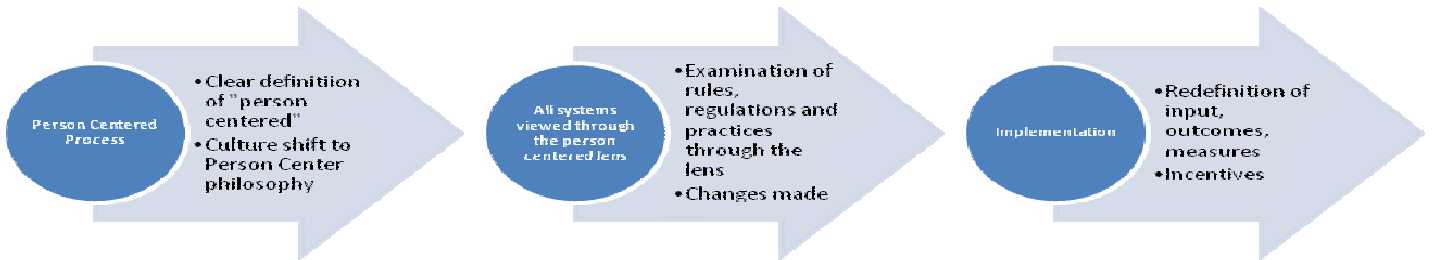


An Outline for the Future of the DD Service Delivery System in Illinois

The Division of Developmental Disabilities has begun efforts to develop a long-term plan for the service delivery system in Illinois. This document provides an outline for that plan and reflects the input and, in many areas, consensus of a variety of stakeholders and advocates involved in the initial discussions. This document will be used as the basis for further planning and presentations with a wider-audience of advocates and stakeholders that will lead to the adoption and implementation of a long-term plan for the Division, a plan that puts those we serve first, and expands on the strengths of the system and genuinely addresses the challenges.

Person-Centered System Change Process

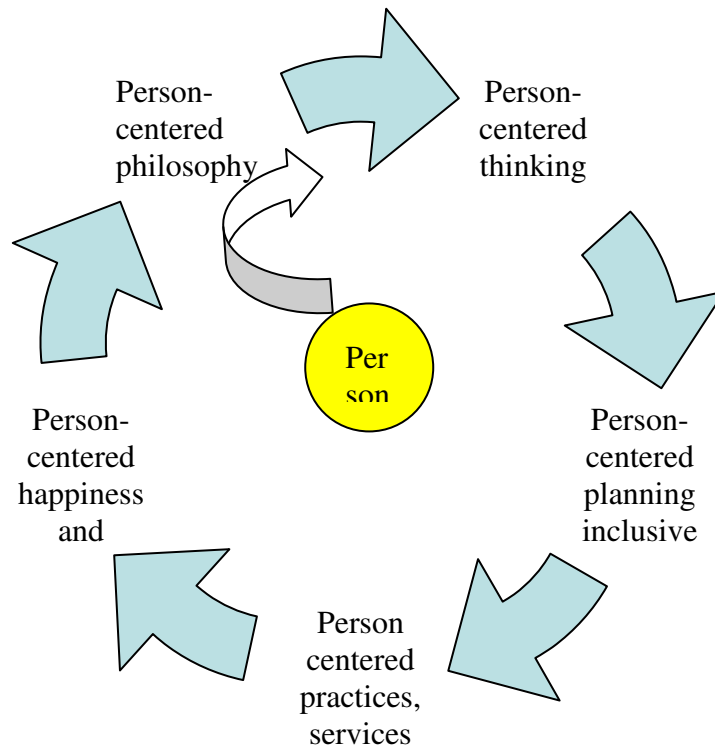
Definition of Person-Centered System: A person-centered developmental disabilities system in Illinois = person-centered planning + person centered funding (rates) = person-driven marketplace (array of resources and supports)



Principles

These Principles have guided the process to date and will continue to be incorporated as the plan is developed, benchmarks are adopted, and the plan is implemented.

Definition of 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.



