to live at home or with families who provide supports – independent of agencies that provide them supports and services
- Evaluate current efforts to offer people-directed services
- Develop methods for families, advocates and self-advocates to actively participate in quality assurance systems.

(ACTION STEPS – See Appendix D)

Policy Direction # 6: Commit to Continuous Improvement of the Workforce: Create a Workforce Development Strategy that Delivers a Stable, High-Quality Direct Care Staff.

Most people with a disability and elders who choose to live in the community rely on paid staff for supports and services critical to them. To varying degrees their ability to achieve their personal outcomes, have personal needs met and enjoy a quality life are dependent on the skills, decision-making abilities, and stability of those paid staff. The public responsibility to support their decisions to live in the community requires a commitment to support the recruitment and retention of a skilled and dedicated workforce.

Recommendations:

- Clearly define the roles, required skills and/or experience and aptitude for quality direct care staff, including the capacity to support choice
- Identify recruitment strategies that have successfully targeted segments of the labor market with appropriate skills and/or aptitudes for direct care
• Identify compensation issues that are directly and positively correlated with effective recruitment and retention of direct care staff with appropriate skills and/or aptitudes
• Examine successful practices in other states to expand and stabilize the workforce.

(ACTION STEPS – See Appendix D)

Policy Direction # 7: Re-engineer the Infrastructure: Improve the State Agency Capacity to Support Choice.

People with a disability and elders are individuals. As such, their decisions regarding what is important to them and the supports they need to pursue things of importance are diverse and fluid. Effective person-centered planning, which transfers some control to the person with disabilities, is critical to them. Public policy that supports choice must be flexible enough to respond to a broad range of options and recognize that a person’s needs and choices often change over time. Balancing this public policy commitment with the need to efficiently manage available resources requires a level of coordination and integration of cross-system capacity and administrative effort. It also requires fiscal policy that supports this commitment.

Recommendations:

• Improve the state agency capacity to coordinate and integrate the various service platforms within the system to ensure maximum leverage of resources and capacity and to maximize the user-friendliness of the system
• Improve the state agency capacity to maximize investment in the long term care system through efficient use of available resources, maximization of federal and other available resources, including the commitment to invest savings in the long term care system
• Create a single vision and mission for long term care for people with a disability and elders that provides a policy framework for all involved strategic initiatives
• Integrate and build on all state-level and regional long-term care plans and initiatives to ensure compatibility and consistency of services and access to housing (e.g. the Older Adult Services Act and the Comprehensive Housing Plan)
• Make sure that specialized or segregated services are not created where they are not necessary
• Create an integrated cross-disability database that provides policy and administrative support to identifying demand, monitoring utilization, and evaluating quality
• Create a long-term care system-wide set of outcomes and performance expectations for case management or service coordination
• Create fiscal payment mechanisms and methodologies that effectively support choice (e.g. money follows the person; create a mechanism that equalizes and
simplifies the financing of housing costs between institutional care and community opportunities) while maintaining the fiscal viability of the provider community

(ACTION STEPS – See Appendix D)