



Access and Choice Design Team Final Recommendations

Team Meeting Dates:

June 20, 2011

July 13, 2011

July 29, 2011

August 16, 2011

August 29, 2011

Contents

Executive Summary	Page 2
Introduction	Page 5
Team Recommendations.....	Page 7
Follow-up Design Questions.....	Page 25
Attachment 1: Needs Assessment Charter Questions (Detailed Responses).....	Attachment 1
Attachment 2: Assessment Tools Technical Subgroup Report.....	Attachment 2
Attachment 3a: Commitments to Choice.....	Attachment 3a
Attachment 3b: Essential Aspects of Individual Choice.....	Attachment 3b
Appendix A – List of Team Members	Page 24
Appendix B – Team Charter.....	Page 26
Appendix C – Resources Used by the Team.....	Page 28



I. Executive Summary:

The purpose of the Access and Choice Design Team is to make recommendations related to waiver and service access and eligibility that addresses each individual's choice and goals, health and safety needs, and rights in the most appropriate community setting with an equitable level of resources/services appropriate to each individual's unique needs. Over the course of five Access and Choice Design Team meetings between June 20, 2011 and August 29, 2011, design team members explored key challenges and brainstormed ideas and recommendations related to the multidimensional and systemic topics outlined in the team's charter.

Design team meetings were supplemented by research and analysis, particularly the work of the Assessment Tools Technical Work Group. This work group was chartered by the team to review specific assessment tools used by other state systems serving people with developmental disabilities in order to provide more specific information for the full team to consider in making recommendations related to valid and equitable needs assessment tools and processes.

The Access and Choice Design Team Charter aligns into the following recommendation categories:

- (1) **No Wrong Door** - Options and considerations to ensure that there is "No Wrong Door" for people with developmental disabilities so that those who need services can access them no matter where they start in the process (e.g., voluntary agency, county social services department, another state agency), and that people needing cross-system services have access to necessary services without regard to state agency auspice.
- (2) **Needs Assessment** - Key factors that need to be considered and integrated to achieve the People First Waiver objective of "a standardized needs assessment instrument and/or tool that will be consistently applied across the People First Waiver to determine each individual's strengths, needs, and preferences. This needs assessment tool will be used to allocate resources equitably and will be administered by an entity that is independent from service delivery." (from Design Team Parameters)
- (3) **Choice in a Managed Care Environment** - Essential aspects of individual choice that should be integrated into the People First Waiver within the managed care/care management structure.



The following is a summary of the Access and Choice Design Team’s recommendations. More detail on these recommendations is included throughout this report.

Recommendation Categories: #1, No Wrong Door #2 Needs Assessment #3 Choice	Summary Recommendations	Page Number(s) for further details
1. No Wrong Door		
✓	Enhance the focus of the NY Connects Statewide Council to integrate No Wrong Door for people with developmental disabilities and other special needs populations.	7, 14-19
✓	Enhance OPWDD’s web portal to create a two-way, online Web portal that provides information as well as accepts information from users. The Web portal should connect to NY Connects and should include the following features: accessibility for people with developmental disabilities; comprehensive information and user friendly search tools; educational and training tools; direct support professional worker registry; local portals through OPWDD Developmental Disability Services Offices (DDSOs) for local community resources and information.	7, 14-19
✓	Clarify roles, responsibilities, processes and procedures related to accessing supports and services and equip DDSOs and a coordinating unit within OPWDD’s Central Office to deliver No Wrong Door functions specific to providing information and referrals across systems for people with developmental disabilities.	7, 14-19
2. Needs Assessment		
✓	Ensure demonstrated independence of the initial needs assessment that drives a resource level from organizations that conduct care coordination, entities that are paid to deliver services, and entities that receive capitated payments.	7-13
✓	Develop and/or adopt needs assessment tools that are person-centered and include assessing the strengths of the person, the family, natural supports as well as recognizing the person’s support needs. Ensure that assessment tools can assess predictive risk factors and transitional support needs. See recommended assessment domains in the report. These assessment tools need to seamlessly lead to a comprehensive person-centered plan.	7-13
✓	Ensure that there is clarity of purpose and transparency so that all individuals and stakeholders understand the assessment tools, what they are used for, and how they are to be applied.	7-13



Recommendation Categories: #1, No Wrong Door #2 Needs Assessment #3 Choice	Summary Recommendations	Page Number(s) for further details
✓	Incorporate regular assessment of health and safety factors to ensure proactive planning and risk mitigation strategies with the person in the comprehensive care planning process. The team recommends that a tool like the Health Risk Screening Tool (HRST) be explored through pilot projects to ensure that this objective can be met.	7-13
✓	Design pilot projects using the Supports Intensity Scale (SIS), the Health Risk Screening Tool (HRST) and other appropriate needs assessment instruments.	9, 13, 25
✓	Ensure consistent training and ongoing skill building, educational requirements, and quality review and other checks and balances (e.g., ongoing testing for assessors to ensure objectivity and inter-rater reliability) to ensure consistency in the administration of the needs assessment system.	11, 12, 15, 17-23
✓	Develop an information management system that integrates No Wrong Door, electronic records, assessments, care plans, service utilization, quality management and other aspects of the new system.	13, 19
✓	Ensure a thorough and iterative testing and development process of assessment tools before finalization and implementation.	13
✓	Engage consultants to conduct cost-benefit analyses to determine whether OPWDD should adopt a national tool such as the SIS or adapt the Developmental Disabilities Profile (DDP) or the Child and Adult Needs and Strengths (CANS) instrument for initial needs assessment that drives a resource allocation level and also for ongoing assessment related to the person-centered care planning process.	12, 25
3. Choice in a Managed Care Environment		
✓	Informed choice as an outcome and quality indicator: “Informed Choice” as defined by our stakeholders should continue to be a goal and outcome for all individuals in the waiver. Care management/care coordination entities should be assessed for their ability to help people make informed choices and deliver on those choices. The outcome should focus on entities creating support for individual goals through informed choice and person-centered planning.	8, 17, 20-22
✓	Person-centered Planning: There must be a real commitment to person-centered planning. Care coordination and other applicable personnel should be required to receive training and certification in person-centered planning and should be evaluated for their competencies in this area. Developmental Disabilities Individual Support and Care Coordination Organizations (DISCOs) should be	8, 10, 16, 19-23



Recommendation Categories: #1, No Wrong Door #2 Needs Assessment #3 Choice	Summary Recommendations	Page Number(s) for further details
	reviewed for their commitment, service delivery, and outcomes related to person-centered planning and service delivery.	
✓	Independent Advocacy: A formal mechanism/process for independent advocacy will be needed in the new system to ensure that individuals and family members are assisted in making informed choices that best meet their needs and interests.	19, 21
✓	Self-Directed Service Options and the Ability to Self-Hire: Self-directed service options and the ability to self-hire neighbors, relatives, friends, and others of the person’s choosing should be widely available along a continuum of options which include budget authority and employer authority.	16, 21
✓	Provide flexible funding options and incentivize sustainable support options desired by individuals: Flexible funding options such as stipends to individuals and families should be made available to be used at the discretion of the individual/family for any legal goods, services, or activities that enable the individual to live with their family or others in non-certified settings. Options that individuals and families want that are person-centered and outcome-oriented such as employment supports, shared living, transitions to non-certified settings, and other sustainable options should be incentivized and supported.	21
✓	Employment: All DISCOs and/or their contractors should have outcome-oriented employment supports that are tailored to individual needs.	22
✓	Direct Support Professionals and Care Coordinators: Create competencies, career ladders, and higher pay for experienced professionals. Ongoing training and certifications in person-centered planning and other necessary skills should be required.	22
✓	Portability, diverse provider networks, ability to go outside of the care management network and elimination of artificial region constraints should be incorporated in the new system.	21

II. Introduction:

The Access and Choice Design Team began its work by discussing key challenges associated with accessing needed supports and services in OPWDD’s current system. The team explored the following challenges:

- The breadth of available service options
- Gaining access to the appropriate supports



varies by geographic location, and choice is restricted to available options.

- Service demand is frequently greater than the resources available for supports and services.
- The infrastructure to support more individualized service options differs geographically.
- Accessing clinical evaluations needed to establish developmental disabilities can be expensive and difficult when there is a lack of qualified practitioners in more rural areas.

when a person's needs cross system services (e.g., mental health and developmental disability) is difficult.

- Priority needs are not consistently managed across districts and agencies resulting in varying access for individuals; Current administrative practice can limit portability and the individual's choice of services and providers.
- OPWDD has numerous providers with varying areas of expertise, but accessing the provider that best fits an individual's needs can be a challenge.
- The current needs assessment tool (the Developmental Disabilities Profile) is inconsistently applied and not used for statewide needs assessment processes.

Guided by the design team parameters that state there will be valid needs assessment that leads to equitable resource distribution, the team recognized that assessment is a fundamental and foundational component of the People First Waiver. The team formed a cross-team technical work group to review assessment tools used in other state systems for people with developmental disabilities in order to better inform the Access and Choice Design Team in making charter recommendations. The technical work group was provided with a list of known specific assessment tools and detailed questions to address for each tool. Each work group member was assigned one assessment tool to investigate and report back to the full Design Team. A final report of the Assessment Tools Technical Work Group was compiled and is contained in **Attachment 2**. The work group report was presented and shared with the full Design Team. Using the work of the technical work group, design team members explored the factors and support needs that should be considered in needs assessment instruments that drive resource allocation decision-making and the factors that should be considered in the administration of systems-wide needs assessment. **Attachment 1** is the team's deliverable associated with this effort.

In other design team meetings, the team explored "No Wrong Door" by reviewing and discussing information from other states and coming up with a series of broad recommendations. The team also focused on individual choice in managed care and developed a series of recommendations during the design team meetings and by completing and submitting "homework". The team's detailed recommendations regarding the essentials of individual choice in managed care are contained in **Attachment 3a and 3b**.



III. Team Recommendations

A. **Charter Question 1: What is not working in the current developmental disability service delivery system related to access and eligibility that needs to be reformed in the People First Waiver?**

The team believes that the following service system reforms are needed:

- (1) **Real person-centered planning is needed:** There needs to be a real system for person-centered planning that includes real tools and strategies. A person-centered focus must first discover the person's life goals and outcomes (where he/she wants to live; what he/she wants to learn and do; who he/she wants to be with, etc.). There must be enough time dedicated to understanding the person before a person-centered plan is developed. The person-centered plan should also include a description of the person's environmental assets, family, friends, etc. Services are tools that help people accomplish their goal. Getting a lot of service is not the end goal. Rather, the right level and type of services can help people grow and meet their goals and personal outcomes. By developing an understanding of each person through person-centered planning and by helping people develop a life plan before a service plan is developed, we can help individuals/families/providers/systems focus on the right things.
- (2) **Statewide needs assessment is needed:** There must be valid, consistent and accurate statewide needs assessment that is strengths-based and flexible to identify needed service changes when the person's needs and circumstances change. The assessment tool should not be deficit-based or put individuals into predetermined service "boxes."
- (3) **Flexible and predictable funding options are necessary:** Currently, there is too much fear that resources will not be there when they are needed. This fear drives individuals and families to take whatever they can get, whenever they can get it, regardless of whether it is needed at that time. In order to ensure that resources are available when they are really needed and individuals/families receive the right supports/services at the right time and in the most appropriate community setting, flexible and predictable funding streams based on accurate and reliable needs assessment is essential. There must be real and clear expectations and ability to deliver on these expectations if we are to rebalance the service system. There must also be real incentives for people and providers to assist individuals to transition from 24-hour staffed settings (see 4 below).
- (4) **We need more individualized and sustainable services/supports options:** In accordance with number 3 above, OPWDD must have service and support options between the "Cadillac" (all inclusive) service package and little or nothing. There needs to be more options for flexible supports and services in non-certified settings including behavioral and crisis supports; blended service options that enable the same staff to provide any type of assistance the individual needs; and shared living assistance and other innovative non-certified residential options.
- (5) **Self-directed options need to be offered to all individuals:** Self-directed service options such as Consolidated Supports and Services (CSS) needs to be offered to all individuals. People should be made aware that such options exist and be given an "informed choice" as defined by our

stakeholders. Self-directed services and all service options must be user friendly, easy to access, and responsive.

B. Charter Question 2: *Review the information provided from other states in relation to the following needs assessment and resource allocation questions.*

- *Should the needs assessment process be independent from care coordination?*
- *Should it be independent of the entities that deliver services and receive payment for service delivery?*
- *What are the various options for entities/organizations that should be considered to carry out the needs assessment?*
- *What are the advantages and disadvantages of each option?*
- *What should the state and/or OPWDD's role be in the needs assessment process?*
- *What are the factors and support needs that should be considered in assessment and the resulting resource allocation decision making for the various subpopulations?*
- *What are the options for how resource allocation decision making can be correlated to needs assessment?*
- *Given that the federal government requires at least annual redetermination for ICF/MR level of care, how often should the People First Waiver needs assessment (and related resource allocation) decision making be reassessed/re-determined?*
- *How should changes in life circumstances and individual goals relate to the needs assessment process for people with developmental disabilities and various subpopulations?*

Although there are a variety of tools and instruments that are used in OPWDD's system to assess needs, there currently is not a consistent statewide system or process that leads to reliable and valid needs assessment that drives resource allocation decision making. As OPWDD's system transitions to a managed care environment, the development of statewide needs assessment is essential to the success of an integrated care management system.

Recognizing that some preliminary research on assessment tools used in other states was necessary to assist the Access and Choice Design Team to make recommendations on their charter, the team established the Assessment Tools Technical Work Group to review:

- the two national needs assessment instruments used in state systems for people with developmental disabilities (i.e., the Supports Intensity Scale (SIS) and the Inventory for Client and Agency Planning (ICAP));
- the Child and Adult Needs and Strengths (CANS) instrument developed by John Lyons and adapted by various states for planning purposes;
- state-specific needs assessment instruments from Wisconsin, Florida, and Connecticut.



- The team also reviewed the Health Risk Screening Tool (HRST), a web-based health screening instrument that detects the potential for health destabilization early in vulnerable populations.

It is important to note that there is not one needs assessment instrument or tool that will enable us to achieve valid and equitable needs assessment. This is an area with which that all states struggle, and there is no perfect solution. The options available to OPWDD appear, on the face, to include the following:

- Adopt a nationally recognized tool in the field of developmental disabilities and develop policy and process to support this tool. The team identified two nationally known assessment instruments in the developmental disability (DD) field—the ICAP and the SIS. Many states using the ICAP are abandoning it, as the ICAP is considered “deficit-based” and somewhat outdated. States typically utilize additional assessment tools along with these to get at more specific information (e.g., the Health Risk Screening Tool is used in some states along with the SIS).
- Modify and update the OPWDD Developmental Disabilities Profile (DDP) by adding elements and/or start with another state’s developed assessment and modify it for OPWDD’s needs.
- Adapt the Child and Adolescent Needs and Strengths (CANS) instrument and modify for OPWDD’s needs.

Regardless of the specific assessment tools to be used, the following are the preliminary recommendations that the team identified as essential to the overall People First Waiver needs assessment system:

From the Individual’s Perspective:

- **Person-centered and strengths based approach:** A person-centered approach must be inherent in needs assessment and resource allocation. Needs assessment should start with communication about the person’s strengths, life goals, and desired outcomes. Identification of the person’s life goal’s and desires should speak to the individual’s home, health, meaningful relationships, meaningful work, and community inclusion as determined through assessments, interviews, clinical assessments, observations, and person-centered planning.
- **Assessment Domains:** The team recommended that assessment include the following domains:
 - Life goals and person’s desires in the area of home, health, meaningful relationships, meaningful work/community inclusion should come first (see above bullet).
 - Strengths and abilities of the person: identification of assets that the family and the individual bring with them when seeking supports and services.
 - Caregiver needs (e.g., presence and stability/reliability of natural supports)
 - Social life

- Comprehension abilities
 - Communication abilities
 - Personal care
 - Health/Medical
 - Daily living skills
 - Employment
 - Behaviors (that interfere with life goals)
 - Mental health needs
 - Safety
 - Support
 - Educational needs
 - Housing needs
 - Transportation needs
 - Culture and ethnicity information/preferences (i.e., ensure multicultural/family history needs are identified and expressed at the time of assessment).
- **Holistic and comprehensive person-centered care plan:** The assessment/assessment tools must seamlessly support development of a holistic, comprehensive, person-centered plan.
 - **Flexibility, predictability, and “no automatic pilot”:** Needs assessment that drives resource allocation needs to be flexible and responsive to addresses emergency and crisis needs. Flexibility is needed to adapt to changes in the person’s support needs (e.g., if a primary caregiver is ill). Resources should be available when people need them so individuals/families won’t need to enroll in as many things as they can (even if they don’t need the supports/services at the moment) to be sure services are available at a later time when they might need them.
 - **Teaching skills proactively:** New skills must be learned as individuals prepare for life transitions. We must be willing and able to teach skills to assist a person to be prepared for new phases in their life. If an individual wants to move from their parents’ home into an apartment, they should possess basic skills prior to the move. Their plan must be flexible to teach skills prior and then assure the transfer of skills once the move occurs.

From the Systems Perspective:

- **Clarity of purpose and transparency:** The purpose and use of the needs assessment process must be clear and transparent. All aspects of assessing need and determining eligibility and resource allocation needs to be transparent. This means that individuals and other stakeholders have easy access to information that explains the process and the tools/methods that will be used. Individuals and other stakeholders should also have access to the resource allocation and funding methodologies/formulas. This information should be publically available on OPWDD’s Web site.
- **Independent from paid providers:** There must be demonstrated independence of the initial needs assessment that drives a resource level from organizations that conduct care coordination,

entities that are paid to deliver services, and entities that receive capitated payments. The team believes that conducting the initial needs assessment may be an appropriate role for the State if there is qualified staff, capacity, and ongoing intensive training. (See recommendation below regarding “intensive and ongoing training and education.”) In addition, the “independence” of the initial needs assessment and ongoing needs assessments should be reviewed in quality reviews to ensure that there are no biases that have resulted in inappropriate referrals for the person and/or referrals that are not made in the best interests of the person.

- **Intensive and ongoing training and education:** As the accuracy and efficacy of any needs assessment instrument and system is largely based on the screening skills and knowledge of the people conducting/administering it, there must be consistent training and ongoing skill building, educational requirements, and independent quality oversight/quality review as well as other checks and balances. In addition, cursory review and discussion with other states indicates that the validity of the needs assessment system is enhanced when there are fewer individuals charged with conducting needs assessment and the needs assessment process/system is not too decentralized. This suggests that the fewer people/organizations charged with conducting needs assessment, the more reliable the results will be as there can be greater focus on ensuring that all assessors have capacity, are properly trained and have ongoing skill building.
- **Reassessment:** Best practice should dictate the frequency of administering formal needs assessment. Reassessments should be triggered whenever the individual’s condition changes (e.g., medical needs, change in level of natural supports, change in behavior, new goals, employment). However, all person-centered comprehensive plans should be reviewed at least annually for any necessary changes.
- **Neutral dispute resolution:** There should be a neutral grievance and dispute resolution system for disagreements related to needs assessment, eligibility and resource allocation decisions.
- **Fair and equitable allocation of resources:** The People First Waiver will include an independent needs assessment that will ensure equitable resource allocation. This means that the people who conduct needs assessment won’t be the same people that receive Medicaid funding. Because needs assessment will be tied to resource allocation, it is important that a separation exists between the entity determining Medicaid funding and the entity receiving Medicaid funding. With equitable resource allocation, Medicaid funding will be distributed in a manner that is fair and balanced.
- **Quality review and oversight:** Reviews of assessments should be independent from the needs assessment and care coordination processes. The State should have ultimate oversight of needs assessment and care coordination to ensure that the individual’s needs are being met as determined in the assessment and described through a comprehensive care plan.



