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**State of Illinois
Illinois Department of Human Services
Division of Developmental Disabilities**

STRATEGIC PLAN FY 2011–2017

July 2010



28 E. Jackson Boulevard Suite 1022 Chicago, Illinois 60604-2263
Phone: 312.922.9920 www.consultmillennia.com

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I. Introduction

The Department of Human Services (DHS), Division of Developmental Disabilities (the Division) is pleased to present its strategic plan for State of Illinois Fiscal Years 2011–2017. This plan has been developed through a process designed to mine the wisdom of a wide array of stakeholders. It has also been developed in response to several important environmental conditions: a recessionary state economy; investigations by the U.S. Department of Justice at Howe and Choate Developmental Centers; *Olmstead* related litigation; a growing waiting list for basic community services and the recognition that Illinois must align its services for people with developmental disabilities in accord with the preferences of those we serve and nationally accepted practices. Current practice calls upon us to aggressively create a comprehensive and coordinated person-centered service delivery system, rooted in community-based structures, that appropriately supports individual preferences, and which meets the needs of all individuals regardless of intensity or severity of need.

This strategic plan is bold and aims to substantively re-orient Division priorities and resources to support a truly person-centered system of services for which there is a popular mandate; however, this plan cannot be implemented with current funding and service structures and declining funding for services. While we will do our part to ensure that new policies, procedures, and strategies follow promising practices, are cost effective, and responsive to individuals with developmental disabilities, the allocation of resources to support people with developmental disabilities must accurately reflect service demand and be a priority at all levels of government and for the citizens of Illinois.

Some will ask, “How is this plan different from the last one?” Our answer is that the majority of goals can be directly tied to research and recommendations made by a wide range of internal and external stakeholders. The Division met with a group of advocates that represent all aspects of the service delivery system—self-advocates, family members, provider agencies, union representatives, and others—and reached consensus on the Strategic Priorities addressed in this plan. In addition, readers will see many of our strategies are drawn from the policy recommendations of our stakeholder groups and from literature in the field that reflects generally accepted best practice. These documents are acknowledged in the bibliography.

II. Overview of the Division of Developmental Disabilities

The Division of Developmental Disabilities has oversight for the Illinois system of programs and services specifically designed for individuals with developmental disabilities. The Division provides direct services and funds services provided by private facilities and local, community agencies. It works as a partner with many local entities statewide to offer an extensive array of services, which enable persons with developmental disabilities to reside with their families or in other integrated living situations, to ensure their health and welfare and achieve their personal goals.

Community services funded through Medicaid waivers for children and adults are provided through about 350 agencies and, for Home-based Services, through 4,100 employees that are directly hired by the person served. These services vary from 24-hour residential services to specialized therapies, personal support services, day programs, Individual Service and Support Advocacy (ISSA), and respite. Medicaid waiver services are to be provided in integrated community settings. Currently, over 16,500 people are served through the Division's Medicaid waiver program.

The Division has administrative oversight of about 300 private Intermediate Care Facilities for Individuals with Development Disabilities (ICFs/DD) and Skilled Nursing Facilities for Pediatrics (SNFs/Ped). These residential settings vary in size and location and provide a continuous program of specialized and generic training, treatment, health services, and related services that are directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible and toward the prevention or deceleration of regression or loss of current optimal functional status (also known as active treatment). There are currently 6,530 people living in private ICF/DD and similar type settings in Illinois.

The Division also manages the operations of residential services to 2,100 individuals with developmental disabilities who reside in eight state-operated developmental centers (SODCs). SODCs provide similar services to ICFs/DD—an array of services and supports that provide training and services to ensure the person is able to function with as much self-determination and independence as

possible. They also provide residential services to persons with developmental disabilities who may have a higher level of need or to individuals in crisis.

In past years, the Division has supported nearly 15,000 children and adults with developmental disabilities through a wide-range of non-Medicaid grant programs offered through 160 community agencies. These programs are unique to the specific needs of the local community and the people served. Many of the people served through these grants, for example, people with mild intellectual disability and a co-occurring mental illness or people with an Autism Spectrum Disorder, need services to achieve personal goals and live successfully in their local community, but may not meet the federal Medicaid eligibility requirements. The continued erosion of this funding will have a far-reaching, negative impact on those receiving services, their families, the local agencies and, ultimately, the entire community.