Closing the Gap

- Funding must be flexible in order to effectively meet people's needs.
- Funding for services for people with developmental disabilities must be expanded.
- Current resources must be used effectively and efficiently to provide services that meet quality standards.

Building Capacity

- Coordination among state agencies involved in providing services to people with developmental disabilities should be improved.
- Systems to accurately collect, assess and forecast future need will be improved and enhanced.
- There needs to be transparency and accountability in all areas of the system.
- A single-point of entry with uniform assessment tool, processes and procedures must be developed.
- There must be an array of services available to appropriately meet the needs of all people served by the system, regardless of the intensity or severity of need.
- Promising practices in behavioral and medical health should be identified for analysis and replication throughout the system.

Workforce Development

- In order for those served by the system to succeed, there must be a skilled and stable direct support workforce supported by competitive wages and benefits.
- A career ladder with clear opportunities for training and advancement are needed to encourage and increase opportunities for the direct support workforce.
- Educational investments should be recognized, supported, and lead to advancement.

Quality and Oversight

- Quality indicators and assurance processes must be aligned with person-centered principles.
- The role and functions of the various oversight entities must be further defined and clarified.
- Quality should be assessed consistently across all areas of the service system.

Current Environment

The Flowchart and the narrative descriptions below reflect current thinking based on the Division's understanding of a number of developments that are now and will continue to impact the service delivery system:

- The current PUNS waiting list and database that indicates there are at least 16,000 people in Illinois that need new, different or additional services.
- The pending consent decree in *Ligas v. Maram*.
- Continued transition of people in SODCs to community settings.
- The RFP in process for Crisis Support Teams.
- Work being done through a federal grant for the Tele-health program to enhance and improve the CART process.
- A recent partnership between the Division of Developmental Disabilities and the SIU School of Medicine to develop a service capacity analysis and report.
- The on-going work of several Sub-Committees of the Statewide Advisory Council.
- Continued need for SODCs to admit and serve people in crisis.
- Continued development of a new Medicaid waiver for people with developmental disabilities and corresponding discussions on amendments to the current waivers.
- A difficult economic environment that continues to stress all areas of the service delivery system.

Introduction

The sections below follow numbered sections on the *Future Process Flowchart*.

While the principles above and the overall goal of creating a person-focused system apply to everyone served by the Division, regardless of setting or funding stream, the *Future Process Flowchart*, in its current form, focuses on people coming into the system through standard channels (PAS Agencies). It does not yet address processes for the following:

- People transitioning to community services from SODCs or other ICF/DDs.
- People entering the system through the Petition and Certificate process.
- A modified process for those that may receive capped waiver services, like Home-Based Support Services.
- With limited exception, specific roles and responsible entities have not been identified.
- Development of a crisis support plan for those that will enter the system needing immediate services.
- As person-centered systems and processes are developed, tested and expanded, a process for people currently receiving services throughout the system (CILA, HBSS, ICF/DD, SODC, etc.) to benefit from the changes.

All of these issues, and others that arise, will be addressed as the plan is developed.

In keeping with the 6-year timeframe established in the proposed Ligas consent decree, the Division's final plan will cover a 6-year period, at minimum.