- **Inter-rater reliability:** Training and ongoing testing for assessors to ensure objectivity and inter-rater reliability is critical.

A systems-wide transition to a statewide needs assessment tool is a major part of the infrastructure necessary to effectuate the People First Waiver. Lessons learned from other states indicate that this transition must be carefully planned to ensure we select from among the best possible alternatives. As each of the above options requires further review, analysis and cost benefit study, the team recommends that a knowledgeable and qualified consultant be employed to analyze OPWDD's options in terms of costs, benefits, implementation workload, resource allocation potential and applicability, and information management systems and provide OPWDD with specific information with which to make an informed decision on how best to proceed.

The team also recommends that a thorough and iterative testing and development process occur before finalization of any new assessment tool. Basic principles of reliability and validity must be adhered to for any proposed combination (or revision) of tools adopted for the People First Waiver. These include: internal consistency of additive indexes or scales, inter-rater reliability, and test-retest (or intra-rater) reliability. Validity judgments should encompass criterion validity (i.e., the tool can clearly distinguish between many types of people and their support needs), construct validity (demonstrated assurance that items truly measure the intended topical constructs), and content (or face) validity as perceived by the most relevant stakeholders.

Third, the team recommends that pilot projects could be designed to "test" the Supports Intensity Scale (SIS) and the Health Risk Screening Tool (HRST), as these instruments could be considered "ready to go" for initial piloting. One particular pilot project to consider would be to assess individuals enrolled in Consolidated Supports and Services (CSS), as these individuals have an individualized budget or personal resource account derived from OPWDD's Developmental Disabilities Profile (DDP). It is also important to design pilots that have a representative sample of individuals selected for the pilot to ensure that assessment tools are sensitive enough for the wide range of needs exhibited by individuals with developmental disabilities (e.g., people with acute medical needs; people with strong need for behavioral supports; etc).

- C. Charter Question 3: *Given that our system is moving to a care management environment with a specialized health home for care coordination for people with developmental disabilities:***
- 1. *What are the various options (and the advantages and disadvantages of each) to ensure that there is “No Wrong Door” for people with developmental disabilities (and the various subpopulations such as children, medically frail, etc.) so that those who need services can access them no matter where they start in the process (e.g., voluntary agency, county social service department), and that people needing cross-system services have access to necessary services without regard to state agency auspice?***
 - 2. *How should information technology work to best support information sharing and access through “No Wrong Door” both within OPWDD’s service system and across systems?***

Summary:

Though methods may vary, the universal philosophy and purpose behind a No Wrong Door model is that nobody will be lost or excluded in attempting to access assistance, services and supports through the long-term care service delivery system where services are provided through multiple agencies/services/resources. A No Wrong Door model should ensure that individuals are directed to the right place and appropriate resources for their needs regardless of where they start in the process (i.e., if they start from a Web site; an email address; a telephone number; a location such as a county office, a provider, a state agency, a state agency’s regional office, etc.). While No Wrong Door and Single Point of Entry are often used interchangeably, Single Point of Entry models are intended to provide smooth access to long term services through one agency or organization which sorts out the range of care alternatives and helps people make decisions about the best and most feasible care alternative. Conversely, a No Wrong Door system assists people in need to connect with needed services across systems and agencies no matter where they begin the process—this happens through coordination among agencies making one-stop shopping possible (O’Shaughnessy). Research by the team indicates that the most effective models include the best aspects of both Single Point of Entry and No Wrong Door models.

The federal government has conceptualized a vision and infrastructure for providing seamless access to integrated long-term services and supports called Aging and Disability Resource Centers (ADRC). Through the use of No Wrong Door and Single Points of Entry, ADRCs provide assistance for people of all ages, disabilities, and income levels (O’Shaughnessy, November 2010). Recent legislation has called for the creation of ADRCs in all states, and the State of New York has obtained a grant for use in initiating an ADRC. The federal government has defined five key functions to serve as requisites for becoming a fully functional ADRC: (1) information and referral/awareness; (2) options counseling; (3) streamlined eligibility determination for public programs and streamlined access to services; (4) person-centered



transition support; (5) quality assurance and continuous improvement. (O’Shaughnessy). Methods for implementing these functions include: establishment of ADRC locations across the state; statewide call centers; publicly accessible databases of information and resources across the state; co-location of staff from various agencies; and various combinations of these methods.

The State of New York initiated an ADRC in 2006 through a joint initiative between the New York State Office for the Aging (NYSOFA) and the New York State Department of Health called NY Connects. NY Connects operates in several counties across the state to enhance the delivery of long-term care services through a single coordinated system of information and assistance. It minimizes confusion, supports informed decision-making, and enhances consumer choice. It connects individuals of all ages needing long-term care to the necessary services and supports regardless of available payment source, be it private pay, public or a combination of both. Key feature of NY Connects are Long Term Care Councils in each participating county. The Councils are made up of individuals, caregivers, providers, advocates, government representatives including Area Agencies on Aging (AAA) Directors, Local Departments of Social Services (LDSS) Commissioners, and other key stakeholders who come together to analyze the local long-term care system, identify gaps, duplication and barriers in the system and make recommendations for improvements. The Councils use their findings to work toward a system that is more streamlined, efficient, and responsive – a system that helps people remain at home and in the community. A State level Council guides the overall policy and work of NY Connects. More information on NY Connects can be found at the following link: <http://www.nyconnects.org/index.shtml>.

The team’s research indicates that in order to implement an effective and comprehensive No Wrong Door model for people of all ages, disabilities and income level there must be buy-in from the highest levels of government and collaboration on its development through the heads of all applicable state agencies. As New York State has already initiated NY Connects, an example of a No Wrong Door model, that has been developing over the last several years, the Access and Choice design team recommends a multi-level approach to ensure that there is “No Wrong Door” for people with developmental disabilities who need to access specialized long-term care services as well as services accessed by the general aging and disability community. The following are the team’s recommendations:

1. Enhance Focus of the State’s ADRC and New York Connects Statewide Council on No Wrong Door for People with Developmental Disabilities:

NY Connects already has a state level council that oversees and guides NY Connects. This council could be enhanced to focus on creating No Wrong Door for people with developmental disabilities through the 1115 waiver across the state, local level, and through private providers and OPWDD’s care management entities.

An enhanced interagency council could help facilitate No Wrong Door for special populations including people with developmental disabilities by developing consistent cross-systems educational and cross training initiatives geared to providing information and referral and options counseling functions, developing policy and procedures for universal application/assessment/financial eligibility screening



tools that work across agencies enabling individuals to complete one set of core application/assessment materials; work out arrangements to share staff and expertise across agencies, and other efforts to accomplish statewide No Wrong Door goals.

This council could also investigate the efficacy and feasibility of developing fully functional statewide cross-systems Aging and Disability Resource Center (ADRC) locations with co-located and/or cross trained staff to perform all ADRC/No Wrong Door functions. O'Shaughnessy points out in a November 2010 article from the National Health Policy Forum on ADRCs that a coordinated, but decentralized model relies on standardized individual intake tools and assessment procedures, formal referral protocols, and electronic data sharing systems. Only by coordinating and standardizing these functions across agencies can we truly have a No Wrong Door.

2. Enhance OPWDD's Online Web Portal and Connect to NY Connects:

The team recommends enhancement of OPWDD's existing Web site to create a two-way online Web portal that provides information as well as accepts information from end users. It would include all information relevant to OPWDD's service system and provide ***cross-systems access to information on supports and service options offered through other systems***. The Web portal must be user friendly, person-centered, and acronym and silo free.

The Web-based portal could function as an information hub to bridge together the fragmented infrastructure of the service delivery system across state agencies and regions. Key ways in which the Web site could accomplish these goals include provision of information and tools for education assessment, care coordination, and person-centered planning, data compilation, linkages to other relevant state agencies and non-governmental developmental disability agencies, as well as providing instruments to facilitate the development of positive relationships.

The team recommends that the two-way, online Web portal include the following specific features:

- **Accessibility for people with developmental disabilities** in accordance with Americans with Disabilities Act (ADA) requirements and best practices (e.g. drop-down menus to change language and the visual appearance of information based on comprehension; diagrams and pictures to help guide individuals with developmental disabilities through the maze of information, etc.). The Web portal can also include a live-chat option to allow individuals to talk to informed representatives. Phone numbers and addresses to physical locations will also be prominently displayed to ensure that individuals have the choice of multiple ways ("doors") to access supports, services and related information.
- **Comprehensive information covering every aspect of the system and user friendly search tools that can be used by county/local officials, providers, state staff, family members, advocates and people with developmental disabilities:** Representatives that talk to individuals using live-chat or telephones will have the tools necessary to respond to questions in real time.

- **Easy to use tools for finding supports and services:** Individuals will be able to learn about different entities to help them make informed choices. Specific features such as online transportation scheduling should be developed to bridge gaps within the service delivery system.
- **A section dedicated to self-directed services:** This section will provide information and tools such as calendars and budget calculators to ensure ease of transition to less restrictive settings.
- **Educational and training tools for people needing to access services as well as people delivering services:** A glossary of terms and pamphlets relating to the developmental disability system will be available online in multiple formats.
- **Worker registry:** Individuals who choose to exercise employer authority by hiring friends, family members and/or neighbors should have access to a statewide worker registry to find pre-screened individuals to provide supports and services in the event that a self-hire becomes unavailable. Intake, screening and training of workers can be performed at ADRC-like organizations. Workers that register can choose to be added to a listserv that sends electronic notification of job opportunities and training programs.
- **Enhanced links to community-based resources at the local level through DDSO/regional No Wrong Door Web portals:** Each DDSO could have a Web portal off the main OPWDD portal that provides specific information for individuals and providers in the geographic area and includes all the features of the main OPWDD two-way Web portal.
- **Care Management/Care Coordination linkages:** The two-way Web-based portal described above would link the person to care management/care coordination options and would enable the care coordinator to link to the system. Real time answers would be available as well as on-line training and resources for individuals, family members, care coordinators, and provider staff.

It is important to ensure that key aspects of the enhanced Web portal are designed for people needing to access and learn about supports and services and how to get them rather than a public-relations type approach to provision of information about OPWDD and the system. A simplified homepage could be divided into three pathways: the first would be for people who aren't familiar with the DD system, the second could be for people who know what services they want, but don't know where to find them, and the third pathway could be for individuals who would like to know more about the array of services. The state of Virginia uses a similar construct for their DD system (see <http://www.easyaccess.virginia.gov/>). The homepage serves as a "single entry point," and the links to different pathways can be seen as unique options to ensure that there are "no wrong doors."

Accessibility can also be increased through the use of media. Educational videos and games can be posted for different audiences. Individuals transitioning to less restricted settings will be able to find



information about subsidized housing, self-directed services and techniques to increase self-sufficiency. Besides tools to enhance system navigation for individuals and families, the web portal can also improve the performance of service providers. Training videos, manuals, assessment tools, person centered planning tools, care coordination tools and other information will ensure that employees, individuals, and families seeking services have universal access to comprehensive materials that can help them access the system and meet goals and objectives.

3. Clarify roles, responsibilities, processes and procedures internal to OPWDD and externally (e.g., other state agencies, Care Management/Care Coordination entities, providers, etc.) related to accessing the system of supports and services and equip DDSOs to deliver No Wrong Door functions.

There needs to be statewide consistency and transparency in how individuals access the system of supports and services.

In order to accomplish this, there must be statewide policies and procedures.

There must also be an **Information Technology Development/Platform** that integrates all components of the new delivery system (i.e., online Web-based portal, electronic records, assessment information, etc.).

All staff both internal and external to OPWDD that have contacts with individuals/family members seeking services need to understand specifically how to direct the person to the right “door” for information on how they can access services and supports.

Each OPWDD Developmental Disability Services Office (DDSO) should have a unit that is responsible for No Wrong Door functions within the district. Staff from this unit should be connected to the NY Connects local councils. OPWDD Central Office should have a function specific to policy/procedures related to service access to ensure statewide consistency across the districts, to liaison with other state agencies and NY Connects, and to ensure that systems that are put in place for No Wrong Door work as intended and may be adjusted as necessary.

4. Early Touch/Light Touch:

An “**early touch**” is needed to point individuals and families in the right direction before they get to the wrong door. The idea is to make contacts earlier in the person’s life to set the stage for better integration and realistic expectations throughout the person’s life. This recommendation requires better and enhanced coordination with the New York State Education Department (NYSED) and Early Intervention (EI) as well as a statewide management information system. It is recommended that ongoing collaboration between stakeholders such as the Department of Health, the Office for Persons with Developmental Disabilities, the New York State Department of Education, New York State Office for



Aging, Local Departments of Social Services, Centers for Independent Living, provider agencies, etc. continue to ensure that each entity is apprised of operations and best practices related to health and human services so that individuals who access these diverse entry points will be directed to the right door.

Conclusion: “No Wrong Door”:

The proposed recommendations are intended to reduce administration costs, increase ease of access and awareness for individuals with all levels of capacity, and create an infrastructure that will be equipped to effectively respond to the growing number of individuals requiring services.

How “No Wrong Door” will help individuals: Many individuals and families are not fully aware of the array of services provided or how to get them once they qualify. The online portal will serve to prevent the circumnavigation caused by redundant phone calls and in-person visits. Individuals will be able to access information from the Web site to find the right numbers to call and the right places to visit. Twenty-four hour online support (or extended business hours such as 7:00 a.m. through the dinner hour) will allow people to engage in a live chat without having to leave their home. These features are especially beneficial for those who have difficulty finding transportation, such as those who live in remote areas. The online portal can also ease the complexities faced by individuals with multiple diagnoses or dual eligibility. Instead of replacing in-person contact, the No Wrong Door Web portal will ensure that quality time is spent with staff members by eliminating administrative inefficiencies and freeing valuable resources. As a result, individuals who do not have Internet access or prefer office visits will spend less time waiting. The efficiencies created by the portal will also ensure that more human resources are devoted to assessment, care coordination and person-centered planning.

How “No Wrong Door” can benefit providers: Care management entities will benefit greatly from an online portal. Electronic record keeping will streamline care coordination and service provision in addition to allowing different agencies within a network to access the same information. This will reduce costs by eliminating the need for unnecessary retesting and interviews. In addition to streamlining the activities conducted within care management networks, the vision for the NYS No Wrong Door online portal is to serve as a conduit between the “silos” of different agencies. This portal can create a cross-systems, Web-based information management system that provides for cross systems assessment and universal application/eligibility tools to the maximum extent possible. This would enable a person needing services to complete one set of assessment and application materials that would be applicable across state agencies and eliminate duplication in administrative efforts for providers.

Implications for State Agencies: The fusion of the fragmented areas within the developmental disability system and related state agencies will better position each entity to provide an early touch to people who are not familiar with DD supports and services. It is recommended that early contact be made to set the stage for better integration and realistic expectations throughout a person’s life. Tools to ensure the success of early touch strategies include a comprehensive and standardized online manual (that can be printed) containing information about developmental disability supports and services in New York State.



The manual should include different sections for individuals, families and providers. This manual will be useful for people entering the system, as well as for individuals transitioning to less restricted settings. Additional materials and educational tools should be made available to ensure informed choice. Not only should individuals be apprised of the array of supports and services available to them, they should also be presented with the quality related expectations developed by OPWDD. This information will allow individuals, families and staff to provide useful feedback. Posting quality ratings on the online portal will create incentive for agencies to improve their services. Other quality assurance strategies can be enhanced using the No Wrong Door model. Educational tools such as training videos and webinars can be posted via the online portal.

D. Charter Question 3a: What aspects of individual choice should be built into a care management model for individuals with developmental disabilities?

The team engaged in substantive discussion regarding choice in managed care. A worksheet was developed that dissected choice into the following components:

- ✓ Care management/managed care organizations
- ✓ Service providers
- ✓ Supports that best meet the person's needs
- ✓ Initial and ongoing person-centered planning
- ✓ Self-direction via personal resource allocations/individualized budgets
- ✓ Independent advocacy
- ✓ Employment meaningful activities
- ✓ Living arrangement
- ✓ Choice of community integration activities
- ✓ Choice of how to spend free time
- ✓ Other

The worksheet (see Attachment 3b) outlined the current barriers and potential system challenges to be addressed in the 1115 waiver along with the desired characteristics and recommendations for what we need to have in managed care contracts to ensure individual choice. The team also discussed and completed a worksheet (see Attachment 3a) that outlines the commitments to choice that OPWDD articulated through communications with stakeholders and CMS and provided input on what design parameters could be implemented to meet these commitments.

As choice is a concept that cuts across all design teams, many of the team's recommendations on choice are echoed by other design teams. The following are the team's summary recommendations regarding the essential aspects of individual choice that should be integrated into the People First Waiver (See **Attachment 3a and 3b** for more detailed information from the team):

- **Informed Choice as an outcome and quality indicator:** “Informed Choice” as defined by our stakeholders should continue to be a goal and outcome for all individuals in the waiver. Care management/care coordination entities should be assessed for their ability to help people make informed choices and deliver on those choices. The outcome should focus on entities creating support for individual goals through informed choice and person-centered planning. The following is the definition of Informed Choice endorsed by the team:

“A person has made an informed choice when he or she has made a decision based on a good understanding of the options available and a good understanding of how that decision may affect his or her life.

A person can make an informed choice on his/her own or may ask family members, friends, or others for assistance if he/she needs help making a good decision. Informed choices can be about everyday things like what to wear, or big life-changing things like where to live, what kind of work to do, or who to be friends with. These decisions can also be about what kinds of services or supports someone wants or needs and where and how to get them.

When making an informed choice, a person should understand the risks involved and what can be done to reduce the risks. A person should also realize that his/her ability or desire to make choices may change over time or may be different for different kinds of decisions. Personal choices should be respected and supported by the people involved in the person’s life.”

It must be noted that decisions made by individuals may not always be the safest or most appropriate choice. Poor decisions can lead to consequences that can sometimes be significant and dire. Individuals and their families must understand and accept the responsibility that comes with making informed choices. Regulations should reflect the right to make informed choices, but also the responsibility and accountability that comes along with this right.

- **Incentivize person-centered planning/outcomes:** There must be a real commitment to person-centered planning and person-centered outcomes as a driving force in the waiver’s framework. Adequate resources must be devoted to changing the overall culture and paradigm to one that **values and incentivizes person-centered planning/outcomes**. There must also be a formal vehicle for person-centered planning that is incorporated into all aspects of planning for, delivering and evaluating the effectiveness of services for each individual. Adequate training and person-centered planning certification should also be part of this framework. Every individual should have the right to a real and viable comprehensive, person-centered plan based on at least the following:
 - ✓ Results of a valid needs assessment process that is independent from service provision and built upon a person-centered, strengths-based perspective;

- ✓ Meaningful input from the individual and his/her chosen circle of support and reflective of the cultural considerations of the person;
- ✓ Availability of independent advocacy and oversight (consider enrollment broker);
- ✓ Opportunities for updates and discussions at the request of the person or when needs and individualized circumstances change;
- ✓ Formal and informal strategies and processes to resolve disagreements that arise in the process; and
- ✓ Informed choice every step of the way.

Independent Advocacy: There needs to be formal mechanisms for independent advocacy and identification of what the expected outcomes of independent advocacy are for people. Advocacy in general should be a quality expectation for all care management and service providers. In accordance with independent advocacy, there should be discussion of having an enrollment broker or an independent entity to assist families and individuals in choosing a provider and services that best meet their needs.