III. Vision

All children and adults with developmental disabilities living in Illinois receive high quality services guided by a person-centered plan that maximizes individual choice and flexibility in the most integrated setting possible. All areas of the State have available a full array of services that meet the needs of children and adults with developmental disabilities living in their local communities regardless of intensity or severity of need. There is no waiting list for services.

IV. Mission

The Illinois Department of Human Services, Division of Developmental Disabilities provides 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.

V. Guiding Principles

The Division of Developmental Disabilities will move forward responsibly with its strategic objective to improve access to person-centered services in community settings. We must recognize and involve a wide variety of stakeholders: self-advocates, families and guardians, providers, legislators, and other advocates. In order to ensure both progress and the overall health and well-being of those we serve, the Division commits to the following guiding principles:

- 1) People with developmental disabilities will be actively involved in policy discussions and decisions and will be respected as partners in the process, making informed choices and decisions in order to support productive and fulfilling lives;
- 2) Families and guardians will be listened to and respected, and we will strive to earn and keep their trust along with the trust of the public;
- 3) As small, home and community-based options are increased and enhanced, we will look at new and creative ways to utilize resources across the service delivery system;
- 4) Public resources will be used effectively and efficiently to help those we serve achieve their goals;
- 5) The integration of habilitation, social, and clinical supports will be considered paramount when enhancing and developing services throughout the delivery system; and
- 6) We will establish goals, monitor our progress, and assure quality for those we serve.

VI. Summary of Strategic Priorities and Success Indicators

Summary of Strategic Priorities	Critical Success Indicators
<p>1. Create person-centered services aligned and strengthened across the developmental disabilities system, such that they are provided in the most integrated setting appropriate to the needs of the individual throughout the lifespan, regardless of intensity or severity of need.¹</p>	<p>By 2017...</p> <ul style="list-style-type: none"> ✓ 100% of people served by the Division will have services that are driven by a person-centered plan that accurately reflects their needs, personal goals, and objectives. ✓ Illinois will implement at least one new, outcome-based model for service delivery that improves the coordination and integration of habilitation, social and clinical care for people with developmental disabilities. ✓ The number of individuals living in the most integrated settings will achieve parity with the national utilization rates.^{2 3} <ul style="list-style-type: none"> • More individuals will live in settings of 6 or less: Illinois would need to increase this option at a rate of 5.5% on average, annually, to achieve parity with the national average by 2017.⁴ • Fewer individuals will live in private ICFs/DD: Illinois would need to serve an average of 2.7% fewer individuals per year (compounding) to achieve parity with the national average by 2017.⁵ • Fewer individuals will live in SODCs: Illinois would need to serve an average of 8.9% fewer individuals per year in state Developmental

¹ The definitions of “person-centered services” and “person-centered organizational change process” were developed by a group of developmental disability agencies, self-advocates, and parents in collaboration with the Division of Developmental Disabilities in the fall of 2008.

² Smith, Agosta, & Daignault, 2008, pp. 15–17. The national utilization rate as of 2007 was 12.6 individual per 100,000 living in large facilities. Illinois’ rate is 21.0 individual per 100,000.

³ Smith, Melda, & Agosta, 2010.

⁴ Smith, 2010, Topic 3, p.4.

⁵ Smith, 2010, Topic 6, p.7.

⁶ Smith, 2010, Topic 7, p.8.

⁷ Smith, 2010, Topic 8, p.9.

	<p>Centers (compounding) to achieve parity with the national average by 2017.⁶</p> <ul style="list-style-type: none"> • More individuals will receive integrated employment services: Illinois would need to serve an average of 20.5% more individuals per year in integrated employment services (compounding) to achieve parity with the national average by 2017.⁷
<p>2. Restructure financing and rates to encourage high quality person-centered services.</p>	<p>✓ Funding for developmental disabilities services will be realigned to reflect the Strategic Priorities and benchmarks identified in this plan.</p>
<p>3. Expand system capacity to accommodate increasing demand.</p>	<p>✓ The number of people receiving Medicaid-funded Home and Community Based Services (HCBS) will achieve parity with national utilization rates.</p> <ul style="list-style-type: none"> • Illinois would need to serve an average of 7% more individuals receiving Medicaid-funded services per year (compounding) to achieve parity with the national average by 2017.⁸ • Illinois would need to serve an average of 14% more individuals receiving HCBS Waiver Services per year (compounding) to achieve parity with national average by 2017.⁹
<p>4. Actively build a strong, compassionate, and professionally trained work force.</p>	<p>✓ The disparity between wages paid to State of Illinois employees and community-based direct service professionals will be reduced.</p>
<p>5. Continue our commitment to measure system performance and engage in continuous quality improvement.</p>	<p>✓ The Division will develop a comprehensive, integrated data management system that captures, aggregates, and analyzes data from various sources, allowing timely analysis of service processes and outcomes.</p>