Narrative

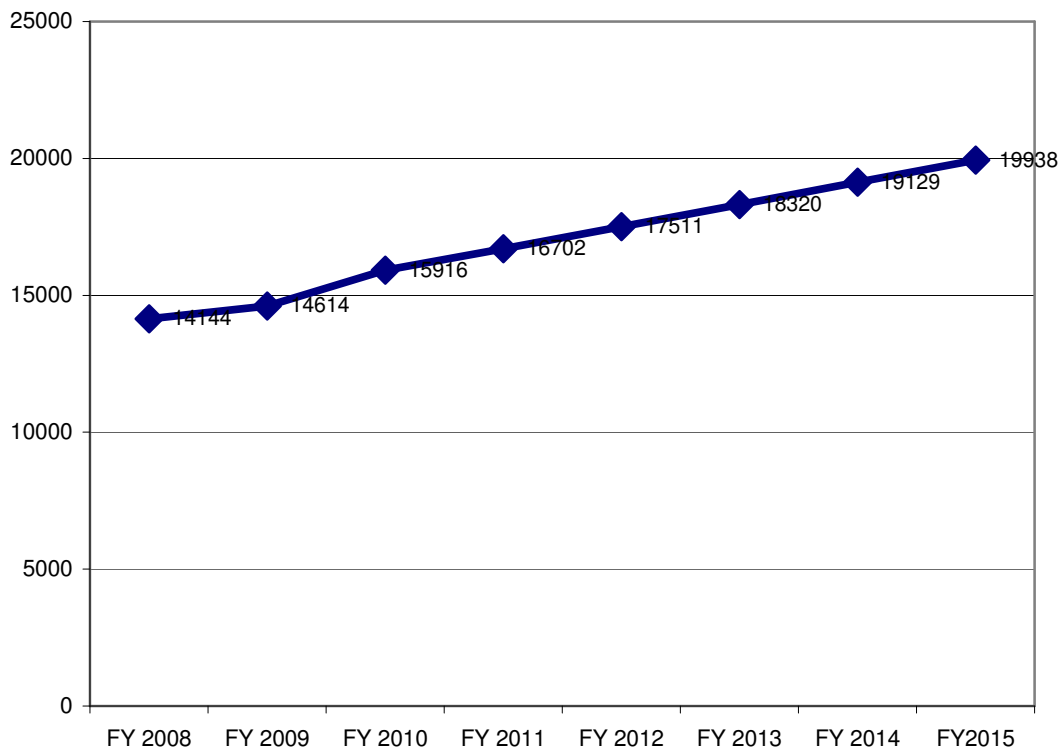
1. Pre-Assessment: Is it likely that the person has a developmental disability?
 - a. Pre-assessment, based on collateral information and clinical reports will be needed to determine if a person is likely to have a developmental disability.
 - b. In those cases where a person does not, modifications to PUNS may make it possible to include them in the data collection process, but exclude them from selection for DD funded services.
 - c. Information and referral to other appropriate resources will be expected and done in partnership with other DHS Divisions.
2. Initial person-centered planning process.
 - a. A scaled-down, person-centered planning process and assessments will need to be developed and adopted system-wide.
 - b. Given limited resources and the potential for a person to wait a significant period of time for services, a full person-centered planning process would be cost prohibitive at this point.

- c. This process should include assessments that assist in determining the person's true urgency of need. That data can be used to group people appropriately in the PUNS waiting list.
 - d. The plan developed through this process will serve as a basis to assist the person and their family in selecting services and service modalities.
3. Crisis or Emerging Crisis determination.
 - a. The information gathered in the step above will be used to assist in determining if a person meets the Crisis or Emerging Crisis criteria.
 - b. It may be possible to make this determination based on an assessment, or parts of assessments, developed for step 2.
 - c. As agreed to in the proposed Ligas consent decree, those individuals that meet the Crisis criteria will be served expeditiously. There will be no cap on the number of people that meet the crisis criteria in a given year.
 - d. The Emerging Crisis definition will be more fully defined in partnership with people served, advocates, providers and others. The proposed consent decree calls for the Division to serve a total of 3,000 additional people who meet this criteria in the 6 years of the decree.
4. Choices made about available service options.
 - a. At this point in the process, persons-served and their families will make decisions about the types of services they would prefer to receive.
 - b. Again, it is expected that the initial person-centered plan and assessments completed as part of step 2 will assist in making these decisions.
 - c. Those people that chose an ICF/DD agency with a vacancy and there is agreement that the agency can meet the needs of the individual, will be able to select that service option.
 - d. For those individuals that must wait for services, it is expected they will receive additional information and referral services to assist them in meeting the needs of their family member while they wait.
5. Identifying people for services from the PUNS waiting list.
 - a. The Division has adopted the PUNS database as its waiting list, to identify people for services who do not meet the crisis criteria. This change was done in an effort to encourage transparency and to ensure equity in the potential to be selected for services.
 - b. These selections are funded primarily by attrition and, when possible, through additional appropriations made available for this purpose.
 - c. The Division will continue to work with the PUNS workgroup and other appropriate groups to finalize criteria for selection. Current discussion is focusing on the importance of selection to be made based on urgency of need and other factors, like geography.
 - d. The Division is using criteria currently approved in the Medicaid waiver. It is expected this criteria will be modified to reflect the work of the PUNS workgroup and the Ligas consent decree.