- **Self-directed service options:** All individuals in the waiver should have the option to choose budget authority and/or employer authority. Individuals should be able to hire their own staff and be able to hire relatives and others that do not work for provider agencies. In accordance with the self-determination philosophy, self-direction opportunities should be offered along a complete continuum as opposed to all or nothing (e.g., choose budget authority or traditional; choose employer authority or traditional). Care management entities that are unable to provide or contract for the full continuum of self-directed service options should not be granted contracts through OPWDD. Back-up systems and self-hire registries should be established. There must also be coordination with the Department of Labor (DOL) to ensure that the goals of self-directed service options can be met and that any obstacles in DOL regulations can be worked through and understood to enable the flexibility desired by these programs.
- **Flexible funding for individuals to enhance and facilitate choice:** Offer stipends as Vermont does with their Flexible Family Funding model to be used at the discretion of individuals for any legal goods/activities such as respite, assistive technology, home modifications, individual/household needs, recreational activities, etc. This would enable the individual to live with family and others (e.g., shared living arrangements) in non-certified settings. Flexible funding could be an incentive (and provide the support needed) for individuals to transition from 24-hour supervised, certified settings to non-certified living arrangements.
- **Portability, diverse provider networks, ability to go out of the care management network for choice of providers and self-hires, and elimination of regional constraints:** The DISCO contract should have contractual language to assure portability of funds between DISCOs and between choice of service providers within the network and outside of the network. There should be opportunities for individuals to self-hire. DISCOs must be mandated to provide a full array of services to their members. Each district and DISCO should be involved in a “network

assessment” and development of a set of services needed in each district. Incentives could be established to allow providers to expand coverage to underserved regions. Consider some statewide DISCOs that could contract with providers in remote geographic areas to offer the more choices.

- **Incentivize sustainable support options that are desired by individuals:** Incentivize service innovation and creativity that meet individual outcomes. Incentivize person-centered planning and outcomes, employment first innovations, movement to non-certified settings, self-directed services, and other sustainable services and support options that help people meet their individual outcomes.
- **Retain qualified Direct Support Professionals (DSPs):** Establish DSP competencies, a career ladder, and higher pay for more experienced workers. DSPs must have ongoing training in person-centered planning, outcomes, day-to-day skill building, and understanding and communicating with people with developmental disabilities. This is important to ensure that individuals with developmental disabilities have the most qualified staff to support them. Relationship building is key. Continued relationships allow both the individual and staff to work together to achieve goals. As the average turnover rate for DSPs exceeds 20 percent, establishing direct support as a career could reduce this turnover and thus improve relationships and outcomes for individuals.
- **Comprehensive and competent care coordination:** Care coordinators must have a leading role in helping individuals to have meaningful lives and goals that are meaningful to them. There must be comprehensive, ongoing training for care coordinators in person-centered planning, advocacy, and other critical skills that are important to helping individuals achieve personal outcomes. Care Coordinators and managed care entities (DISCOs) should be reviewed for how they support people to achieve their life goals.
- **Create more opportunities for employment:** Every DISCO, through its own efforts or that of its contractors, should have a comprehensive employment program which is compatible with the diverse range of abilities, needs, and expectations of people with developmental disabilities (i.e., vocational rehabilitation should not be seen as a universal answer). DISCOs and/or DISCO contractors should form partnerships with companies to create opportunities that can lead to employment for people (e.g., internships, job shadowing, workshops, training programs, apprenticeships). DISCOs and/or contractors should encourage the creation of social entrepreneurial initiatives to provide employment and volunteerism to individuals with developmental disabilities. Benefits counseling is needed so individuals understand the effect different levels of employment have on their benefits.
- **Increase shared living, family care, and other non-certified residential options:** OPWDD’s family care model should be revamped and reinvigorated to create a range of new living options for individuals with developmental disabilities. Shared living models should also be developed.



Final Design Team Recommendations

Comment Line: 1-866-946-9733
E-mail: people.first@opwdd.ny.gov

Options and criteria for smart technology for homes must be developed to provide more independent options for people.



IV. **Follow-up Design Questions** – list questions/issues that define the next steps in furthering the final design of this aspect of the waiver.

No Wrong Door:

- In order to move forward with next steps, it must be determined whether New York State will coordinate all of its related No Wrong Door initiatives through the development of a multi-agency cross-systems Web portal and/or a single point of entry (such as through NY Connects) or whether OPWDD should proceed to design No Wrong Door within its own system as the single entry point for people with developmental disabilities.

Needs Assessment:

- Further review, investigation, and cost-benefit analysis of assessment tools that have merit as identified by the team should be pursued (i.e., Supports Intensity Scale; redesign of the DDP; Health Risk Screening Tool; Child and Adolescent Needs and Strengths). In addition, there may be other tools that exist in other states that could also be examined. The team recommends engaging consultants to pursue the recommendations of the design team.
- A significant question is whether and how OPWDD's People First Waiver will seek to assess all individuals in the waiver and account for resources if individuals are found to be underserved or are over-served.
- Pilots of the Supports Intensity Scale (SIS) and the Health Risk Screening Tool (HRST) could be designed to start within the next couple of months.

Appendix A – List of Team Members

- **Gerald Huber**, Director, Long Island DDSO, OPWDD
- **Bradley Pivar**, Parent,
- **Shameka Andrews**, Self Advocate, Self Advocacy Association of New York State
- **Al Coley**, Chief Executive Officer, Maranatha Human Services, Inc.
- **Joe Gerardi**, Parent, New York Self Determination Coalition



- **John Gleason**, Director, Broome DDSO, OPWDD
- **John Maltby**, Parent, Director of Community Support Programs, Westchester Institute for Human Development
- **Neil Mitchell**, Planning and Research, OPWDD
- **Maryellen Moeser**, OPWDD People First Waiver Unit
- **Chris Muller-Dahlman**, Planning and Research, OPWDD
- **Shelly Okure**, Division of Policy and Enterprise Solutions HCBS Waiver Unit, OPWDD
- **Wendy Orzel**, Self Advocate/OPWDD staff,
- **Roger Sibley**, Executive Director, Franziska Racker Centers
- **Peter Smergut**, Executive Director and CEO, Life's Worc
- **Barbara Wale**, President and CEO, ARC of Monroe
- **Lauren Lange**, OPWDD People First Waiver Unit

Appendix B – Team Charter

Access and Choice: The purpose of the Access and Choice Design Team is to make reform recommendations related to waiver and service access and eligibility that addresses each individual’s choices and goals, health and safety needs, and rights in the most appropriate community setting with an equitable level of resources/services appropriate to each individual’s unique needs.

1. What is not working in the current developmental disability service delivery system related to access and eligibility that needs to be reformed in the People First Waiver?
2. Review the information provided from other states in relation to the following needs assessment and resource allocation questions.
 - Should the needs assessment process be independent from care coordination? Should it be independent of the entities that deliver services and receive payment for service delivery?
 - What are the various options for entities/organizations that should be considered to carry out the needs assessment? What are the advantages and disadvantages for each option?
 - What should the state and/or OPWDD’s role be in the needs assessment process?
 - What are the factors and support needs that should be considered in assessment and the resulting resource allocation decision making for the various subpopulations (e.g., dually diagnosed; medically frail; children; forensics/risk issues; etc.)?
 - What are the options for how resource allocation decision making can be correlated to needs assessment (e.g., models for individual resource allocation; tiers – high, medium, low; etc.)?
 - Given that the federal government currently requires at least annual redetermination for ICF/MR level of care, how often should the People First Waiver needs assessment (and related resource allocation) decision making be reassessed/redetermined? What should trigger a reassessment?
 - How should changes in life circumstances and individual goals relate to the needs assessment process for people with developmental disabilities and various subpopulations?
3. Given that our system is moving to a care management environment with a specialized health home for care coordination for people with developmental disabilities:



- What are the various options (and the advantages and disadvantages of each) to ensure that there is “No Wrong Door” for people with developmental disabilities (and the various subpopulations such as children, medically frail, etc.) so that those who need services can access them no matter where they start in the process (e.g., voluntary agency, county social service department), and that people needing cross-system services have access to necessary services without regard to state agency auspice?
- What aspects of individual choice should be built into a care management model for individuals with developmental disabilities?
- How should information technology work to best support information sharing and access through “No Wrong Door” both within OPWDD’s service system and across systems?



Appendix C – Resources Used by the Team

Agency for Persons with Disabilities. State of Florida. <http://apd.myflorida.com/>.

Agosta, J.; Fortune, J.; Kimmicj, M.; Melda, K.; Smith, D.; Auerbach, K.; and Taub, S. (2009, April). Ten issues for States to Consider in implementing Individual or Level based budget Allocations. Independent Living Research Utilization Community Living partnership.

American Association on Intellectual and Developmental Disabilities is a site that promotes policies, research and practices for individuals with developmental disabilities. www.aaid.org.

Arizona Health Care Cost Containment System. *Self Directed Attendant Care: Is It Right For You?* Web. 26 Aug. 2011. <http://www.azahcccs.gov/shared/Downloads/SDACbrochure.pdf>.

Arizona Health Care Cost Containment System. *Self Directed Attendant Care (SDAC) Option*. Web. 26 Aug. 2011. <http://www.azahcccs.gov/shared/Downloads/MedicalPolicyManual/Chap1300.pdf>.

Bourne, P. (August 2011). Connecticut Manager of large voluntary day services provider. Interview.

Brazzell H. (August 2011). Florida Director of Budget. Interview.

Brom, J. (August 2011). State of Wisconsin Department of Children and Families, Division of Safety and Permanence. Interview.

Burnette, R. (2010, October). Supports Intensity Scale Pilot Project. North Carolina Joint legislative oversight committee on Mental Health, Developmental Disabilities and Substance Abuse Services.

Center for Health Care Strategies (CHCS). (2010, November). Profiles in State Innovation: Roadmap for Improving Systems of Care for Dual Eligibles.

Connecticut Advisory Committee (2011, January). DDS Legislative Rate Study Committee Report, Summary of Frequently Asked Questions, Advisory Committee Report and Executive

Connecticut Department of Mental Retardation. (2006, July 1). Level of Need Assessment Screening Tool.

"Coordinating Medicaid and Chip: State Experiences." *Center for Children and Families*. Georgetown University Health Policy Institute. Web. 26 Aug. 2011. <http://ccf.georgetown.edu/index/state-experiences-coordinating>.



- Draughon, V. (August 2011). Florida Support Coordination, Medicaid Waiver, Family Care council Health Service/Facility consultant. Interview.
- Duvall, D. (August 2011). Connecticut employee and former waiver manager. Interview.
- Fields, P. (August 2011). Connecticut Manager of a large voluntary residential & other supports provider. Interview.
- Fortune, J.; Agosta, J., and Bershadsky, J. (2011, March). 2011 Validity and Reliability Results Regarding the SIS. Human Services Research Institute.
- Fortune, J.; LeVelle, J.; Meche, S.; Severance, D.; Smith, G; Stern, J.; Van Loon, J.; Weber, L.; and Campbell, E. (2008, June). Resource Allocation and the Supports Intensity Scale: Four Papers on Issues and Approaches.
- Georgia Department of Human Resources Division of Mental Health, Developmental Disabilities and Addictive Diseases, Office of Developmental Disabilities. (2008, May 1). Implementation in State of Georgia. Supports Intensity Scale Case Review Protocol.
- Georgia Department of Behavioral Health and Developmental Disabilities. (2011, May 24). Health Risk Screening Tool Policy. http://centralstatehospital.org/policy/Policy%2002-803%20HRST%20w.%20Appedix_Rev%201_eff%206.1.11.pdf.
- "Glossary." *South Shore Elder Services, Inc.* Web. 26 Aug. 2011. http://www.southshoreelderservices.com/?page_id=231
- Health Risk Screening Tool is a site that explains what the Health Risk Screening Tool is. <http://www.hrsonline.com/index.php>.
- Health Risk Screening Tool. (2011, July 26). Presentation.
- Hennike, J.; Myers, A.; Ealon, R.; Thompson, T. (2006, June). Development and Validation of a Needs Assessment Instrument for Persons with Developmental Disabilities. *Journal of Developmental and Physical disabilities*.
- Lamoureux-Hebert, M.; Morin, D.; and Crocker, A. (2010). Support needs of Individuals with Mild and Moderate Intellectual Disabilities and Challenging Behaviors. *Journal of mental health Research in Intellectual Disabilities*.
- Kansas Department of Social & Rehabilitation Services. (2001, May). Basic Assessment and Services Information System Forms Instruction Manual. <http://www.srs.ks.gov/agency/css/Documents/DD%20Waiver/basismanual60.pdf>.



K.C., Africa H.; Allison Taylor Johns; L.S., Ron S.; And D.C And Penny C. V. Lanier Cansler, North Carolina Secretary Of The Department Of Health And Human Services, Pamela Shipman, Area Director of Piedmont Behavioral Health Care Area Mental Health, Developmental Disabilities, and Substance Abuse Authority, and Piedmont Behavioral Healthcare Area Mental Health, Developmental Disabilities And Substance Abuse Authority (2011).

Kimmich, M.; Agosta, J.; Fortune, J.; Smith, D.; Melda, K.; Auerbach, K.; and Taub, S. (2009, April). Developing individual budgets and Reimbursement Levels using the Supports Intensity Scale. Independent Living Research Utilization Community Living partnership.

Kodner, Dennis L. "Consumer-Directed Services: Lessons and Implications..." *International Journal of Integrated Care* 3 (2003). Web. 26 Aug. 2011.
<http://www.ijic.org/index.php/ijic/article/view/URN%3ANBN%3ANL%3AUI%3A10-1->

Massachusetts Office of Health and Human Services. *Intersecting Activities and Initiatives Related to Financing of Long-term Services and Supports*. Web. 26 Aug. 2011.
http://www.mass.gov/Eeohhs2/docs/eohhs/ltc/200912_activities.pdf.

McCall, Nancy. "Lessons from Arizona's Medicaid Managed Care Program." *Health Affairs* 16.4 (1997): 194-99. Web. 26 Aug. 2011. <http://content.healthaffairs.org/content/16/4/194.full.pdf>

McGarrity, T. (August 2011). Florida Community Improvement Deputy Director. Interview.

My Benefits. Office of Temporary and Disability Assistance. Web. 26 Aug. 2011.
<http://www.mybenefits.ny.gov>.

New York Department of Health. Medicaid Redesign Team. *MRT Recommendations - Questions and Answers*. Web. 26 Aug. 2011.
http://www.health.state.ny.us/health_care/medicaid/redesign/docs/medicaid_redesign_team_questions_and_answers.pdf.

"New York Makes Work Pay." Cornell University. Web. 26 Aug. 2011.
<http://www.ilr.cornell.edu/edi/nymakesworkpay/index.cfm>.

New York State Developmental Disabilities Profile and User Guide.
http://www.opwdd.ny.gov/wt/images/wt_DDP2_User_Guide.pdf.

Norman, Al, ed. "States Seeks Money Follows the Person Grant." *At Home Newsletter*. Mass Home Care, Feb. 2011. Web. 26 Aug. 2011.
<http://www.masshomecare.org/AtHomeDetailEntire.asp?Issue=February-2011>.



- NYS Office for Persons With Developmental Disabilities. *Guide to Eligibility Assessment Resources*. Web. 26 Aug. 2011.
http://www.opwdd.ny.gov/wt/forms/wt_guide_to_eligibility_assessment_resources_final.pdf.
- NYS Office for Persons With Developmental Disabilities. *Statewide Comprehensive Plan 2009 - 2013*. 2009. Web. 26 Aug. 2011.
http://www.opwdd.ny.gov/507plan/images/hp_507plan_statewidecomprehensiveplan0913.pdf.
- Ohio Department of Mental Retardation and Developmental Disability. (2004, January). Ohio Developmental Disability Profile (ODDP). <http://www.dodd.ohio.gov/medicaid/docs/ddp-all2.pdf>.
- Ohio. (2010, July 01). Home and Community-based Services Waivers –Payment for Wavier Services 5123. <http://mrdd.ohio.gov/rules/documents/5123-2-9-06Effective07-01-10.pdf>
- Ohio Department of Mental Retardation and Developmental Disability. ODDP Training Worksheet for Determining Frequency of Behavioral Occurrences. <http://www.dodd.ohio.gov/training/docs/oddp-frequencyworksheet.pdf>.
- Ohio Department of Mental Retardation and Developmental Disability. (2008, April). Acuity Assessment Instrument (AAI). Fact Sheet. <http://www.dodd.ohio.gov/medicaid/docs/AAIFaq.pdf>.
- O’Shaughnessy, Carol V. Aging and Disability Resource Centers (ADRCs): Federal and State Efforts to Guide Consumers through the Long-term Services and Supports Maze. National Health Policy Forum, Background Paper No. 81, November 2010.
- Pettinger, J. (August 2011). Assistant Commissioner, OPWDD Behavioral and Clinical Solutions. Interview.
- Praed Foundation is a site that has information on evidence-based assessments and on the Child & Adolescent Needs and Strengths, the Family Advocacy and Support Tool, the Crisis Assessment Tool, and the Adult Needs and Strengths Assessment. www.praedfoundation.org.
- Robison, J. and Evans, J. Connecticut’s Long-Term Care Needs Assessment, A Road Map for the Future.
- Smith, G. and Fortune, J. (2006, June 30). Assessment Instruments and Community Services Rate Determination: Review and Analysis. Division of Developmental Disabilities Colorado Department of Human Services. Human Services Research Institute.
- State of Nebraska Developmental Disabilities System and MERCER Government Human Services Consulting. (2004, September 1). Developmental Disabilities Objective Assessment Process: Legislative Bill 297 Work Group Report and Recommendations.



State of Oregon. Restructuring Budgets, Assessments and Rates (ReBAR).

<http://www.oregon.gov/DHS/dd/rebar/>.

State Refor(u)m An Online Network for Health Reform Implementation. National Academy for State Health Policy and the Robert Wood Johnson Foundation. Web. 26 Aug. 2011.

<http://statereforum.org>.

TennCare. *TennCare CHOICES In Long-Term Care*. Web. 26 Aug. 2011.

<http://www.tn.gov/tenncare/CHOICES/index.html>.

Texas Case Management Optimization: Best Practices and Emerging Trends in Case Management. Rep. Navigant Consulting. Web. 26 Aug. 2011.

http://www.hhsc.state.tx.us/about_hhsc/reports/CaseManagement_BestPractices.pdf.

Texas Department of Aging and Disability Services. Inventory for Client and Agency Planning (ICAP) Resources. <http://www.dads.state.tx.us/providers/guidelines/icap/index.html>.

Tritz, Karen. 2005. Long-Term Care: Consumer-Directed Services under Medicaid. CRS Report for Congress. Washington, D.C.: Congressional Research Service, U.S. Library of Congress, January 21.

<http://www.law.umaryland.edu/marshall/crsreports/crsdocuments/RL322191212005.pdf>. Accessed August 2012.

USA. Administration on Aging and the Centers for Medicare & Medicaid Services. *The Aging and Disability Resource Center Program*. Web. 26 Aug. 2011. <http://www.adrc-tae.org/tiki-index.php?page=ADRCHomeTest>.

Utah Division of Services for People with Disabilities. (2006, January). AAMR - Supports Intensity Scale (SIS) Questions from Providers and Answers from DSPD.

Vermont Division of Disability and Aging Services. *Flexible Family Program Funding Guidelines*. 2009. Web. 26 Aug. 2011. <http://www.ddas.vermont.gov/ddas-policies/policies-dds/fff-guidelines>.