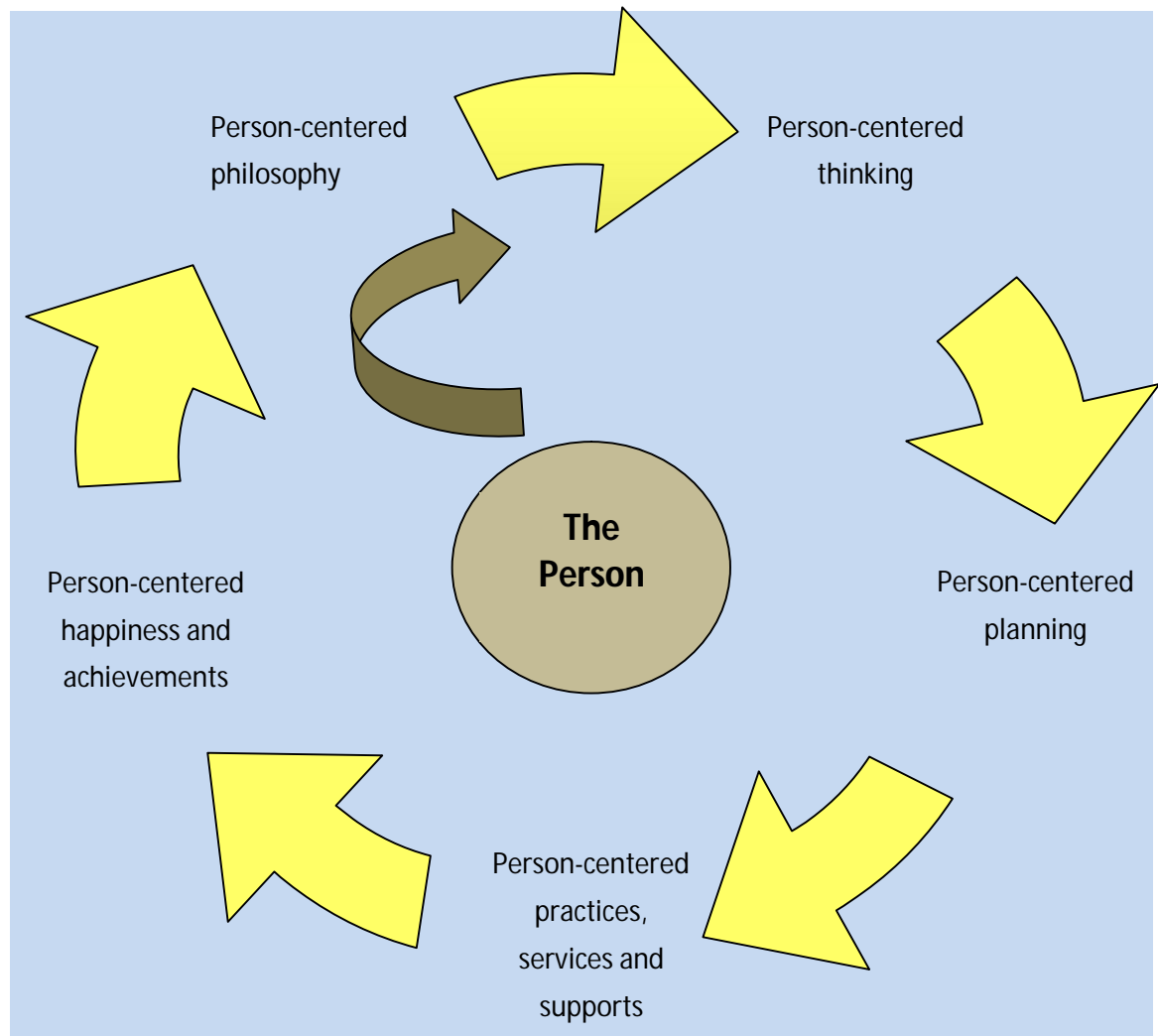
⁸ Smith, 2010, Topic 1, p.2.

⁹ Smith, 2010, Topic 2, p.3.