- e. It should be noted that children are selected for service based on randomness, length of time on the database and urgency of need.
6. Complete a full eligibility screening process.
 - a. At this point, when the person has met the crisis criteria, has been selected from PUNS, or has selected ICF/DD services, a full eligibility screen will be completed.
 - b. The Division will continue to identify options for improving the eligibility determination process. For example, clinical resources that become available within the Division may be able to provide assessments when other resources are not available or when there are additional concerns about eligibility not addressed in provided documentation.
 - c. The Division will clarify eligibility requirements for the waiver. There continues to be some level of confusion about eligibility for those with 'related conditions.'
 - d. A policy that provides guidance on assessing deficits in the 3 of 6 life skill areas will be developed as the "active treatment" requirement is removed from the waiver.
 - e. The Division continues to work with the Waiver Ad-Hoc committee and is open to discussing eligibility options for those with dual diagnosis and other challenging issues. In addition, DDD and DMH continue to work together to develop a more effective model for serving this population in the community and in state institutions.
 7. A full person-centered plan is developed and based on that and other information, a budget amount or rate for services is determined and the person chooses a service model (provider, self-directed or a mix).
 - a. At this point, the person, their family and others that are identified as part of their Individual Support Team will develop a full person-centered plan.
 - b. The PCP process will be led by a person or entity, specifically trained and approved by the Division to facilitate person-centered planning processes.
 - c. The Division will identify criteria for acceptable person-centered planning, to ensure the plans are truly person-focused, thorough and appropriate, but does not expect to limit or prescribe specific modalities.
 - d. The Division will work with the Waiver Ad-Hoc Committee, the Rate Sub-Committee and other groups to develop a funding methodology that appropriately reflects rates that are driven by sound policy goals, fiscal realities (good and bad), equity and individual need.
 - e. The Division expects to use this process to enhance the opportunity for people served to live in smaller settings and have available a full range of options for day activities and residential services.
 - f. The development of a new rate structure provides the opportunity to review and, where needed, more appropriately fund critical clinical services.