Vermont Division of Disability and Aging Services. *Management Options for Developmental Disability Services*. Web. 26 Aug. 2011. <http://www.ddas.vermont.gov/ddas-programs/programs-dds/programs-dds-addl-webpages/programs-dds-management-options>.

Vermont Division of Disability and Aging Services. *Shared Living in Vermont: Individualized Home Supports For People with Developmental Disabilities*. 2010. Web. 26 Aug. 2011.

<http://www.ddas.vermont.gov/ddas-publications/publications-dds/publications-dds-documents/dd-publications-other/shared-living-individual-home-supports>.



Virginia Department for the Aging. *No Wrong Door*. Web. 26 Aug. 2011.

<http://www.vda.virginia.gov/nowrongdoor.asp>.

Virginia Department for the Aging. *Virginia Easy Access*. 2008. Web. 26 Aug. 2011.

<http://www.easyaccess.virginia.gov/>.

Waiver Provider is a site that provides information on various waiver services in Florida.

(<http://waiverprovider.com/>).

Walton, B. (August 2011). Indiana Family and Social Services Administration. Interview.

"We Help Vermonters Find Direct Care Workers." *Rewarding Work*. Rewarding Work, Inc. Web. 26 Aug. 2011. <http://www.rewardingwork.org/State-Resources/Vermont.aspx>.

Wehmeyer, M.; Chapman, T.; and Little, T. (2009, January). Efficacy of the Supports Intensity Scale (SIS) to Predict Extraordinary Support Needs. *AAIDD Journal*.

Weiss, J.; Lunskey, Y.; Tasse M.; and Durbin, J. (2009, June 28). Support for the construct validity of the Supports Intensity Scale based on clinician rankings of need.

Wisconsin Department of Health Services. Long term Care Functional Screen Instructions.

<http://www.dhs.wisconsin.gov/lcicare/functionalscreen/LTCFSinstrux-clean.pdf>.

Wisconsin Department of Health Services. Long term Care Functional Screen Overview.

<http://www.dhs.wisconsin.gov/lcicare/functionalscreen/LTCFSoverview.HTM>.

**ATTACHMENT 1
ACCESS AND CHOICE DESIGN TEAM RECOMMENDATIONS
NEEDS ASSESSMENT**

CHARTER QUESTIONS RELATED TO NEEDS ASSESSMENT (in italics) And Other Considerations (shaded)	RECOMMENDATIONS
PURPOSE FOR NEEDS ASSESSMENT/TOOLS/INFORMATION IN OPWDD PEOPLE FIRST WAIVER	
	<p>At individual level:</p> <ul style="list-style-type: none"> • Provide basis for person-centered planning, comprehensive care plan, and individualized self-directed budget methodology • Provide basis for determining whether individual needs and outcomes are met • Provide basis for quality review and oversight <p>Provider Level:</p> <ul style="list-style-type: none"> • Provide information for decision making related to staffing needs and information to plan appropriate individualized and person-centered service provision. • Early warning of potential health risks so that protective measures can be integrated <p>Systems Level:</p> <ul style="list-style-type: none"> • Statewide equitable resource allocation • Information from which to derive cost of service provision and to develop capitated payments for managed care entities and risk adjustment (if applicable) • Provide aggregate information about our population for research and planning purposes as well as quality improvement and oversight
CHARACTERISTICS OF ENTITIES THAT ADMINISTER NEEDS ASSESSMENT	
<p><i>Should the needs assessment process be independent from care coordination? Should it be independent from entities that deliver services and receive payment for service delivery?</i></p>	<ul style="list-style-type: none"> • Independent and Unbiased: There must be demonstrated independence from organizations that conduct care coordination, entities that are paid to deliver services, and entities that receive capitated payments.

**ATTACHMENT 1
ACCESS AND CHOICE DESIGN TEAM RECOMMENDATIONS
NEEDS ASSESSMENT**

CHARTER QUESTIONS RELATED TO NEEDS ASSESSMENT (in italics) And Other Considerations (shaded)	RECOMMENDATIONS
<i>What are the various options for entities/organizations that should be considered to carry out the needs assessment? What are the advantages and disadvantages for each option?</i>	<ul style="list-style-type: none"> • Options for performing needs assessment include: the NYS OPWDD or its contractor; managed care organizations/care coordination or their contractors; a cross-systems regional resource center such as regional resource development centers. • The team believes there should be demonstrated independence of needs assessment from entities that are paid to deliver and/or contract for services/supports on behalf of individuals. Therefore, the state/state employees, or contractors with no conflicts of interest that are closely overseen by the state should conduct needs assessment.
<i>What should the state and/or OPWDD's role be in the needs assessment process?</i>	<ul style="list-style-type: none"> • NYS OPWDD's role should be to directly conduct and/or contract for needs assessment and eligibility determination processes. • OPWDD should make final decisions about resources that are allocated to each managed care/care management organization (MCO) as a result of a valid and equitable needs assessment process. • OPWDD should monitor that individuals who choose "budget authority" are receiving the right amount based on guidelines to be established. • OPWDD should ensure that there are diverse networks of qualified providers through MCOs to deliver choice to individuals that align with their needs and cultural preferences. • NYS OPWDD should be responsible for quality oversight as it relates to needs assessment, eligibility determinations and resource allocation. • NYS should be responsible for ensuring that there is a neutral grievance and dispute resolution system for disagreements related to needs assessment, eligibility, and resource allocation decisions. • New York State should ensure that there is independent advocacy or support brokerage provided either through OPWDD or through contractors (or through reliable and consistent grass roots efforts) that are independent from managed care/care management organizations to help individuals navigate through the needs assessment, eligibility, and resource allocation processes and reassessments when changes are needed or warranted. <p><u>Key Issues:</u></p>

ATTACHMENT 1
ACCESS AND CHOICE DESIGN TEAM RECOMMENDATIONS
NEEDS ASSESSMENT

<p style="text-align: center;">CHARTER QUESTIONS RELATED TO NEEDS ASSESSMENT (in italics)</p> <p style="text-align: center;">And Other Considerations (shaded)</p>	<p style="text-align: center;">RECOMMENDATIONS</p>
	<ul style="list-style-type: none"> • If NYS OPWDD or its contractors will be responsible for the valid and equitable needs assessment process, we must ensure that appropriate capacity exists in terms of skills and resources to manage this statewide in a consistent, fair, and equitable manner. • Decisions must be reached in an efficient timeframe so as to ensure that individuals have their needs met.
<p>Other recommendations related to organizations and qualifications for needs assessment?</p>	<ul style="list-style-type: none"> • Individuals conducting assessment and person-centered planning need to understand the effects of a disability from real experience with people who have disabilities. These individuals also need to have an attitude of caring which translates into good listening skills. • Intensive and on-going training is necessary for all people who conduct needs assessment. • Ongoing testing for assessors to ensure objectivity and inter-rater reliability is critical. • An information management system that provides for comprehensive cross-systems assessment tools and electronic records is needed. It should be used to gather information with standardized tools as well as provide information (see “No Wrong Door” recommendations). The system should be able to gather essential information to make a comprehensive assessment at the point of entry and make this information available to all who need it across systems. • Tools for strengthening needs assessment skills should also be made available through a “No Wrong Door” model. <p><u>Key Issues/Considerations:</u></p> <ul style="list-style-type: none"> • The accuracy of any needs assessment tool is largely based on the skills of the person who conducts the needs assessment. • Lessons learned from Assessment Tool subgroup research from other states is that the fewer the number of assessors the more reliable the assessment results.

**ATTACHMENT 1
ACCESS AND CHOICE DESIGN TEAM RECOMMENDATIONS
NEEDS ASSESSMENT**

CHARTER QUESTIONS RELATED TO NEEDS ASSESSMENT (in italics) And Other Considerations (shaded)	RECOMMENDATIONS
FACTORS AND SUPPORT NEEDS (DOMAINS) THAT SHOULD BE INCLUDED IN PEOPLE FIRST WAIVER NEEDS ASSESSMENT	
<p><i>What are the factors and support needs that should be considered in assessment and the resulting resource allocation decision making?</i></p>	<ul style="list-style-type: none"> • Strength-based approach: the strengths of the person need to be part of the needs assessment process. In addition, the ability of the person to make decisions and self-advocate should also be assessed. • Person-Centered Needs Assessment: Any needs assessment adopted through the People First Waiver should start from a person-centered strengths based approach-e.g., conversations and identification of strengths and preferences of the person and their desired outcomes and life goals and desires as well as the needs of the person. In addition, the areas in which improvement and/or habilitation are needed should also be included as well as clinical and family interviews. <ul style="list-style-type: none"> • Domains: <ul style="list-style-type: none"> ✓ Life goals and person’s desires in the area of home, health, meaningful relationships, meaningful work/community inclusion should come first. ✓ Strengths and abilities of the person: identification of assets that the family and the individual bring with them when seeking supports and services ✓ Caregiver needs (e.g., presence and stability/reliability of natural supports) ✓ Social life ✓ Comprehension ✓ Communication ✓ Personal care ✓ Health/Medical ✓ Daily living ✓ Communication ✓ Employment ✓ Behaviors (that interfere with life goals) ✓ Mental Health needs ✓ Safety and Support ✓ Educational needs ✓ Transportation ✓ Housing Need ✓ Culture and Ethnicity information/preferences (i.e., ensure multicultural/family history needs are identified and expressed at the time of assessment).

**ATTACHMENT 1
ACCESS AND CHOICE DESIGN TEAM RECOMMENDATIONS
NEEDS ASSESSMENT**

CHARTER QUESTIONS RELATED TO NEEDS ASSESSMENT (in italics) And Other Considerations (shaded)	RECOMMENDATIONS
	-
ADMINISTRATIVE FRAMEWORK/MANAGEMENT OF ASSESSMENT SYSTEM	
	<ul style="list-style-type: none"> • Intensive and Ongoing Training and Education: The efficacy and accuracy of any needs assessment tool is largely based on the skills of the person/person(s) who conducts the needs assessment. Intensive, consistent and ongoing training must be provided to individuals/entities that conduct needs assessment. • Ongoing Skill Building: Resources/Tools (e.g., web-based training modules) for strengthening needs assessment and person-centered planning skills should be made universally available through a “No Wrong Door” model. • An Information management system that is web-based and integrated into a “No Wrong Door” and provides for comprehensive and consistent cross-systems assessment tools and electronic records is necessary. A No Wrong Door model should be used to gather consistent information with standardized cross systems tools as well as provide needed cross system information to appropriate parties. A general characteristic of a “No Wrong Door” as stated by Aging and Disability Resource Center (ADRC) is streamlined eligibility determinations that create an administratively effective, efficient, and seamless process regardless of what agency/program someone ends up eligible for or the types of services they are eligible to receive. Thorough use of web-based technology. • Transparency: transparency of needs assessment tools and processes is necessary. This means that individuals and other stakeholders have easy access to information that explains the process and the tools/methods that will be used. Individuals and other stakeholders should also have access to the resource allocation and funding formulae methodologies. This information should all be available publically on OPWDD’s website. • Checks and Balances: There needs to be consistency in qualifications, training for people that complete assessments, independent quality review of assessments, and other checks and balances in the system. Ongoing testing for assessors to ensure objectivity and inter-rater reliability is critical. • Comprehensive Person-Centered Plan: Regardless of which entities conduct needs assessment, the

**ATTACHMENT 1
ACCESS AND CHOICE DESIGN TEAM RECOMMENDATIONS
NEEDS ASSESSMENT**

CHARTER QUESTIONS RELATED TO NEEDS ASSESSMENT (in italics) And Other Considerations (shaded)	RECOMMENDATIONS
	<p>assessment tool(s) must be able to perform an assessment that seamlessly transitions into a holistic, comprehensive person centered plan.</p> <p><u>Key Issues/Considerations:</u></p> <ul style="list-style-type: none"> • Strong interagency collaboration/prioritization at highest levels of government will be necessary to achieve cross-systems recommendations related to technology and uniform assessment/application.
CONSIDERATIONS FOR RESOURCE ALLOCATION THROUGH NEEDS ASSESSMENT PROCESS	
	<ul style="list-style-type: none"> • Flexibility: Needs assessment that drives resource allocation needs to build in flexibility to address emergency and crisis needs without staffing for these emergencies all the time. Flexibility is needed to adapt to changes in the person’s support needs (e.g., if a primary caregiver is ill). The needs assessment cannot be on “automatic pilot”. • Predictability: resources should be available when people need them. Consider developing resource needs based upon the person’s worst day so that there is some flexibility to address emergency and crisis needs without having to go through lengthy application processes. • No Denial of Needed Services: Care Management/Managed Care Organizations (MCOs) should not be able to deny any needed services/supports/resources that are identified through the needs assessment process. • All individuals should have the right to choose “budget authority”—which is an individualized budget that the individual can self-direct (i.e., make choices about how individualized budget is used for supports and services) which is derived from the needs assessment and person-centered planning process. In choosing this option, individuals and families need to understand the advantages and disadvantages as well as the benefits and the risks so that an “informed choice” can be made about self-directed service options. <p><u>Key Issues/Considerations:</u></p> <ul style="list-style-type: none"> • How do we ensure availability of self-hires and backup for self-hires who do not show up? • In care management model, what are the entities that will be the financial management/fiscal

**ATTACHMENT 1
ACCESS AND CHOICE DESIGN TEAM RECOMMENDATIONS
NEEDS ASSESSMENT**

CHARTER QUESTIONS RELATED TO NEEDS ASSESSMENT (in italics) And Other Considerations (shaded)	RECOMMENDATIONS
	<ul style="list-style-type: none"> intermediaries? • How will incident reporting be handled with self-directed services?
TRIGGERS FOR REASSESSING NEED	
<i>Given that the federal government currently requires at least annual redetermination for ICF/MR level or care, how often should the People First Waiver needs assessment (and related resource allocation) decision making be reassessed/redetermined? What should trigger a reassessment?</i>	<ul style="list-style-type: none"> • Best practice should dictate the frequency of administering formal needs assessment. However, all person-centered comprehensive plans should be reviewed at least annually for any necessary changes. • Re-assessments should be triggered whenever the individual’s condition changes. Examples of conditions include: medical needs, change in level of natural supports, change in behavior, new goals, employment, etc. • The re-assessment process should not be redundant/duplicative but should be able to draw from a comprehensive and cross-systems information management system that shares information across service systems that the individual is associated with.
<i>How should changes in life circumstances and individual goals relate to the needs assessment process for people with developmental disabilities and various subpopulations?</i>	<ul style="list-style-type: none"> • Person-centered planning must be inherent in needs assessment and resource allocation. The person’s individual life goals should be the starting point for the needs assessment process. • There should be a formal vehicle for person-centered planning built universally into the waiver and this thread should be carried through all aspects that touch the person from the single point of entry through a “No Wrong Door” to the needs assessment process through agency quality performance measurement. Person-centered planning/outcomes should be a continuous quality improvement element expected of care management and be integrated into contract language. • Every individual should have the right to a real and viable person-centered plan based on at least the following: <ol style="list-style-type: none"> 1. The results of a valid needs assessment process that is independent from service provision and is built upon a person-centered strengths based perspective; 2. Meaningful input of the individual and their chosen circle of support and reflective of the cultural considerations of the person; 3. Availability of independent advocacy/oversight (such as an ombudsman, enrollment/support broker, non-profit advocacy representative, OPWDD staff etc.). In addition to guarding against conflicts of interest from provider self-referral, the presence of

**ATTACHMENT 1
ACCESS AND CHOICE DESIGN TEAM RECOMMENDATIONS
NEEDS ASSESSMENT**

CHARTER QUESTIONS RELATED TO NEEDS ASSESSMENT (in italics) And Other Considerations (shaded)	RECOMMENDATIONS
	<p>an advocate/oversight entity will help ensure that individuals are aware of all available options (i.e., informed choices) and are not wrongfully persuaded.</p> <ol style="list-style-type: none"> 4. Opportunities for updates and discussions at the request of the person or when needs and individualized circumstances change 5. Formal and informal strategies and processes to resolve any disagreements that arise in the process 6. Informed Choice. <p><u>Key issues/considerations:</u></p> <ul style="list-style-type: none"> • Risk
	Quality Review and Oversight of Needs Assessment
	<ul style="list-style-type: none"> • The review of the quality of the assessment should be independent from the needs assessment and care coordination processes. • The state should have oversight of needs assessment. The state should also have oversight of care coordination to ensure that the individual's needs are being met as determined in the assessment and described through a comprehensive person-centered plan. • Assessments and the planning process should start with personal outcomes. Quality measurements should then ensure that these are being met for the individual. There needs to be full acceptance of an individual's dream with a clear dialogue about how to best realize desired outcomes (Quality Design Team). • The People First Waiver must ensure that needs are addressed with an appropriate plan of care in line with the assessment and that quality is measured based upon the degree to which the plan is implemented and effective to bring about positive outcomes in the person's life. The level of complexity of the care plans, and related quality oversight, will be driven by the level of assessed need (Quality Design Team).

**ATTACHMENT 1
ACCESS AND CHOICE DESIGN TEAM RECOMMENDATIONS
NEEDS ASSESSMENT**

CHARTER QUESTIONS RELATED TO NEEDS ASSESSMENT (in italics) And Other Considerations (shaded)	RECOMMENDATIONS
	<p><u>Key Issues/Considerations:</u></p> <ul style="list-style-type: none"> • Quantifiable measures will likely be necessary
RECOMMENDATIONS FOR NEXT STEPS	
<p>A systems-wide transition to use of needs assessment tools is a major part of the infrastructure necessary to effectuate the People First Waiver. Lessons learned from other states indicate that this transition must be carefully planned for and proper steps taken to select among the best possible alternatives. As each of the above options requires further review, analysis and cost benefit study, the team recommends that a knowledgeable and qualified consultant be employed to work with the recommendations of the design teams to analyze OPWDD’s options in terms of costs, benefits, implementation workload, resource allocation potential and applicability, and information management systems solutions and provide OPWDD with specific information with which to make an informed decision on how best to proceed.</p> <p>A thorough and iterative testing and development process is then recommended before finalization of any new assessment tool. Basic principles of reliability and validity must be adhered to for any proposed combination (or revision) of tools adopted for the People First Waiver. These include: internal consistency of additive indexes or scales, inter-rater reliability, and test-retest (or intra-rater) reliability. Validity judgments should encompass criterion validity (the tool can clearly distinguish between many types of people and their support needs), construct validity (demonstrated assurance that items truly measure the intended topical constructs), and content (or face) validity as perceived by the most relevant stakeholders.</p> <p>In conjunction with consultants or prior to employing consultants, the team recommends that pilots could be designed to “test” the Supports Intensity Scale (SIS) and the Health Risk Screening Tool (HRST) as these instruments could be considered “ready to go” for initial piloting.</p>	



**Attachment 2
Assessment Tools Technical Workgroup Report
August 16, 2011**

Table of Contents	Page Number
I. Purpose	2-3
II. Background	3-5
III. Needs Assessment in OPWDD’s Current System	6-8
IV. Assessment Tool Reviews; Health Risk Screening Tool (HRST)	8, Attachment 2A, 2B
V. Lessons Learned	8-9
VI. Considerations and Recommendations	9-13
VII. Recommended Next Steps	14-16, Attachment 3
VIII. Assessment Tool Sources: Attachment 3	17-20

Respectfully Submitted to the Access and Choice Design Team by the Assessment Tools Technical Subgroup:

Jerry Huber, Access and Choice Design Team, Long Island DDSO Director
 Maryellen Moeser, OPWDD People First Waiver Unit
 Anne Swartwout, OPWDD People First Waiver Unit
 Lauren Lange, OPWDD People First Waiver Unit
 John Maltby, Access and Choice Design Team, Parent, Program Director/WIHD
 Barbara Wale, Access and Choice Design Team, Monroe ARC
 Peter Smergut, Access and Choice Design Team, WORC
 Chris Muller, Access and Choice Design Team, OPWDD Research and Planning
 Chris Nemeth, Access and Choice Design Team, OPWDD Director-Research and Planning
 John Kemmer, Fiscal Sustainability Design Team, NYSARC
 Hope Levy, Care Coordination Design Team, IAC

Other contributors:

Jill Pettinger, OPWDD Assistant Commissioner
 Pat Dowse, NYSACRA
 Kate Bishop, OPWDD People First Waiver Unit
 Diane Woodward, Wildwood





Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

Purpose:

The purpose of this report prepared by the Assessment Tools Technical Workgroup is to provide information to the Access and Choice Design Team to use to help team members make informed recommendations related to individual and administrative factors that should be incorporated into the People First Waiver in order to move towards the goal of statewide valid needs assessment and equitable resource allocation.