VI. Key Definitions, Strategic Priorities and Goals

Person-Centered Services:

Services and supports characterized by a comprehensive understanding of individuals' strengths, desires, hopes, and aspirations and provided in a manner that reflects a sincere commitment to maximizing opportunities for individuals to function with as much independence and self-determination as possible.



A person-centered organizational change process requires a systematic review of all policy, procedure, and program design to align with new service model.



Strategic Priority #1: Create person-centered services aligned and strengthened across the developmental disabilities system, such that they are provided in the most integrated setting appropriate to the needs of the individual throughout the lifespan, regardless of intensity or severity of need.¹⁰

Statement of Current Reality: Individuals with developmental disabilities and their families are more often than not frustrated by the current system of care and its philosophical underpinnings which seem to favor a rigid, bureaucratic approach to service delivery that puts the interests of rules and regulations ahead of the individual's. Instead, they would like to see a person-centered service system that provides services and supports characterized by a comprehensive understanding of individuals' strengths, desires, hopes, and aspirations, and provided in a manner that reflects a sincere commitment to maximizing opportunities for individuals to function with as much independence and self-determination as possible.

Key Intent: This priority represents a substantial departure from past Division practice, reorienting services such that they are philosophically and *operationally* designed to achieve person-centered services, provided in the most integrated setting. Policy, procedure, practice, and system of services will be realigned to support person-centered service planning in a rational, incremental process to take place over the next seven years. Our intent is that this transition is accomplished in a thoughtful manner that does not jeopardize current services to individuals and grows capacity in our system. We will partner with those we serve and provider agencies to ensure organizations providing person-centered, quality service,

¹⁰ The definitions of "person-centered services" and "person-centered organizational change process" were developed by a group of developmental disability agencies, self-advocates, and parents in collaboration with the Division of Developmental Disabilities in the fall of 2008.

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remain stable and viable. We recognize that in some cases state and federal policy must be changed to accommodate this new emphasis and will work toward those adjustments. It is also important to note that Misericordia, a high quality, large private campus with historical importance and broad-based community support, will maintain significance in our system.

Goals

- 1.1. Establish a Person-Centered Service Plan and planning process that is driven by the individual and is philosophically committed to services and supports that are provided in the most integrated setting. The planning process will encourage development of plans that include a wide range of supports both paid and unpaid, and will include but not be limited to: assessment of living situation, family situation, and urgency of need, personal goals, clinical needs, and preferred service types.
- 1.2. Strengthen the Point of Entry System for people with developmental disabilities such that it is widely known to the broader community, performs system intake, pre-admissions screening, and appropriate referral to service agencies using consistent and uniform protocols.
- 1.3. Strengthen and adequately fund the independent service coordination function, making the service coordination and advocacy function more robust. Service coordinators will work with individuals and families to develop the person-centered plan, assist them in locating service providers, perform periodic monitoring of service plan implementation, and provide a foundation for a sound quality assurance system.
- 1.4. Conduct a geographic analysis of supports and services; identify gaps between required supports and services within region and person-centered requirements. Continually review data and analyze the environment creating a feedback loop.
- 1.5. Ensure an inclusive continuum of care in which all individuals are appropriately served, regardless of intensity or severity of need.
- 1.6. Align Division policy, practice, procedure with a person-centered organizational structure and service system.
- 1.7. Restructure community services funding along person-centered lines to promote flexibility in service plan design and portability.
- 1.8. Increase availability and usage of self-directed services.

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- 1.9. Define and align roles of current institutional and community services to ensure they fit the person-centered model.
- 1.10. Better coordinate service delivery among key state agencies.
- 1.11. Adopt policies that encourage downsizing of SODCs and ICFs/DD to support the transition of individuals to the most integrated setting.
- 1.12. Adopt policies that support the transition of people that live in private ICFs/DD to the most integrated setting.
- 1.13. Preserve safety net services for people with extreme needs.
- 1.14. Ensure people with significant medical and/or behavioral needs and those with dual diagnosis (DD/MI) have access to person-centered supports and services that meet their needs in community settings.

Strategic Priority #2: Restructure financing and rates to encourage high-quality, person-centered services.