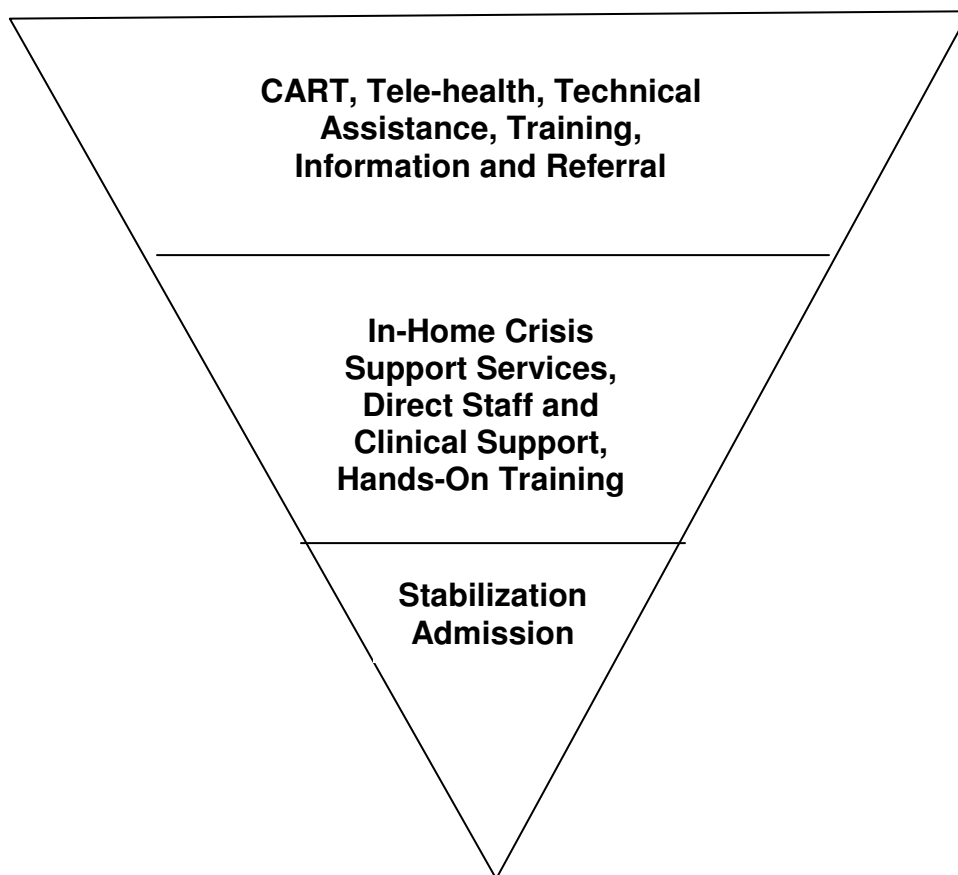
- g. Recommendations of the Rate Sub-Committee and developments made as the new waiver is developed will also be considered and appropriately adopted in the current waiver.
 - h. In order to maximize flexibility, we will work to implement a system that provides a multitude of options. Including, an individual budget allocation option, a traditional provider option or a mix of the two options.
 - i. The recommendation that rates for all options (self-directed services, traditional provider services on the waiver, and even ICF/DD rates) be established through the same process will be reviewed and considered as DDD proceeds. Clearly, significant changes will need to be made to statute and rules to implement similar rate methodologies across all of these systems.
- 8. The Individual Support Team develops the Individual Support Plan based on the person-centered plan.
 - a. Development of an Individual Support Plan that reflects and long-term goals identified in the person-centered plan will be key to the overall satisfaction and success of those served by the Division.
 - b. Completion of the ISP will be done as part of the IST process and will be led by a trained professional appropriately approved by the Division.
 - c. In conjunction with people served and families, the Division expects to establish improved and enhanced requirements for the ISP. Requirements will reflect an expectation that the process is person-centered and that the goals in the plan are meaningful and appropriate for the person served.
- 9. Services begin.
 - a. With projects currently underway in the Division, it is estimated that the waiver program(s) will significantly increase and expand over the next 6 years:

Estimated Waiver Growth



- b. As waiver services expand, it is expected that the ICF/DD system and the SODC system will adjust to reflect census changes as people transition from those systems to waiver services.
- c. In preparation for the impending changes in the service system, the Division recently expanded its partnership with SIU-School of Medicine. The goal of the new initiative is to develop a system-wide capacity report that will provide an analysis of the extent to which vital services are available for people with developmental disabilities throughout the state.
- d. Use of this report to assess what services are needed and where, will drive efforts to fill gaps in the system and ensure all people have reasonable access to services.
- e. Once a clearer picture of where and what types of services need to be developed, the Division will initiate a plan to fill the service gaps.
- f. This process is expected to require the development and expansion of all types of services – residential, day activities, clinical, dental, behavioral, therapeutic, etc. – throughout the state.
- g. In order to address the need, the Division will develop a clinical service system that will involve universities, community service providers and appropriate SODCs, based on the specific need identified in a given area and the most effective method or mechanism for meeting that need.

- b. The Division will adopt and modify policies, procedures, rules and regulations based on information garnered from analysis of the quality data.
 - c. As new programs are modified and new programs introduced, quality data will be used to analyze and modify the programs, as appropriate.
13. As needed, a full crisis support system is available during behavioral, medical or other crisis.
- a. The Division will develop a full crisis response system in order meet the needs of those in crisis, their families and their providers.
 - b. The crisis system will include a variety of components and will be focused on preventing a person from having to leave their home:



Next Steps

1. Gather in-pu from advocates and stakeholders.
2. Develop a more detailed plan with benchmarks and specific timeframes.
3. Finalize the plan, begin implementation and tracking to benchmarks.