The Assessment Tools Technical Subgroup was chartered by the Access and Choice Design Team to review selected needs assessment instruments utilized in other states/systems for identifying individual supports/service needs and resulting resource allocations for people with developmental disabilities. Key questions that the subgroup was to explore for each assessment instrument included the following:

- Domains/factors assessed for each instrument
- What is missing from the New York State Developmental Disabilities Profile (DDP) that is in the reviewed assessment instrument and what is the value of assessing these factors/domains for applicability to New York State OPWDD's system?
- What is the process/administrative framework for administering the instruments and managing the assessment system?
- How is person-centered planning and individual goals integrated with needs assessment?
- How does the needs assessment process lead to a comprehensive care plan?
- How are changes in life circumstances taken into account after the assessment has been completed and resources, supports and services allocated? How often are needs reassessed? What triggers reassessment?
- What are the organizations that administer the needs assessment and what is the role of the state in the process?
- What are the qualifications of the organizations and specific individuals who conduct the needs assessments? What are the training requirements and expectations for ongoing training?
- How are individuals and families apprised of how the needs assessment process and methodology works? Are individuals and families trained on how the instruments are used?
- How are the needs assessment instruments used to allocate resources? How does the methodology work? Are any needs carved out of the methodology? How are medical needs assessed?
- How is quality oversight of needs assessment done?



Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

- What input was obtained on various instruments from people who receive services such as self-advocates and other stakeholders. How do stakeholders view the instruments?
- How did states associated with the instruments reviewed come to use them? Was there a shift from using a different instrument? How was the transition implemented?
- What are the overall strengths and weaknesses of the instruments reviewed?

Background:

A foundational component of OPWDD's People First Waiver is to establish valid needs assessment and equitable resource allocation as such an infrastructure will enhance the ability of people with developmental disabilities to access the service system and the level of supports and services that are most appropriate to meet individualized needs and goals in the most appropriate community integrated setting.

As OPWDD's service system transitions to a managed care environment, the development of statewide needs assessment is essential for the success of an integrated care coordination model. The Design Team parameters distributed to all Design Team members and publically posted on OPWDD's website reinforces the following, "There will be a standardized needs assessment instrument and/or tool that will be consistently applied across the People First Waiver to determine each individual's strengths, needs, and preferences. This needs assessment tool will be use to allocate resources equitably and will be administered by an entity that is independent from service delivery."

The People First Waiver Access and Choice Design Team was established to make reform recommendations related to access, eligibility, and choice that encompasses individual choice and goals, health and safety needs, and rights with an equitable level of resources/services appropriate to each individual's unique needs. Much of the Access and Choice Design Team's charter relates to identifying essential individualized components that should be included in any needs assessment process undertaken by the People First Waiver as well as to identify administrative and systemic considerations regarding needs assessment and resource allocation.

In order for the Access and Choice Design Team to respond to this task within the limited period of time designated for design team work, the team established a technical workgroup with working members from the Access and Choice Design Team, as well as the Fiscal Sustainability Design Team, and the Care Coordination Design Team. The group was charged with reviewing assessment tools, processes and administrative factors in use in developmental disability systems in other states. The group preparing a written report for the Access and Choice Design



Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

Team to use to help them make informed recommendations related to factors that should be incorporated into the People First Waiver in order to move towards the goal of statewide valid needs assessment and equitable resource allocation.

To complete work on the Technical Workgroup charter, each technical workgroup member was assigned one assessment tool previously identified by the Access and Choice Design Team and provided with a template to identify assessment components that are not currently encompassed in OPWDD’s Developmental Disability Profile (DDP), which is the instrument that is currently used in OPWDD’s system to collect information about the population served for planning and policy making purposes. Team members were further asked to identify the value of the identified needs assessment components and to answer additional questions related to the assigned tool and to provide overall comments and observations.

The overall goal of the Assessment Tools Technical Subgroup was not to recommend a specific assessment tool or tools but to help inform the broader based recommendations of the Access and Choice Design Team and to guide further research and exploration of assessment tools.

The team first met on June 30, 2011 (10 days after the Access and Choice Design Team kickoff meeting) and initial assignments were made (see below). Another meeting was held on July 13, 2011 to review progress of the team members. On July 26, 2011, the team viewed a presentation and demonstration of the Health Risk Screening Tool (HRST), which was brought to the attention of the technical workgroup by Pat Dowse, a member of the Services and Benefits Design Team (see Appendix 2 for information on this tool). Written reviews of assigned tools was due on July 25, 2011 and the compiled report was due on August 1st so an initial draft of this report could be compiled for the August 16, 2011 meeting of the Access and Choice Design Team.

The membership of the technical workgroup and assignments were made as follows:

Subgroup Assignments	Owner
Create template/grid for answering questions about other assessment tools, provide report compilation	Maryellen Moeser (People First Waiver Unit)
Review Supports Intensity Scale (SIS) and submit written answers to questions	John Maltby (Access and Choice Design Team)
Review Inventory for Client and Agency Planning (ICAP) and submit written answers	Peter Smergut (Access and Choice Design Team)
Review Connecticut Level of Need (LON) and submit written answers	Chris Nemeth and Chris Muller (Access and Choice Design Team and





**Attachment 2
Assessment Tools Technical Workgroup Report
August 16, 2011**

	OPWDD Research and Planning)
Review Florida Situational Questionnaire and submit written answers	Barbara Wale (Access and Choice Design Team)
Review the DDP-2 adaptations from other states (Kansas and Ohio) and submit written answers	John Kemmer (Fiscal Sustainability Design Team)
Review Wisconsin functional screen and submit written answers	Jerry Huber (Access and Choice Design Team lead/LI DDSO Director) and Lauren Lange (People First Waiver Unit)
Review Child, Adolescent, and Adult needs and strengths (CAANS) and submit written questions	Anne Swartwout (People First Waiver Unit)
Health Risk Assessment Tool (HRAT) —Research and analysis	Hope Levy (Care Coordination Design Team)

See Appendix 1 which outlines review information for each Assessment Tool assigned to team members.

Needs Assessment In OPWDD’s Current System:

OPWDD’s service system does not have a statewide system or process for consistent, reliable and valid needs assessment. Rather, there are a variety of tools and instruments that are used for various planning purposes and in various programs/settings depending upon a number of factors including the person’s residential setting, waiver enrollment status, program enrollments, etc. Below is an outline of some of the most common instruments used in the current service system and their purpose.

Tool	Description	Purpose
Developmental Disabilities Profile (DDP) 2 and 4	In general, the DDP is a four page tool developed by OPWDD (then OMRDD) in 1990 to provide descriptions of characteristics of people with developmental disabilities related to service needs. The DDP provides a snapshot of individual capabilities.	The DDP 2 is designed to document key characteristics of persons with developmental disabilities simply and briefly. DDP 2 initially developed over 20 years ago to inform ICF and Day Treatment rate setting methodologies. Today, the DDP 2 is still used to inform and/or determine reimbursement levels in certain





**Attachment 2
Assessment Tools Technical Workgroup Report
August 16, 2011**

	<p>The DDP 2 Includes a range of information on diagnostic, adaptive, maladaptive and medical issues, skills, and challenges. The content of DDP dimensions includes three factors. The first factor is dominated by indexes of adaptive limitations, covering such domains as self-care, daily living, cognitive, communication, and motor limitations. Factor two focuses on maladaptive behavior—frequency and consequences of problem behavior. The third factor is oriented to health/medical issues and, though the weakest factor, is a significant feature of the data set with obvious face validity.</p> <p>The DDP is typically completed by provider agency staff who know and work with the person. There does not currently exist any consistent or formal oversight or review processes by OPWDD of the data submitted with the DDP.</p>	<p>programs such as ICF/DD, Day Treatment, Family Care, IRA rate appeals/price adjustments for staffing needs. The DDP 2 is used as a basis/resource for determining personal resource accounts/individualized budgets for the Consolidated Supports and Services (CSS) Program and the Portal Pilot Project. At an aggregate level, the DDP 2 is used for research and planning purposes to inform policy makers. Other than with CSS/Portal, the DDP is not linked to individual assessment and individual needs/resource allocation or person-centered planning in a meaningful way that is driven by OPWDD requirements/infrastructure. Various providers may use the DDP 2 as a resource within their own agency structures to assess and provide services to individuals.</p> <p>DDP 4—identifies unmet needs</p>
<p>ICF/MR Level of Care Eligibility Determination Form (LCED)</p>	<p>Used for the initial determination and annual redetermination of an individual’s eligibility to receive waiver services.</p>	<p>It is a requirement of the Home and Community Based Services (HCBS) Waiver that individuals meet the level of care requirements and be redetermined to meet level of care annually.</p>
<p>Individualized Service Plan (ISP)</p>	<p>The ISP is a readable and usable written personal plan that reflects the informed choices of individuals with developmental disabilities</p>	<p>Services should be delivered in accordance with the service plan, including in the type, scope, amount, duration, and frequency specified in</p>





**Attachment 2
Assessment Tools Technical Workgroup Report
August 16, 2011**

	<p>who are enrolled in PCSS or MSC. It summarizes the help a person wants and needs to live a successful life in the community and pursue his or her valued outcomes.</p>	<p>the service plan.</p>
ICF Functional Assessment	<p>Within 30 days after admission into an ICF, a comprehensive functional assessment must be completed and take into consideration the client's age, the implications for active treatment at each stage, and identify the individual's needs and strengths.</p>	<p>The comprehensive functional assessment is then used to prepare for each client an individual program plan that states the specific objectives necessary to meet the client's needs, and the planned sequence for dealing with those objectives.</p>
Developmental Disability Eligibility Assessment Tools	<p>Evaluations and assessments that are in accordance with national professional standards and with the testing and diagnostic guidelines included in the manuals for the applicable testing instruments.</p>	<p>Determines whether a person has a developmental disability and is eligible for OPWDD funded services.</p>
Functional Analysis, Behavior Support Plans, Clinic Treatment Plans, etc.	<p>Varies</p>	<p>Determines underlying reasons for why an individual may present with certain behaviors and/or helps to develop a behavior support plan or habilitative needs.</p>
CANS, used for Intensive Behavioral Services, new HCBS Waiver service	<p>An information integration tool for children, adolescents and adults with Developmental Disabilities and their families), that is used for Intensive Behavioral Services, a new HCBS Waiver service</p>	<p>CAANS-DD is used to assist with determining authorization for Intensive Behavioral Services and is also used as a pre- and post-evaluation instrument in Intensive Behavioral Services.</p>





**Attachment 2
Assessment Tools Technical Workgroup Report
August 16, 2011**

<p>implemented in July 2010</p>	<p>implemented in July 2010.</p> <p>The CAANS-DD is a tool developed to assist in the management and planning of services to children, adolescents, adults with developmental disabilities and serious mental, emotional and behavioral disorders, and their families, with the primary objectives of permanency (ability to remain in the family/caregiver home), safety, and improved quality of life.</p>	
---------------------------------	--	--

There has been discussion of using the DDP as the statewide needs assessment tool. However, the DDP which was first developed over 25 years ago (and then considered “state of the art”) is no longer considered comprehensive enough nor “person-centered” and strengths-based to adequately be used to accomplish statewide needs assessment unless there is revision, adaption and testing.

By way of further background, additional stakeholder criticism of the DDP includes the following:

- Inconsistent results depending upon who is administering the instrument which calls into question the validity as there is potential bias from the staff who complete them
- Duplicative processes—required too many times in too many settings
- Insufficient training on how to administer it
- Since DDP results may relate to provider reimbursement levels, it could be construed that incentives exist to skew results
- Difficulty using to identify staffing and support needs because not enough on behavioral needs

Within the last few years, OPWDD research and policy staff has reviewed the DDP for the purpose of determining whether additional information could be included to derive more accurate predictors of support needs for people who self-direct individualized budgets. OPWDD’s preliminary policy staff analysis concluded the following:





Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

- OPWDD has heavily invested in the infrastructure of the DDP as the Tracking and Billing System (TABS) is built on DDP fields. In addition, data from the instrument has been used for research and planning functions over the last 20+ years.
- Strong need exists to revamp OPWDD's DDP support system such as training investments, checks and balances and audit and control framework, and processes and procedures.
- Past studies have indicated that the DDP can successfully predict support staffing needs.
- The DDP has inter-rater reliability
- The DDP likely needs to be enhanced to capture key areas such as natural supports and community safety needs
- cursory review of other state approaches to needs assessment practices finds that the simple majority do not allow providers to complete the needs assessment.

See **Appendix 1** for more information on the DDP as well as information from Kansas and Ohio that also use the DDP.

Assessment Tool Reviews

Appendix 1 includes the review of each assessment tool assigned to technical workgroup members.

Lessons Learned from Reviews/Discussions of Other States' Assessment Systems

The following are some lessons learned from the review of other state assessment instruments in the field of developmental disabilities.

- All states appear to be struggling with the issue of needs assessment for people with developmental disabilities. As the field has evolved so have assessment and planning instruments.
- A single instrument may not accomplish all of our objectives. We are likely to need several assessment and planning tools to be used in combination and/or adapt or design our own state specific instruments.
- Intensive and ongoing training of assessors is necessary to ensure the integrity of the assessment system as the quality of the information obtained is only as good as the interviewer/assessor who is asking the questions. There must be someone who is skilled at interviewing and communicating with people with developmental disabilities (and family members/natural supports).
- There must be time for observation of individuals built into the assessment system.





Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

- The quality and clarity of the policies and procedures that accompany the assessment tools is just as important as the tools themselves.
- One state noted that they reduced the number of assessors from 600+ (500 were case managers) to approximately 100 and therefore were able to focus more on training, skill building, and review of the work of the assessors which seemed to contribute to the overall quality and validity of the assessment system. This may suggest that using fewer and better trained and more independent screeners results in better assessment results.
- An information management system that integrates assessment, resource allocation funding methodology, and comprehensive care planning is critical.
- Engaging stakeholders from the beginning of the process when transitioning to new assessment tools, particularly those that will drive resource allocation, is critical.
- Due process and dispute resolution is necessary.
- The traditional assessments are often not sufficient as many of these individuals have strong daily living skills (ADLs) and are young and healthy physically. It is important that assessed needs relative to offending behavior, mental health needs, and significant behavioral challenges drive sufficient resource levels to meet these complex needs effectively.
- According to the Center for Health Care Strategies (CHCS) Profiles in State Innovation: Roadmap for Improving Systems of Care for Dual Eligibles, November 2010, "The best systems link screening, assessment, utilization, and cost data across the continuum of care , allowing states to compare care experiences for subsets of the long-term care populations." The article further expresses that in best practice states, the care plan emerges from an automated comprehensive assessment system.

Considerations and Recommendations:

The following considerations are in addition to the recommendations on needs assessment outlined in the June 20, 2011 meeting summary (see http://www.opwdd.ny.gov/2011_waiver/images/access_and_choice_062011_summary.pdf):

- **Clarity of Purpose and Transparency:** First and foremost there needs to be **clarity of purpose** and **transparency** with regard to the use of any needs assessment instrument(s) put to use in the People First Waiver. All individuals and stakeholders need to understand the assessment instruments and how they are to be applied. It is the team's recommendation that People First Waiver decision makers consider and formalize the following purposes as related to OPWDD needs assessment:



Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

Individual Level:

- ✓ Identification of person’s strengths and life goals to facilitate and enhance person-centered planning—use of consistent approach to collect information on support needs, priorities, and circumstances of persons with developmental disabilities will provide valid and reliable information to inform individual service and support care coordination/planning.
- ✓ Identification of individual health and safety risk factors to ensure proactive planning and mitigation strategies, e.g., proactive identification of risk areas to address for the person to avert health and safety crises.
- ✓ Identification of support needs and resource levels; also stipend level for individual/family residing in non-certified settings if such flexible funding as recommended by the Access and Choice Design Team is adopted
- ✓ Identification of a prospective individual budget/personal resource account that will be made available as an option for self-direct/family-direct
- ✓ Identification and planning for cross-systems needs and information sharing

Systems Level:

- ✓ With regard to health and safety, valid, reliable health and safety assessment tools could be used partially to meet required evidentiary assurances for health and safety (and other assurances) for administration of the waiver.
 - ✓ Appropriate assessment tools enable enhanced Olmstead related activities using aggregated data from assessment tools so that appropriate resources can be targeted to less restrictive settings with appropriate support services
 - ✓ Improve system fairness, equity, transparency
 - ✓ Provide a basis for conducting more accurate, comparative statistical analyses of collected data, to be used for statewide planning and quality improvement and oversight
 - ✓ Tiered funding levels could be developed using valid and equitable instruments to ensure that only those individuals who truly need institutional and restrictive and/or 24 hour staffed settings are approved for these settings
- **Domains and Review Factors that should be included in People First Waiver needs assessment.** Based on cursory review of other needs assessment instruments, the following domains/individual support factors should be included for consideration in the assessment instruments:





Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

- ✓ Life goals and person's desires in the area of home, health, meaningful relationships, and meaningful work/community inclusion should come first.
 - ✓ Strengths and abilities of the person: identification of assets that the family and the individual bring with them when seeking supports and services.
 - ✓ Caregiver needs (e.g., presence and stability/reliability of natural supports)
 - ✓ Social life
 - ✓ Comprehension
 - ✓ Communication
 - ✓ Personal care
 - ✓ Health/Medical
 - ✓ Daily living
 - ✓ Communication
 - ✓ Employment
 - ✓ Behaviors (that interfere with life goals)
 - ✓ Mental Health needs
 - ✓ Safety and Support
 - ✓ Educational needs
 - ✓ Transportation
 - ✓ Housing Need
 - ✓ Culture and Ethnicity information/preferences (i.e., ensure multicultural/family history needs are identified and expressed at the time of assessment).
- **Streamline collection of information to that which is necessary, value added, and non-duplicative.** OPWDD should look to simplify and streamline all required assessment paperwork and related care planning documents as much as possible and orient them to value-added components from the system and individual/family perspective.

In OPWDD's current system, there are a variety of tools that must be used for a single individual to determine eligibility, access services, and continue to receive services. For example, as an OPWDD HCBS Waiver participant, the participant must be subjected to an initial and an annual redetermination of ICF/MR level of care. The waiver participant also must have an Individualized Service Plan with semi-annual reviews regardless of whether there are any changes in the person's life. If the waiver participant receives habilitation services, there would also need to be a plan developed along with required processes for each habilitation service. Should the participant reside in an OPWDD certified residential setting, an Individual Plan of Protective Oversight (IPOP) would be required. The DDP is also required every two years to be completed by each service



Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

provider. If the participant receives Medicaid Service Coordination (MSC), there is additional paperwork that must be completed.