Statement of Current Reality: Illinois' funding of developmental disability services is low compared to other states. Residential care for people with developmental disabilities is disproportionately delivered through a system of State Operated Developmental Centers (SODCs) and large congregate care facilities rather than in small, integrated community settings. The state's rate structure is largely a prospective reimbursement system and generally does not reimburse agencies for the full cost of services rendered. Our current funding models are based on beds and "slots" and are not truly person-centered. This limits flexibility and forces people into rigid programs, rather than shaping services around a person's specific needs and personal goals. As a result, there is not always a strong correlation between a person's level of need and the funding he or she receives from the Division.

Key Intent: Every individual has a person-centered plan. This plan will be supported by an equitable budget amount or rate for services determined and recorded during plan development. The person chooses a service model (traditional provider budget option, self-directed budget option, or a mix) and subsequent services are determined by the person, his or her guardian, and his or her Individual Support Team. Services are realigned across the system such that there is adequate reimbursement, and there is

a strong correlation between level of need and level of funding. As discussed earlier, the Division has authority over some, but not all, funding policies, and we recognize that changes in funding mechanisms may require legislative or administrative action by state and federal entities.

Goals

- 2.1. Define an “adequate” rate for residential, day, and employment services.
- 2.2. Restructure funding models so that the service plan is tied to a Person-Centered Budget Allocation that adequately supports high-quality, outcome-based services delivered by all providers along the service continuum.
- 2.3. Institute global budgeting that combines waiver and ICF/DD funding into one line.
- 2.4. Obtain adequate appropriations to fund services in a timely fashion, eliminating the need for any payment cycle (i.e., payment delay).
- 2.5. Invest in information technology that supports budget development for person-centered planning.
- 2.6. Restructure funding models to support people with significant medical and behavior needs in community settings.
- 2.7. Enhance mechanisms for funding to essentially follow people who transition from SODCs and private ICFs/DD to integrated community settings.

Strategic Priority # 3: Expand system capacity to accommodate increasing demand.

Statement of Current Reality: Illinois has not kept up with demand for developmental disabilities services. In August 2007, 35% of emergency and critical service needs, as reflected on the Prioritization of Urgency of Needs (PUNS) system, were unmet and estimates are that this number will double by 2014.¹¹ The PUNS system serves as the Division’s waiting list for services, tracks demand, and provides data to inform decisions about system-wide service needs. Only those people in significant crisis are able to receive community-based, waiver services without waiting. Our ability to meet demand and eliminate the waiting list is dependent

¹¹ Smith, Agosta, & Daignault, 2008, pp. 29–32.

on increased flexibility and realignment of current funding structures, and adequate funding for outcome-driven services and supports.

Key Intent: Reduce the time people must wait to access necessary services state-wide. Increased community capacity will include habilitation, day, and employment services provided in the most integrated setting, and will also include access to appropriate nursing, medical, dental, behavioral health and other clinical services. We will increase our ability to meet a broad and deep range of needs across the state.

Goals

- 3.1. Increase Home and Community Based service system capacity such that we will achieve parity with national utilization rates for these services.
- 3.2. Develop a robust and statewide clinical services network for people with developmental disabilities that includes university, community service providers, and state employees in community offices and/or a select number of SODCs.
- 3.3. Scale up use of self-direction system-wide.
- 3.4. Support and encourage development of system capacity in underserved areas.
- 3.5. Reduce the amount of time adults and children in non-crisis situations must wait for services.
- 3.6. Develop a community economic impact statement that quantifies such benefits as job creation and well-being (report card).

Strategic Priority #4: Actively build a strong, compassionate, and professionally trained work force.

Statement of Current Reality: A number of reports have established that direct service professionals in the developmental disability service system are in short supply, underpaid, and over-worked. Turn-over rates are high and cost the system dearly. If the system is to deliver quality services, achieve successful outcomes for individuals with developmental disabilities, and grow in professionalism, then action must be taken to attract and retain highly qualified workers to the field. This outcome requires

increased career development opportunities, as well as improved working conditions, wages, and benefits across the system.

Key Intent: Substantially improve training, recruitment, retention, wages, and benefits for direct service professionals throughout the system. This effort will significantly improve the lives of individuals with developmental disabilities by ensuring their care is entrusted to professionals that are well qualified, appropriately trained and adequately paid.