It is recommended that as much as possible, each “tool” required in the People First Waiver, have a purpose that adds value to individualized outcomes and to the extent possible, eliminates duplicative information among different tools and planning documents by integrating electronically and/or consolidating tools. For example, utilize a single assessment tool to accomplish all the goals/purposes stated in this paper for initial assessment as well as to determine whether the participant meets ICF/MR level of care (if still required in this waiver) rather than creating two separate tools.

- **Considerations in Selection/Purchase vs. State-Specific Development of Valid and Reliable Assessment Tools:**
 - The roles and responsibilities in the waiver of the individual and family; the state; the managed care entity/care coordination entity; the contracted providers; independent advocates, and other stakeholders likely need to be clarified before attempting to develop and/or select assessment instruments.
 - The Colorado HSRI report cited in Attachment 3 (pages 18-20) outlines several methods states have used in deciding what assessment tools should be employed to link payment to assessed need. Some states have elected to design their own assessment tools while other states have adopted nationally recognized assessment tools (e.g., Inventory for Client and Agency Planning (ICAP), Supports Intensity Scale (SIS)). The same Colorado report states that “Employing a national tool avoids the challenges associated with *de novo* tool development. ***In general, the national tools sometimes enjoy broader stakeholder acceptance because they are less subject to tinkering and have more credibility.***”
 - OPWDD’s People First Waiver should develop or select assessment tools that balance the need to have sufficient assessment information and statistical data about each individual to be able to aggregate statewide by managed care organization/care coordination and by contracted providers with the time, complexity, and cost of administering the assessment system from the individual, provider and systems levels.



Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

The Colorado report indicates that regardless of whether a state-developed or national tool is selected, a very important consideration is how robust the tool is in terms of measuring support needs. “Individual support needs are multi-dimensional. In practice, the less robust a tool, the more difficult it is to link payments/funding to support needs accurately and appropriately.” Consequently, while it may be important to select a tool that can be administered quickly, the danger with very brief tools is that they are insufficiently sensitive to key differences among individuals (page 10-11).

Most important, whatever instrument OPWDD chooses or devises needs to be functionally based rather than deficit based, as it could be argued that deficit based instruments promote dependency, stigmatization and objectification.

- **Institutional transition:** A significant consideration for New York State OPWDD will be the assessment of individuals transitioning from institutional settings into a community based treatment model. Individuals who are residing in institutional settings have often had failures in the community-based system of supports; their clinical and supervision needs are high. Based on these high needs, the resource level to support them effectively in the community will likely be outside of the traditional parameters for support costs, i.e., “outliers”. It will be imperative to ensure that the assessment tools can assess predictive risk factors and transitional support needs for individuals who are transitioning out of these settings or who would have required that level of support due to unavailable community support options. The traditional assessments are often not sufficient as many of these individuals have strong daily living skills (ADLs) and are young and healthy physically. It is important that assessed needs relative to offending behavior, mental health needs, and significant behavioral challenges drive sufficient resource levels to meet these complex needs effectively.
- **Information Management/Use of Technology and Connection to No Wrong Door:** Comprehensive information management system must work with assessment tools and must integrate the translation of the tools to comprehensive person-centered care planning and outcome attainment. According to the Center for Health Care Strategies (CHCS) Profiles in State Innovation: Roadmap for Improving Systems of Care for Dual Eligibles, November 2010, “The best systems link screening, assessment, utilization, and cost data across the continuum of care , allowing states to compare care experiences for subsets of the long-term care populations.” The article further expresses that in best





Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

practice states, the care plan emerges from an automated comprehensive assessment system.

Implementation and Transition Considerations: A significant question is whether and how OPWDD's People First Waiver will seek to assess all individuals in the waiver and provide additional resources if individuals are underserved and decrease resources to people who are over served as a result of the needs assessment process.

Recommended Next Steps:

1. Based upon the cursory reviews by workgroup members and some literature review, the team believes the following assessment tools merit further investigation for applicability to the People First Waiver:
 - **Health Risk Screening Tool (HRST):** schedule discussion with the creators/owners of the tool for a broader audience of OPWDD staff; contact other states that use the instrument for further information. Do field testing of instrument with individuals in OPWDD operated settings.
 - **Supports Intensity Scale (SIS):** Schedule conference call with developers of the SIS, and perform a literature review and feasibility study by knowledgeable OPWDD staff, and feasibility study to look at resource allocation aspects as well. Learn from OPWDD providers who are already using the instrument.
 - **Child, and Adolescent Needs and Strengths (CANS):** Investigate how the NYS Office for Mental Health and Office for Children and Family Services utilize the CANS and what information management systems and infrastructure components could be employed across systems; investigate/analyze study how resource allocation could come out of the CANS. Investigate modifications that might be necessary if OPWDD were to utilize the instrument.
 - **State specific instruments--Wisconsin Functional Screen and Resulting Needs Assessment; and Connecticut Level of Need Instrument:** Review feasibility of adapting applicable components with the DDP and steps that would be necessary to do so.

Information must also be obtained to determine the intended implementation of the Medicaid Redesign Proposal for **Uniform Assessment** and whether this process will impact on OPWDD's People First Waiver population.



Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

2. Engage consultants:

As a next step to bring the People First vision of needs assessment (i.e., person-centered valid needs assessment process that results in equitable resource allocation) to fruition, the Assessment Tools Technical Subgroup recommends that a knowledgeable consultant be employed to work with the recommendations of the Assessment Tools Technical Subgroup to conduct cost vs. benefits study of adapting the DDP for statewide needs assessment vs. adopting a nationally recognized tool such as the SIS in conjunction with the HRST. It would also be helpful to know whether there are any other tools that should be considered by OPWDD.

3. Design **pilot demonstrations** with a component related to needs assessment to test nationally recognized and/or canned assessment tools vs. the DDP. Consider piloting the SIS and the HRST in these demonstrations.



Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

Attachment 3 - Assessment Tool Subgroup Sources:

Agency for Persons with Disabilities. State of Florida. <http://apd.myflorida.com/>.

Agosta, J.; Fortune, J.; Kimmicj, M.; Melda, K.; Smith, D.; Auerbach, K.; and Taub, S. (2009, April). Ten issues for States to Consider in implementing Individual or Level based budget Allocations. Independent Living Research Utilization Community Living partnership.

American Association on Intellectual and Developmental Disabilities is a site that promotes policies, research and practices for individuals with developmental disabilities (www.aaid.org).

Bourne, P. (August 2011). Connecticut Manager of large voluntary day services provider. Interview.

Brazzell H. (August 2011). Florida Director of IBudget. Interview.

Brom, J. (August 2011). State of Wisconsin Department of Children and Families, Division of Safety and Permanence. Interview.

Burnette, R. (2010, October). Supports Intensity Scale Pilot Project. North Carolina Joint legislative oversight committee on Mental Health, Developmental Disabilities and Substance Abuse Services.

Center for Health Care Strategies (CHCS). (2010, November). Profiles in State Innovation: Roadmap for Improving Systems of Care for Dual Eligibles.

Connecticut Advisory Committee (2011, January). DDS Legislative Rate Study Committee Report, Summary of Frequently Asked Questions, Advisory Committee Report and Executive

Connecticut Department of Mental Retardation. (2006, July 1). Level of Need Assessment Screening Tool.

Draughon, V. (August 2011). Florida Support Coordination, Medicaid Waiver, Family Care council Health Service/Facility consultant. Interview.

Duvall, D. (August 2011). Connecticut employee and former waiver manager. Interview.



Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

Fields, P. (August 2011). Connecticut Manager of a large voluntary residential & other supports provider. Interview.

Fortune, J.; Agosta, J., and Bershinsky, J. (2011, March). 2011 Validity and Reliability Results Regarding the SIS. Human Services Research Institute.

Fortune, J.; LeVelle, J.; Meche, S.; Severance, D.; Smith, G; Stern, J.; Van Loon, J.; Weber, L.; and Campbell, E. (2008, June). Resource Allocation and the Supports Intensity Scale: Four Papers on Issues and Approaches.

Georgia Department of Human Resources Division of Mental Health, Developmental Disabilities and Addictive Diseases, Office of Developmental Disabilities. (2008, May 1). Implementation in State of Georgia. Supports Intensity Scale Case Review Protocol.

Georgia Department of Behavioral Health and Developmental Disabilities. (2011, May 24). Health Risk Screening Tool Policy. http://centralstatehospital.org/policy/Policy%2002-803%20HRST%20w.%20Appendix_Rev%201_eff%206.1.11.pdf.

Health Risk Screening Tool is a site that explains what the Health Risk Screening Tool is. (<http://www.hrsonline.com/index.php>).

Health Risk Screening Tool. (2011, July 26). Presentation.

Hennike, J.; Myers, A.; Ealon, R.; Thompson, T. (2006, June). Development and Validation of a Needs Assessment Instrument for Persons with Developmental Disabilities. *Journal of Developmental and Physical disabilities*.

Lamoureux-Hebert, M.; Morin, D.; and Crocker, A. (2010). Support needs of Individuals with Mild and Moderate Intellectual Disabilities and Challenging Behaviors. *Journal of mental health Research in Intellectual Disabilities*.

Kansas Department of Social & Rehabilitation Services. (2001, May). Basic Assessment and Services Information System Forms Instruction Manual. <http://www.srs.ks.gov/agency/css/Documents/DD%20Waiver/basismannual60.pdf>.

K.C., Africa H.; Allison Taylor Johns; L.S., Ron S.; And D.C And Penny C. V. Lanier Cansler, North Carolina Secretary Of The Department Of Health And Human Services, Pamela Shipman,



Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

Area Director of Piedmont Behavioral Health Care Area Mental Health, Developmental Disabilities, and Substance Abuse Authority, and Piedmont Behavioral Healthcare Area Mental Health, Developmental Disabilities And Substance Abuse Authority (2011).

Kimmich, M.; Agosta, J.; Fortune, J.; Smith, D.; Melda, K.; Auerbach, K.; and Taub, S. (2009, April). Developing individual budgets and Reimbursement Levels using the Supports Intensity Scale. Independent Living Research Utilization Community Living partnership.

McGarrity, T. (August 2011). Florida Community Improvement Deputy Director. Interview.

New York State Developmental Disabilities Profile and User Guide.

(http://www.opwdd.ny.gov/wt/images/wt_DDP2_User_Guide.pdf).

Ohio Department of Mental Retardation and Developmental Disability. (2004, January). Ohio Developmental Disability Profile (ODDP). <http://www.dodd.ohio.gov/medicaid/docs/ddp-all2.pdf>.

Ohio. (2010, July 01). Home and Community-based Services Waivers – Payment for Waiver Services 5123. <http://mrdd.ohio.gov/rules/documents/5123-2-9-06Effective07-01-10.pdf>

Ohio Department of Mental Retardation and Developmental Disability. ODDP Training Worksheet for Determining Frequency of Behavioral Occurrences. <http://www.dodd.ohio.gov/training/docs/oddp-frequencyworksheet.pdf>.

Ohio Department of Mental Retardation and Developmental Disability. (2008, April). Acuity Assessment Instrument (AAI). Fact Sheet. <http://www.dodd.ohio.gov/medicaid/docs/AAIFaq.pdf>.

Pettinger, J. (August 2011). Assistant Commissioner, OPWDD Behavioral and Clinical Solutions. Interview.

Praed Foundation is a site that has information on evidence-based assessments and on the Child & Adolescent Needs and Strengths, the Family Advocacy and Support Tool, the Crisis Assessment Tool, and the Adult Needs and Strengths Assessment. (www.praedfoundation.org).

Robison, J. and Evans, J. Connecticut's Long-Term Care Needs Assessment, A Road Map for the Future.



Attachment 2 Assessment Tools Technical Workgroup Report August 16, 2011

Smith, G. and Fortune, J. (2006, June 30). Assessment Instruments and Community Services Rate Determination: Review and Analysis. Division of Developmental Disabilities Colorado Department of Human Services. Human Services Research Institute.

State of Nebraska Developmental Disabilities System and MERCER Government Human Services Consulting. (2004, September 1). Developmental Disabilities Objective Assessment Process: Legislative Bill 297 Work Group Report and Recommendations.

State of Oregon. Restructuring Budgets, Assessments and Rates (ReBAR).
<http://www.oregon.gov/DHS/dd/rebar/>

Texas Department of Aging and Disability Services. Inventory for Client and Agency Planning (ICAP) Resources. <http://www.dads.state.tx.us/providers/guidelines/icap/index.html>.

Utah Division of Services for People with Disabilities. (2006, January). AAMR - Supports Intensity Scale (SIS) Questions from Providers and Answers from DSPD.

Waiver Provider is a site that provides information on various waiver services in Florida.
(<http://waiverprovider.com/>).

Walton, B. (August 2011). Indiana Family and Social Services Administration. Interview.

Wehmeyer, M.; Chapman, T.; and Little, T. (2009, January). Efficacy of the Supports Intensity Scale (SIS) to Predict Extraordinary Support Needs. *AAIDD Journal*.

Weiss, J.; Lunsky, Y.; Tasse M.; and Durbin, J. (2009, June 28). Support for the construct validity of the Supports Intensity Scale based on clinician rankings of need.

Wisconsin Department of Health Services. Long term Care Functional Screen Instructions.
<http://www.dhs.wisconsin.gov/ltcare/functionalscreen/LTCFSinstrux-clean.pdf>.

Wisconsin Department of Health Services. Long term Care Functional Screen Overview.
<http://www.dhs.wisconsin.gov/ltcare/functionalscreen/LTCFSoverview.HTM>.



**Attachment 2A:
Access and Choice Design Team Assessment Tools Technical Subgroup Report
Team Member Reviews of Selected Assessment Instruments
August 16, 2011**

Background and Purpose:

According to Design Team parameters, the People First Waiver will include: “a standardized needs assessment instrument and/or tool that will be consistently applied across the People First Waiver to determine each individual’s strengths, needs, and preferences. This needs assessment tool will be used to allocate resources equitably and will be administered by an entity that is independent from service delivery.”

The Access and Choice Design Team chartered the Assessment Tools Technical Subgroup to review selected needs assessment instruments used in other state systems for people with developmental disabilities. The primary purpose of this task was to provide information on various assessment domains and factors (including administrative and other considerations) used to assess the need for supports and services. This information allowed the Access and Choice Design Team to make informed recommendations related to charter questions on needs assessment. It was not the purpose of the Assessment Tools Technical Subgroup or the Access and Choice Design Team to make a final recommendation on what assessment tool(s) should be used in the People First Waiver (see report of the Assessment Tools Technical Subgroup for further information on the team’s charge).

The following tools were reviewed by the team:

- **Developmental Disabilities Profile (DDP) adapted by other states**
- **Supports Intensity Scale (SIS) *national tool***
- **Inventory for Client Assessment and Planning (ICAP) *national tool***
- **Florida Situational Questionnaire**
- **Connecticut Level of Need (LON)**
- **Wisconsin Functional Screen**
- **the Child and Adult Needs and Strengths (CANS) assessment**
- **Health Risk Screening Tool (HRST)**

Methods for obtaining the data summarized in the chart below included the following: review of the instruments and comparison to OPWDD’s DDP; web-based research; phone calls to state officials, stakeholders, and others (see Appendix B for Resources). The chart identifies the questions that each team member was assigned to answer as part of their review of each tool. Areas left blank indicate a need for more information.



Attachment 2A: Assessment Tools Technical Subgroup Report

As a next step, the Assessment Tools subgroup recommends that one or more knowledgeable consultants be brought in to take the teams work to the next level by further analyzing and assessing the most efficient, person-centered, and cost-effective means to implement a systems wide needs assessment. Such an analysis should detail the costs vs. benefits (from individual and systems perspective) of revamping the current DDP tool used by OPWDD vs. adopting a different nationally recognized instrument such as the SIS with appropriate adaptations/supplements for NYS use and the CANS.



Details on Assessment Tools Reviewed by Team Members

Tool Reviewed	Background
OPWDD Developmental Disabilities Profile 2 (DDP2)	The DDP 2 was designed by OPWDD (then OMRDD) to document key characteristics of persons with developmental disabilities simply and briefly. DDP 2 initially developed over 20 years ago to inform ICF and Day Treatment rate setting methodologies.
Developmental Disabilities Profile (Kansas)	The Kansas Department of Social and Rehabilitation Services (SRS), which is the state's DD agency, has been using the DDP (BASIS) for purposes of establishing funding levels since 1992. Kansas originally selected the DDP because of its validity and reliability at the time and because it was available at no cost. However, it appears that only the DDP information is used for purposes of establishing payment for services.
DDP (Ohio)	Ohio transitioned to the DDP based reimbursement system in 2007.
Supports Intensity Scale (SIS)	Published by the American Association on Intellectual and Developmental Disabilities to measure practical support requirements of adults with intellectual and developmental disabilities in 85 daily living and medical and behavioral areas. Studies have been conducted comparing the SIS to other instruments and to reliability in the field. Developed over five years by experts and then field tested and it is used by over 20 states.
Inventory for Client and Agency Planning (ICAP)	The ICAP can be used to assess children and adults with developmental disabilities, people who become handicapped as adults through accident or illness, and elderly people who have gradually lost their independence often need special assistance at home, at school and at work are.
Florida Situational	The current questionnaire is a redesign of another tool they used. They developed the QSI with input from behavioral specialists, family members, self-advocates, clinicians including speech/language pathologists and occupational therapists, state workers and administrators. Upon its finalization, training was done for the assessors. They are hired by the state although they receive no full-time benefits. They receive significant training and must participate in inter-rater reliability on a regular basis. Florida assessed 30,000 individuals with disabilities in 18 months following the training of their assessors.



Attachment 2A: Assessment Tools Technical Subgroup Report

Connecticut Level of Need	<p>The state was using its own tool called the Waiting List Assessment. It was not judged as sufficiently comprehensive so CT set about a large scale instrument development effort using funds from a CMS Real Choice type (systems change) grant in 2003. This was a multi-phase, multi-year effort led by a consultant from the University of Conn. Following extensive literature review, a multi-disciplinary team was formed and started the design process qualitatively by holding focus groups and doing key informant interviews with all stakeholder types. The tool was iteratively revised and pilot tested over three phases with a cumulative case total involving over seven thousand assessments. . Reports have shown that this tool is reliable and valid.</p>
Wisconsin Functional Screen	<p>During development, stakeholders were at state meetings and many rounds of sample tests were performed. The screen was developed over years prior to implementation.</p> <p>The tool incorporates both the medical and independent living aspects in one tool. The algorithms behind the screen are predictors of need for nursing home levels of care. The state had a lot of interaction with the public and counties when this was developed. They continue to do thorough interaction with screeners about clarity and training.</p>
Child and Adolescent Needs and Strengths Assessment (CANS)	<p>A multi-purpose tool developed for children’s services to support decision making, including level of care and service planning, to facilitate quality improvement initiatives, and to allow for the monitoring of outcomes of services. Versions of the CANS are currently used in 25 states in child welfare, mental health, juvenile justice, and early intervention applications.</p> <p>To decide on the CANS, states form a cross-system group and reviewed other tools, they then developed the CANS to meet their states needs. Development took from 7 months to 2 years.</p>
Health Risk Screening Tool (HRST)	<p>Created in 1992, The Health Risk Screening Tool (HRST) is a web-based rating instrument developed to screen for health risks associated with a wide variety of disabilities, including developmental disabilities, physical disabilities, disabilities associated with aging, and many other conditions, which specifically affect systems of the body and the person’s ability to engage in functional activities. It was field tested on 6000 individuals and is used in at least 4 states and by private providers.</p>
Tool Reviewed	How are resources allocated based on the assessment?



OPWDD Developmental Disabilities Profile 2 (DDP2)	Funding levels for the Consolidated Supports and Services program are determined using the DDP 2. The DDP 2 is still used to inform and/or determine reimbursement levels in certain programs such as ICF/DD, Day Treatment, Family Care, IRA rate appeals/price adjustments for staffing needs.
Developmental Disabilities Profile (Kansas)	<p>Score results in the assignment of an individual to one of five funding tiers. Each program or service type has a different payment amount for each tier.</p> <p>In home supports is paid entirely outside of the tier method and unrelated to the results of the DDP assessment since it was not useful for this purpose.</p> <p>Each tier also has a “super-tier” which is higher for each service based upon the need for extraordinary care. The super tier levels were established to address individuals being deinstitutionalized from state developmental centers in the process of closure, such individuals typically exhibited either high medical or high behavioral needs (or both). Since the DDP does not distinguish frequency of behavioral episodes, the super-tier designation is not driven by the DDP results. Such designation is based upon anecdotal information and negotiation between the provider and the state.</p>
DDP (Ohio)	DDP in Ohio is used to determine the funding limits or thresholds that an individual requires and is used throughout the state of Ohio for all persons served in the Options Waiver. DDP links the assessment of the individual to funding range. An Individual Service Plan is then developed. The ISP identifies the actual services needed by the individual and develops a funding level based on the funding range. Once the funding level and ISP is established, the actual funding for specific services is developed based on a “Cost Projection Tool”.
Supports Intensity Scale (SIS)	<p>Two types of methodology:</p> <ol style="list-style-type: none"> 1. Development method – based on the person centered plan and once completed is used to calculate the budget. Works well for individuals but does not necessarily ensure resources are distributed evenly 2. Prospective method – relies on collection of data relating to costs incurred by each person, and determinants, including geography, support needs, regulatory factors. Formulas created to describe those relationships, Individualized Budget Allocation generated <p>Two types of payments</p>



Attachment 2A: Assessment Tools Technical Subgroup Report

	<ol style="list-style-type: none"> 1. Prospective Budget or individualized Budget Amount which sets an upper limit on funding authorized to purchase goods and services on a person behalf. Persons with similar needs have similar global budgets. 2. Service Payments sets standardized provider payments for the delivery of particular services, taking into account differences in support needs of propel served by the provider. This is the Level Base Amount.
Inventory for Client and Agency Planning (ICAP)	The ICAP was not originally developed to support rate determination or resource allocation strategies, although it has been employed in several states to do so.
Florida Situational	Florida is converting to the iBudget (Individualized Budget) over the next 10 months and will use the Florida Situational to do that.
Connecticut Level of Need	<p>The LON is used to generate a need score ranging from 1 to 8. A predetermined payment figure per score category and within program type 'bands' (day hab, supported employment, differing intensities of residential settings) is then allotted for the person's service provision. Health needs are included and the only carve outs are for transportation and respite, which are covered in a separate state waiver (Individual and Family Support Waiver).</p> <p>The instrument is used for all people in the service system for planning and DD systems analysis; however the rate setting application has been implemented gradually. At first only new entrants were incorporated into the LON financial methodology but this caused confusion and unhappiness with widely disparate payments within and between providers case mix. The state is now struggling with a phased in, FULL implementation of the methodology. All day programs have now switched to the new payment scheme, with core type residential service modules to follow sometime in 2012.</p>
Wisconsin Functional Screen	Capitated payments are provided to the managed care agencies based on the level of care. Carve outs are present (personal care is a carve out of the self-directed (IRIS) model, Medicare services are carved out of Family Care and IRIS models)
Child and Adolescent Needs and Strengths Assessment (CANS)	One state takes a base rate and then multiplies an amount by any elements that had "high" scores showing need.
Health Risk Screening Tool (HRST)	The individual ratings and overall score derived from the Health Risk Screening Tool guide the independent support coordinator and health care manager in the provision of appropriate levels and types of health care support and surveillance. Overall scores are used to assign a HEALTH CARE LEVEL, which is associated with a specific DEGREE OF



Attachment 2A: Assessment Tools Technical Subgroup Report

HEALTH RISK.								
Tool Reviewed	Domains							
OPWDD Developmental Disabilities Profile (DDP) 2	Disability description/ diagnosis	Medical	Sensory Motor	Cognitive/ communication	Behaviors	Self Care/Daily Living/ADLs	Clinical Services	
DDP (Kansas)	Same as above							
DDP (Ohio)	Same as above							
Supports Intensity Scale (SIS)	Community Living	Exceptional medical	Employment	Social Activities	Exceptional Behavioral	Lifelong Learning	Health/ Safety	Protection & Advocacy
Inventory for Client and Agency Planning (ICAP)	Community Living		Motor skills	Social and communication	General maladaptive behavior index	Personal Living Skills		
Florida Situational	Community inclusion and fulfillment	Physical status	Functional status		Behavioral intervention and support status	Essential living skills		
Connecticut Level of Need	Unpaid Support	Health & Medical	Social Life, Recreation, and Community Activities	Comprehension and understanding, and Communication	Behavioral and Mental Health	Home or Residence and Day, school, job or vocational level of Support	Transportation	Overnight support, monitoring or assistance



Attachment 2A: Assessment Tools Technical Subgroup Report

Wisconsin Functional Screen	Demographics & living situation	Diagnoses (with medical diagnoses)	Risk	Communication and Cognition	Behaviors/Mental health	ADLs	Health Related Services	Overnight Care & Employment
Child and Adolescent Needs and Strengths Assessment (CANS)	Life domain functioning	Strengths (individual & environmental)	Risk behaviors	Acculturation	Behavioral / emotional needs	Developmental needs	Co-morbidities	Caregiver strengths & needs
Health Risk Screening Tool (HRST)	Functional Status	Physiological	Frequency	Safety	Behaviors			
Tool Reviewed	How is person-centered planning and individual life goals integrated with needs assessment?							
OPWDD Developmental Disabilities Profile 2 (DDP2)	No consistent process that connects the DDP information with the individual’s person-centered service plan.							
Developmental Disabilities Profile (Kansas)	--							
DDP (Ohio)	--							
Supports Intensity Scale (SIS)	A functional needs assessment tool that when used in conjunction with a person-centered planning process leads to a plan that addresses the individual’s hopes and dreams by identifying areas of support.							
Inventory for Client and Agency Planning (ICAP)	--							
Florida Situational	Assessor meets with a nurse, a waiver support coordinator, and a behavior support coordinator. From there another support coordinator meets with the individual and family and determines an individualized budget and life goals.							



Attachment 2A: Assessment Tools Technical Subgroup Report

Connecticut Level of Need	The individual and family are part of the team that provides input to the case manager completing the tool. And this tool drives development of the plan.
Wisconsin Functional Screen	Long Term Care program focuses on individual requested outcomes correlating to the screened assessment of needs.
Child and Adolescent Needs and Strengths Assessment (CANS)	Tool does not use “diagnostic” or “medical” language and looks at the functioning level and strengths of the individual.
Health Risk Screening Tool (HRST)	Typically used in conjunction with an assessment tool.
Tool Reviewed	How does the needs assessment process lead to a comprehensive care plan?
OPWDD Developmental Disabilities Profile 2 (DDP2)	---
Developmental Disabilities Profile (Kansas)	--
DDP (Ohio)	--
Supports Intensity Scale (SIS)	SIS is designed to identify needs and updates will show how those needs might fluctuate. It can be the basis and reference point for a person-centered plan.
Inventory for Client and Agency Planning (ICAP)	--
Florida Situational	Score helps to determine a support level and the assessment is then used by “service coordinators” to develop the comprehensive care plan.
Connecticut Level of Need	The individual and family are part of the team that provides input to the case manager completing the tool. And this tool drives development of the plan.



Attachment 2A: Assessment Tools Technical Subgroup Report

Wisconsin Functional Screen	The assessment correlates to outcomes on the Person Centered Plan. To the degree possible, individuals choose their level of requested assistance. There is a level of risk when choosing no assistance in a needed area.
Child and Adolescent Needs and Strengths Assessment (CANS)	The tool is designed for communicating with the individual and other stakeholders so that a comprehensive plan can be developed. In certain states, it is helps develop treatment planning and any areas identified as high need are required to be addressed in the plan.
Health Risk Screening Tool (HRST)	Tool used as a preliminary measure before the plan is developed, the score and outcome is shared with the team that is responsible for the care plan.
Tool Reviewed	How are changes in life circumstances taken into account after the assessments are completed and resources, supports and services allocated, i.e. what triggers a reassessment? How often are needs assessed?
OPWDD Developmental Disabilities Profile 2 (DDP2)	<ol style="list-style-type: none"> 1. Within thirty days of when an individual moves to a new program/service, 2. Whenever a significant change occurs to an individual’s characteristics, 3. At least every two years
Developmental Disabilities Profile (Kansas)	<ol style="list-style-type: none"> 1. When entering the system 2. Every year
DDP (Ohio)	--
Supports Intensity Scale (SIS)	<ol style="list-style-type: none"> 1. When entering the system 2. Every four to five years 3. Recommended when there is a significant change
Inventory for Client and Agency Planning (ICAP)	--
Florida Situational	<ol style="list-style-type: none"> 1. Within months of entering the system 2. When there is a change in health (physical, behavioral and mental) or unpaid caregiver support and when there is interaction with the criminal justice system.



Attachment 2A: Assessment Tools Technical Subgroup Report

	3. Every 3 years		
Connecticut Level of Need	<ol style="list-style-type: none"> 1. Completed Annually 2. Whenever there is a significant change in service that needs to be addressed. 		
Wisconsin Functional Screen	<ol style="list-style-type: none"> 1. Completed Annually 2. Whenever there is a significant change, such as a new diagnosis, living arrangement, or a change in ability/independence 		
Child and Adolescent Needs and Strengths Assessment (CANS)	<ol style="list-style-type: none"> 1. Completed within 30 days of placement or before authorization of services 2. Flexibility 3. Some states require an update every six months 		
Health Risk Screening Tool (HRST)	1. Usually annually and whenever there is a significant change (dependent upon the policies in each state).		
Tool Reviewed	Which organizations administer the tool?	What are the qualifications of the organizations & assessors?	What is the role of the state?
OPWDD Developmental Disabilities Profile 2 (DDP2)	Agencies delivering the service	A staff member who knows the person best and consults with clinical staff or family members, as necessary.	Aggregate DDP-2 data is to be used to describe, plan, and manage the system of services. State also completes DDP2s as it delivers services.
Developmental Disabilities Profile (Kansas)	Not-for-profit agencies or local governmental units, which may be service providers.	A person, who is not a case manager, but is a professional that receives quarterly training.	Assigns level of payment based on an individual's score.
DDP (Ohio)	County level government, which may be service providers.	A county staff person who is trained and certified.	--
Supports Intensity Scale (SIS)	States can decide. Counties, state staff, contracted employees, does not appear to be	Human service professional with a four-year degree	--



Attachment 2A: Assessment Tools Technical Subgroup Report

	direct service providers when it is implemented in a state-wide fashion		
Inventory for Client and Agency Planning (ICAP)	--	Professional who has known the person for at least three months and sees the person on a daily basis.	--
Florida Situational	State.	Bachelor's degree and 4 years of professional experience with individuals with developmental disabilities. Preference given to those with 2 years experience in working in direct services. Staff cannot be employed by an agency that provides services to individuals with DD. Must pass a two- day training.	The state administers the assessment
Connecticut Level of Need	State agency	Qualifications are similar to a Medicaid Service Coordination (Associates Degree in a social services field and one year experience working with individuals with DD)	The state processes the assessment and assigns a level of need category.
Wisconsin Functional Screen	Initial screening is done by a state regional office. Agencies and MCOs perform updates.	Bachelor's degree in a human services field and 2 years of online certification	
Child and Adolescent Needs and Strengths Assessment (CANS)	Providers of service, county and state workers	Flexible. Although some states require a bachelor's. Online certification that lasts 6 months to two years.	Quality oversight and assignment of base level payment.
Health Risk Screening Tool			



(HRST)			
Tool Reviewed	How is quality of the needs assessment determined?		
OPWDD Developmental Disabilities Profile 2 (DDP2)	Not Applicable		
Developmental Disabilities Profile (Kansas)	<p>There is quarterly training for assessors as well as assessor reviews to test for inter-rater reliability.</p> <p>Assessors may also be service providers but must have a separate supervisory structure for the contracted assessment function.</p>		
DDP (Ohio)	Administered by trained, certified county professionals.		
Supports Intensity Scale (SIS)	<p>Developed over five years by experts and then field tested.</p> <p>Studies have been conducted comparing the SIS to other instruments and to reliability in the field.</p>		
Inventory for Client and Agency Planning (ICAP)	Designed to be administered by a professional who has known the person for at least 3 months and sees the person day to day.		
Florida Situational	Assessors have distinct educational and experience requirements and then they are trained for a minimum of 2 days in the classroom. They also are given an online test that gives them potential situations to consider. They engage in inter-rater reliability testing to ensure consistency.		
Connecticut Level o f Need	When contested, assessments may be formally reviewed by a Program Review Administrative Team that may revise items that result in changing funding scores. Any supplemental rate awarded has a utilization review.		
Wisconsin Functional Screen	Quality assurance includes the assessor completing an online certification course, inter-rater reliability testing, random sampling for accuracy and consistency, and new assessors have monitoring and mentoring, State staff review screens and quality assurance methods and agencies must correct and amend screens that are done incorrectly.		
Child and Adolescent Needs and Strengths	Reviews that include how the CANS has been integrated into the plan. Auditors score the CANS against the information in an individual's record to see if they arrive at the original score. And recertification training includes inter-reliability testing.		



Attachment 2A: Assessment Tools Technical Subgroup Report

Assessment (CANS)	
Health Risk Screening Tool (HRST)	Scores that identify potential health and safety risk issues are reviewed by nurses and medical professionals. Reports and results can be shared with auditing and reviewing parties. There is ongoing training and technical assistance for providers who need it.
Tool Reviewed	What is the involvement of families i.e. is it transparent and how are families apprised of the tool?
OPWDD Developmental Disabilities Profile 2 (DDP2)	--
Developmental Disabilities Profile (Kansas)	--
DDP (Ohio)	--
Supports Intensity Scale (SIS)	All states reviewed have a mandatory requirement that the individual and their family be shown how SIS works (or have information sites and booklets). Individuals and families can be trained on the instruments.
Inventory for Client and Agency Planning (ICAP)	--
Florida Situational	Families can access the website to learn more about the assessment.
Connecticut Level of Need	Self-advocates and families were involved in the development of the assessment. Through outreach and education, transparency and family understanding have grown in the last five years ago.
Wisconsin Functional Screen	Individuals and families are told about the process and shown the screen in paper format (they can have a copy if they wish). The screen, instructions for the screen and all webcast training are online for anyone to view. All eligibility determinations from the screen are formally appealable; individuals can request a 2nd screening by a different screener.
Child and Adolescent Needs	Tool is made available online and agencies performing assessments are to tell families about the tool.



and Strengths Assessment (CANS)		
Health Risk Screening Tool (HRST)	The tool can be shared with the family and individual. The HRST does not need the family and individual present, as it can sometimes be completed through a record review.	
Tool Reviewed	Strengths	Weaknesses
OPWDD Developmental Disabilities Profile 2 (DDP2)	<ul style="list-style-type: none"> • Past studies have indicated that the DDP can successfully predict support staffing needs. • The DDP is relatively simple and quick to complete and score. • It can be completed by direct support professionals • OPWDD has heavily invested in the infrastructure of the DDP as the Tracking and Billing System (TABS) is built on DDP fields. In addition, data from the instrument has been used for research and planning functions over the last 20+ years so there is availability of a large quantity of data from which to use as a baseline for future comparisons. 	<ul style="list-style-type: none"> • The instrument is deficit based instead of strengths-based • the DDP does not include sufficient information on natural supports and community safety needs • Inconsistent results depending upon who is administering the instrument • Duplicative processes—required too many times in too many settings • Insufficient training on how to administer it • Since DDP results may relate to provider reimbursement levels, it could be construed that incentives exist to skew results • The DDP is outdated and has not kept up with advances in the field of developmental disabilities • Instrument does not assess individual’s preferences.
Developmental Disabilities Profile (Kansas)	<ul style="list-style-type: none"> • Originally selected because of its validity and reliability at the time and because it was available at no cost. 	<ul style="list-style-type: none"> • The DDP fails to account for depth of need in behavioral supports, medical conditions and physical disabilities • Does not truly weight needs across the system or uniformly weight needs • Individuals felt that they were not assigned to the



Attachment 2A: Assessment Tools Technical Subgroup Report

		<p>appropriate tier</p> <ul style="list-style-type: none"> • Important adaptive behaviors such as the ability to see, hear and walk without assistance have no weighted value • Not appropriate for children
DDP (Ohio)	--	<ul style="list-style-type: none"> • Uses additional assessment tools to make up for the limitations of the DDP.
Supports Intensity Scale (SIS)	<ul style="list-style-type: none"> • SIS is rationally rooted and due to its high inter-rater reliability is likely to be equitable • SIS was developed through rigorous process that incorporated current best practice • Been used in over 20 states, and has built a substantial body of data and ability to compare needs and costs across states. Data can be used to acquire and order data at a granular level • While not endorsed by CMS it appears to be aligned with their view of best practice • SIS methodology is transparent and directly involves the person with I/DD • SIS allows for personal growth and development and potential reduction of support needs • SIS has multiple options for access including web based or static • Nationally organized with ability to assist states in comparing services and cost to other states and insulated from established political arrangements and the provider industry. • Supports need based rather than deficit based and is based on employment first perspective 	<ul style="list-style-type: none"> • Initial and ongoing costs to use as it is a proprietary, copyrighted instrument • There is substantial training required, which is ongoing • SIS may need to be supplemented (e.g. HRST) for certain health and behavioral areas in addition to being modified to take into account regulatory requirements



	<ul style="list-style-type: none"> • Readily adaptable as a budgeting tool • Can apply to spectrum of peoples’ needs as the approach permits access to services from multiple perspectives and providers of health services • Already translated into many languages 	
Inventory for Client and Agency Planning (ICAP)	<ul style="list-style-type: none"> • According to Colorado report, strengths include the following: <ul style="list-style-type: none"> ○ Reliable for measuring adaptive and problem behavior ○ Acceptably differentiates among individuals with respect to extent of adaptive and maladaptive behavior ○ May be applied to both children and adults ○ Exhibits psychometric properties ○ Supports compiling robust information concerning people receiving services ○ Scoring is relatively straightforward ○ Is in relatively wide-use among states in various applications 	<ul style="list-style-type: none"> • Initial and ongoing costs to use as it is a proprietary, copyrighted instrument • Minimal information is collected on the individual’s health status and health status is not considered in calculating the Service Level Index score. • Tool is not widely used to support the development of individual service plans. • Adaptive behavior scoring does not directly measure the frequency or intensity of the support necessary to assist the person. • Tool does not collect info about the extent to which non-paid caregivers are available to meet individual needs • Does not have much on employment/vocational supports • Is deficit based rather than strengths based • May have inherent biases based on the type of individual completing it • The same behavior can be rated again in several categories. Allowing for errors in scoring.
Florida Situational	<ul style="list-style-type: none"> • Allowed the state to have good data collection for placement issues. • The tool helps to identify extraordinary needs; this is useful for individualized budgeting. • The tool assists the support coordinator to get to know new people. 	<ul style="list-style-type: none"> • Does not specifically address subpopulations (i.e., dual diagnosed, aging, children, hearing impaired, individuals with seizures, individuals in residential settings) • There should be more questions regarding the continued availability of care providers. An example would be to understand the physical capabilities and condition of care