Goals

- 4.1. Conduct a full-scale, system-wide study of direct service professionals' wages, benefits, and hours of work, etc.
- 4.2. Boost and realign funding for community services, so that community agencies can attract and retain competent direct service professionals by paying competitive wages with solid benefits. Reduce the disparity between wages paid to state employees and community direct service staff.
- 4.3. Reduce annual turnover and vacancy rates for direct service professionals.¹²
- 4.4. Adequately staff all services, so that reliance on over-time is reduced and staff burnout is eliminated.¹³
- 4.5. Create supports and incentives for effective training, recruitment, and retention of direct-service professionals by providers throughout the developmental disabilities system (e.g., increased training to prevent and manage difficult behaviors, on-call capacity to provide technical assistance to providers/direct-service professionals facing challenging conditions).
- 4.6. Partner with institutions of higher education (e.g., Illinois Community College Board) to create career pathways supported by certification and degree programs.
- 4.7. Provide incentives for current direct services professionals to seek additional education and credentialing.
- 4.8. Develop an orderly, supportive, and phased process for transitioning displaced state employees into *comparable* positions in community-based services.

¹² Powers, Powers, & Merriman, 2007, pp. 53–54.

¹³ AFSCME Council 31, 2007, pp. 10–12.

Strategic Priority # 5: Continue our commitment to measure system performance and engage in continuous quality improvement.

Statement of Current Reality: A serious shift to a person-centered system requires the development of benchmarks aligned with person-centered goals and outcomes. Statutes, rules, and regulations were established over a decade ago and have not kept pace with emerging or generally accepted standards in the field. In general, the existing rules and regulations should be updated to strengthen and expand the emphasis on goals and outcomes of the individual, rather than on buildings and structures. In addition, information management systems are disparate and aging. It is becoming increasingly difficult to track quality assurance data in a manner that produces useful information to guide policy and quality of care decisions.

Key Intent: Clearly define person-centered quality measures, monitor performance, and use data and lessons learned to inform future policies and procedures. Use information gathered through this effort to strengthen the quality assurance feedback loop, ensuring a systematic, on-going process for review and improvement of rules, regulations, policies and procedures.

Goals

- 5.1. Define quality indicators and assurance processes so that they are aligned with person-centered principles and requirements of state and federal oversight entities.
- 5.2. Measure performance and engage in continuous quality improvement to guide better system performance and ensure better outcomes for people with developmental disabilities.
- 5.3. Enhance IT capacity to clearly and consistently measure system performance.
- 5.4. Adequately fund the Division's infrastructure to effectively monitor and assure quality standards.
- 5.5. Institute performance-based contracts.
- 5.6. Realign current licensure and certification processes with person-centered, outcome-based quality objectives.

VII. Glossary of Terms

Adequate Funding: Funding for services that reasonably covers the cost of providing services that are high in quality, appropriate to the person's needs, equitable for all people with similar needs, and ensures government funding is used in an efficient and responsible manner.

Integrated Employment: Jobs held by people with developmental disabilities that are paid at minimum wage, or preferably higher, and occur in an integrated work environment.

Person-Centered Services: Services and supports characterized by a comprehensive understanding of individuals' strengths, desires, hopes, and aspirations and provided in a manner that reflects a sincere commitment to maximizing opportunities for individuals to function with as much independence and self-determination as possible.

Person-Centered Budget: A budget allocation identified for each person served through standard assessment and review of a person-centered plan, that ensures adequate funding is available to meet the persons specific medical, clinical and habilitation needs, and achieves their identified goals. Funding may be used by the person and their Individualized Support Team to purchase self-directed services, services offered through a provider agency or a combination of both, based on the needs and goals of the person served.

Integrated Community Setting: A home (house or apartment) or place of employment that is integrated into a local neighborhood, among similar homes or places of business where people with and without developmental disabilities live, work, and play.

Most Integrated Setting: "The most integrated setting appropriate to the needs of qualified individuals with disabilities" to mean "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." (28 CFR pt. 35, App. A, p. 450 Americans with Disabilities Act (ADA) regulations, 1998).

Clinical Service Network: A statewide network of clinical service providers in a specific region or area of the state, who work in partnership with each other, with people with developmental disabilities, their families and guardians, provider agencies, and the State to meet the clinical needs of people with developmental disabilities living in the region.

Money Follows the Person: A mechanism by which funding for services "follow" a person from one setting to another. It is generally used to describe a mechanism for funding to follow a person from an institutional setting into an integrated community setting. For purposes of this plan, it does not mean that the exact amount of funding available to a person in an institutional setting is available for services in the integrated, community setting.

Self-Directed Services: A service model by which people with developmental disabilities are empowered to direct the nature and duration of services they receive and are able to directly manage their personal support staff.

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