Attachment 2A: Assessment Tools Technical Subgroup Report

	<ul style="list-style-type: none"> • Research supports that the tool is reliable and that it measures what it is intended to measure. 	<p>providers.</p> <ul style="list-style-type: none"> • Scales are built on the expectations of deficits and levels of interventions. Deficiency – based approach. • It does not address individual interests or related needs for support. • Based on the “medical model.” • Not consistent with individual choice, self-determination. • Self advocate experts do not consider the language used in the targeted scales to be respectful of the people they are intended to assess. For example, item 23 is titled “self-protection”, yet the supports described in the rating scale are what others can do to the person rather than what the person can do to protect him or herself.* • Since 72% of individuals served in Florida live at home while another 8% live on their own, question about whether the scale truly reflects people who need group living. Level of supports determined by the tool did not truly correspond to the level of supports needed for an individual. For example: supervision in the community was difficult to score on this tool.
Connecticut Level of Need	<ul style="list-style-type: none"> • The instrument is short but covers a large amount of different domains. • The LON does not necessarily require supplemental assessments for rate setting purposes • The assessor requires advanced clinical training. • And though the form is copyrighted, CT’s view is that the tool is largely public domain as it was devised with federal money. 	<ul style="list-style-type: none"> • The form is relatively new and has not been adopted by other states; thereby the validation data is not large. • There are questions about sensitivity to extreme ‘outlier’ needs or characteristics. This is attended to partially by way of open ended text fields and the ‘appeals’ process.
Wisconsin	<ul style="list-style-type: none"> • Can be completed by non-medical staff 	<ul style="list-style-type: none"> • Individuals don’t always understand that their self-report



Attachment 2A: Assessment Tools Technical Subgroup Report

<p>Functional Screen</p>	<ul style="list-style-type: none"> • Easy to administer and is not intimidating for individuals to answer questions • The training is available on-line • Computerized model enables quicker eligibility determinations • The functional screen and the individualized assessment process capture social and medical data in one place for care planning and provide consistency statewide. 	<p>isn't the only determinant in their eligibility and that medical verification is used as well as financial need for the service. This is especially true of people who might not understand the difference between services available for people whose service needs are due to mental health disabilities rather than physical/developmental disabilities.</p>
<p>Child and Adolescent Needs and Strengths Assessment (CANS)</p>	<ul style="list-style-type: none"> • Takes into account where those needs are already being met by a natural support. In these instances, "formal" supports would not be offered or required unnecessarily. • It is a public domain tool. That means that it can be modified to meet the needs of a population or of the system. It also does not have proprietary costs and will be cheaper to use in the long run. • This tool does not require certain qualifications of the assessor. States can have the flexibility to mandate them. • OMH is already using this tool and OCFS is using the tool in their Bridges to Health Waiver. • Has been tested for reliability and validity 	<ul style="list-style-type: none"> • Focuses on Children although there are variations that have been created for adults. • Would require modifications to address needs of subpopulations (e.g., medically frail, forensic, dually diagnosed) • May not be a weakness but a major difference between the CANS and the DDP-2 is that this tool is not specific (e.g. DDP-2 asks "can pick up a small object). As the CANS is a planning tool, • The idea is that where a person has needs, the actual plan would give the specifics to this. • Time would be needed to develop the tool to fit OPWDD's specific population • An algorithm would need to be developed to use as reimbursement.
<p>Health Risk Screening Tool (HRST)</p>	<ul style="list-style-type: none"> • According to contractor, CMS will reimburse 50% of cost of tool. CMS cited tool in Quality HCBS report for Georgia. • HRST comes with a software package with built in logic and decision trees. The software also makes 	<ul style="list-style-type: none"> • This is a health risk screening tool; it is not an assessment tool and therefore would be a supplement to any assessment tool chosen.



	<p>training and care planning recommendations based on responses.</p> <ul style="list-style-type: none"> • The training is available on-line • Ability to aggregate health outcomes based on individual and trend over time as well as statewide aggregation or aggregation by specific categories such as DDSO or region. • Comes with a variety of aggregated reports. Company willing and available to write new reports upon request. • The electronic software package can interface with most other systems. For example, the HRST works well with the Supports Intensity Scale (SIS) in states such as Georgia that are using both instruments. • Web-based system allows individual information to be shared with a team of professionals and assists with the monitoring of health care needs. The tool was also developed to diminish incorrect results by detecting errors. • In general, the tool allows a proactive approach which results in decreased health crises which results in decreased costs. 	
Tool Reviewed	Other Comments	
OPWDD Developmental Disabilities Profile 2 (DDP2)	DDP could be revised to be strengths based and enhanced to include missing components from other instruments, however, revisions would need to be undertaken by trained professionals and tested for validity and outcome attainment.	



Developmental Disabilities Profile (Kansas)	--
DDP (Ohio)	--
Supports Intensity Scale (SIS)	<p>Other states:</p> <ul style="list-style-type: none"> • Hawaii is currently using ICAP but switching to SIS for a more responsive tool to assess support needs • North Carolina switched from ICAP to NC SNAP to SIS • Oregon adopted SIS via ReBAR redesign process • Colorado adopted under pressure from CMS to create more equity in waiver spending • Georgia reformed its approach to services around IBA principles and adopted SIS • Missouri adopted SIS in response to growing HCBS waiver costs • Rhode Island using SIS to move to IBA environment • Utah went from ICAP to SIS statewide as PC policy and to control cost • There is some feedback that CMS has favored IBA adoption and is comfortable with SIS <p>Populations: The SIS does not define need by disability or degree of illness, but instead assesses degree of support required, allowing for changed in conditions either internal to the person or exogenous</p>
Inventory for Client and Agency Planning (ICAP)	--
Florida Situational	<p>Discrete assessors complete the document. They use a number of tools including assessments, observation and interviews to gather their information.</p> <p>Florida assessed 30,000 individuals with disabilities in 18 months following the training of their assessors.</p> <p>Lessons learned:</p> <ul style="list-style-type: none"> • Better marketing of the program – make sure individuals and their families understand the process. • Create additional buy-in from the field. • Be sure not to create unrealistic expectations for individuals and their families. There are still over 19,000



Attachment 2A: Assessment Tools Technical Subgroup Report

	<p>individuals waiting for services, some since 2003.</p>
<p>Connecticut Level of Need</p>	<p>The state was using its own ‘homegrown’ tool called the Waiting List Assessment. It was not judged as sufficiently comprehensive so CT set about a large scale instrument development effort using funds from a CMS Real Choice type (systems change) grant in 2003. This was a multi-phase, multi-year effort led by a consultant from the University of Conn. Following extensive literature review, she formed a multi-disciplinary team and started the design process qualitatively by holding focus groups and doing key informant interviews with all stakeholder types. The tool was iteratively revised and pilot tested over three phases with a cumulative case total involving over seven thousand assessments</p>
<p>Wisconsin Functional Screen</p>	<p>The initial screen is conducted independent of the MCO by county resource centers. MCOs cannot be involved with the screen prior to enrollment but can perform “rescreens”</p> <p>Training for the screen is conducted on-line. The online approach is more efficient and environmentally conscious. Easier to conduct calculations on-line and easier to transfer/share data. By using computerized model, eligibility determinations are prepared instantaneously upon completion of the functional screen.</p> <p>The LTC Functional Screen replaced another screening assessment. The new screen incorporates both the medical and independent living aspects in one tool. The LTC functional screen is correlative to the MDS in the Nursing Home setting. The algorithms behind the screen are predictors of need for nursing home levels of care. The old system was too open to screener bias to the outcomes.</p> <p>The state had a lot of interaction with the public and counties when this was developed. They continue to do thorough interaction with screeners about clarity and training.</p>
<p>Child and Adolescent Needs and Strengths Assessment (CANS)</p>	<p>The original CANS is for children and adolescents only, but ANSA (Adult Needs and Strengths Assessment) has been developed and it is specifically for adults. The tool is not specific to individuals with DD, but other states have modified the tool to incorporate this population.</p> <p>Some variations include the CAANS-DD developed for OPWDD IB Services and was modified to include individuals with dual diagnoses and the ANSA-T was modified to focus on individuals transitioning from school.</p> <p>All of the states included John Lyons (the creator of the CANS) as a consultant when deciding to implement the CANS in</p>



	<p>their state.</p> <p>The variations on the CANS have decision trees. Every person has a core of questions that are asked and then depending on other needs additional questions are included (e.g. if there is a history of addiction or criminal activity, more questions are asked).</p> <p>Lessons learned: Do not implement statewide right away. Implement it regionally to better ensure that it is being integrated into the planning. Do assessments of everyone before setting rates, as reimbursement may have to be reestablished otherwise). They wish they had a baseline using the CANS and then used it. They have found that most push back is due to the rates. They offered us to use any of their materials online and hoped we would share anything as well, if we chose to use this. They also felt that nothing was being asked of staff to do anything that they shouldn't already be doing (i.e. integrating the assessment and addressing the needs into a plan). Wisconsin: They are still rolling it out and making changes. However, they wished they had done assessments of everyone before setting rates (they may have to reestablish the rates). They wish they had a baseline using the CANS and then used it. They have found that most push back is due to the rates. They offered us to use any of their materials online and hoped we would share anything as well, if we chose to use this. They also felt that nothing was being asked of staff to do anything that they shouldn't already be doing (i.e. integrating the assessment and addressing the needs into a plan).</p>
<p>Health Risk Screening Tool (HRST)</p>	<p>This type of tool could help providers be pro-active and prevent destabilization especially for more vulnerable populations. Direct care staff are typically non-medical, therefore, this screening could allow support staff to be aware of risks and prevent the probability of more intensive intervention. Identification of red flags allows for better planning.</p> <p>With the move to care management and care coordination with a managed care structure, this tool could provide preliminary health information in a useable way to establish baseline performance data. In addition to use at the individual level, it seems that the tool could be used to determine effectiveness of integrated care coordination/care management.</p> <p>Other States:</p>



- Oklahoma Developmental Disabilities uses the HRST as part of their health care policy.
- Louisiana uses it as part of the children’s waiver.
- State of Georgia uses it for their state DD waiver and it is integrated with the states electronic case management system. Georgia first used the tool in 1997 when a group of developmentally disabled individuals were being transitioned from a congregate care setting into the community. The HRST was used to indicate the level of nursing needs, services and supervision required.
- Kentucky is using the tool for 3,500 people with dd. Southern California used it to transition 390 individuals out of a developmental center and into the community.
- Tennessee, Oklahoma, and Florida use it to determine the type and extent of professional support and training and its use is mandated by policy.
- Tennessee’s Division of Mental Retardation Services (DMRS) requires that all recipients of residential services in the department receive a health care level determination using the Health Risk Screening Tool.
- In Illinois, people are re-rated within 3 - 6 months to determine if their health care status is stable.



Overview

The Health Risk Screening Tool (HRST) is a web-based screening instrument that was developed to screen for health risks associated with a wide variety of disabilities, including developmental disabilities, physical disabilities, disabilities associated with aging, and many other conditions, which specifically affect systems of the body and the person's ability to engage in functional activities. Part of the instrument examines the health risks associated with psychiatric or behavioral disorders, particularly those that result from medications, self-injurious behavior or restriction of movement.

The most important outcome of the HRST screening is to guide in the provision of health care support and surveillance. The instrument is used to determine the types of further assessment and evaluation required by the person to be safe and healthy in a less restrictive setting.

The HRST was developed for use by non-licensed staff, such as case managers, independent support coordinators, program staff and others who directly impact services and supports for individuals in specialized health care settings.

Features / Functions:

- Detects health destabilization EARLY in vulnerable populations
- Helps meet CMS health and safety requirements
- Quantifies the level of health risk based on objective criteria
- Defines acuity
- Identifies health related support needs of an individual
- Determines what types of further assessment, evaluation and staff training might be required
- Enables less restrictive settings
- Provides web-based, real-time data accessibility and oversight.
- Establishes a health baseline and allows the health status of an individual or group to be monitored and tracked over time
- Assists with budgeting and supports allocation

History of HRST

The Health Risk Screening Tool (HRST) originated in Oklahoma in the early 90's as part of a class action court case: *Homeward Bound v. Hissom Memorial Center*. This case was overseen by a federal judge, James Ellison, in the Northern district of Oklahoma. With nearly 1100 class members, including a number of children using a range of medical technology, the institution was scheduled to close in 1994. Judge Ellison appoint a nurse to the panel (Karen Green McGowan) to assist him in protecting the health and safety of those class members whose fragile health status was of great concern to him.

The consent decree mandated that no class member could be placed in a residential facility larger than three(3). Further requirements were that the cost of all residential placements could not, on the average, exceed the daily cost at Hissom. A Federal magistrate had been appointed to mediate disagreements between the parties and/or families when there was a dispute as to the type of placement. Most families, particularly those with young children, were used to 24-hour nursing coverage. There was no mechanism to measure the fragility of these individuals and so the outcome of the disputes most often went to the families. The cost of nursing coverage for 3 person settings was often doubled in order to fulfill this requirement.

Judge Ellison asked Ms. McGowan to develop a mechanism to measure the fragility of the class members who were rapidly being placed into the community. Most of these individuals were being placed in the Metro-Tulsa area, but 25% of these class members were scheduled to be places in other areas of the state, most of which were quite rural and devoid of health care supports. At this point, there was one registered nurse serving in each of the state's three Developmental Disabilities service regions. Health care surveillance for persons with disabilities in the community was nearly non-existent at the time.

Ms. McGowan and the Area II RN, Shirley McKee, brought together a group of nurses along with an out-of-state nurse consultant, to brainstorm for a few days about the requirements for a surveillance process to protect the health and safety of this population. Since nursing supports were nearly non-existent in the three regional systems, the group decided that the tool would need to be used by someone who knew the individuals well, but who had relatively little medical background. Hence, the group that the tool was designed for became the case managers. Class Members were assigned to community consumers at a ratio of 1:25, and during the first 12 months, 1:10 following transition from Hissom.

The original paper tool was known as the Physical Status Review (PSR). This paper instrument was field tested by the RNs in the State DD system on some 6000 individuals, including those from the other two state facilities. This allowed for the honing of the instrument on a broad range of individuals with disabilities and resulted in a number of changes to the instrument. At that time there were also efforts to develop a state-wide health care policy, Health Care Policy for DDSD (Developmental Disabilities Services Division) specified that health supports were tied to Health Care Levels determined by the Physical Status Review (now called the *Health Risk Screening Tool*)

Health Care Levels were assigned based on points accumulated on the PSR, with Levels I and II being low risk, Levels III and IV being moderate risk, and Levels V and VI being the highest risk. Level VI were the

only individuals designated as qualifying as eligible for 24 hour nursing care. This designation of eligibility based on an objective instrument administered by trained and experienced health care personnel now allowed the state to win its arguments with the Federal Magistrate. This allowed the state to reduce its residential costs to meet the other requirements of the Settlement Agreement. The tool was also used to drive surveillance requirements, such as RN review, referral for therapy assessments and medical specialty assessments. Training requirements for staff were additionally delineated by the instrument.

The HRST (PSR) remained paper based until 1998, when the first attempt at an electronic version was developed in Oklahoma. This was a single user version that allowed up to 300 individuals to be entered on a single laptop and then to analyze their health care stability over time and in relation to each other.

The web-based version began development in 2005 and was introduced in Georgia in 2007. Previous to this, Georgia had some 10,000 consumers on the paper tool, but found the utility of the paper tool very limited. From 2007-2011 some 14,000 consumers were entered into the HRST Online, allowing the state the ability to monitor health status of individual consumers by region, by case manager, by provider or other individual entity.

Examples of Use

The HRST is used in a number of states to determine the type and extent of professional support and training and its use is mandated by policy. The tool is also used independently by numerous private and non-profit agencies to monitor the health and safety of their clients.

- **State of Georgia, Division of Developmental Disabilities:** The state began using the paper form of the tool under the guidance of Karen McGowan in 1999. The state was the first to implement the web-based HRST in 2007 and is now in its fifth year of use with over 13,000 individuals rated in the system. The HRST has been written into the state DD waiver and provider manual, and is also used in the state training centers. The HRST is integrated with the state's electronic case management system as well as the Systems Intensity Scale (SIS). The HRST is used to determine rate setting and exceptional rates in the state.
- **State of Kentucky, Department for Behavioral Health, Developmental & Intellectual Disabilities:** Kentucky is the second state to implement the web-based HRST state-wide. The HRST Online is written into the state DD waiver and 3,500 individuals are in the system.
- **Tennessee Department of Intellectual and Developmental Disabilities:** The Department requires that all recipients of residential services in the department receive a health care level determination using the Health Risk Screening Tool. The state currently uses the paper form of the tool and has for years.
- **Maryland Developmental Disabilities Administration:** Paper version of the HRST advocated and used by state regional nurse and broadly by providers but it is not mandated. State is currently using web-based HRST as part of a Nursing Assessment Project to assist in determining requirement of nursing for individuals at low level of health risk.

- **Louisiana Office for Citizens with Developmental Disabilities:** The paper version of the tool was originally implemented in 1998 and used in the state Training Centers, in the community and state crisis management teams. Karen McGowan initially assisted with implementation of the paper HRST and then the state carried forward with its own training on the tool. Currently the HRST is a part of the Louisiana Children’s Choice Waiver and another state Waiver and has continued to be used in the state Training Centers.
- **Southern California Integrated Health and Living Project:** This is the project that is responsible for transitioning the 390 individuals currently in the Lanterman Developmental Center in Pomona, CA into the community. The project is using the web-based HRST to establish a health baseline on all the individuals and then track their health status over a three year period once they are transitioned into the community. The HRST was chosen for use by this project due to its objective rating system, web-based data accessibility and oversight reporting features.
- **Oklahoma Developmental Disabilities Services Division:** This is the state where the HRST originated from (see History section above). The Division has incorporated the use of the HRST (known there as the Physical Status Review or PSR) as part of the health care policy—OAC 340:100-5-26.

Outcomes and Uses

There are several potential outcomes and uses for the HRST results. The instrument assigns point scores to twenty two (22) distinct rating items. The resulting numerical totals are assigned HEALTH CARE LEVELS associated with DEGREES OF HEALTH RISK.

Each individual screened is assigned a health care level, ranging from one to six. **The initial ratings for a group serve the purposes of developing a health baseline and determining the range of clinical supports, services and surveillance needs.**

HEALTH CARE LEVELS

Level 1 (LOW RISK): 0 - 12 Points

Level 2 (LOW RISK): 13 - 25 Points

Level 3 (MODERATE RISK): 26 - 38 Points

Level 4 (HIGH MODERATE RISK): 39 - 53 Points

Level 5 (HIGH RISK): 54 - 68 Points

Level 6 (HIGHEST RISK): 69 or greater

The HRST supplies the provider/support team with guidance in determining the person’s need for further assessment and evaluation to address identified health risks as well as guidance in determining general and individual-specific staff training.

Acuity and Accurate Supports Allocation

The HRST Health Care Levels are based on quantifiable and objective criteria. **The HRST defines acuity and gives the ability to accurately look at the health status of individuals in a region or served by a provider or case managers, among others.** Cost can be allocated for persons who truly need a higher rate, rather than assuming that high rates are needed for persons simply because they are in wheelchairs or look like they are medically complex. Conversely, the HRST identifies individuals, such as those with behavioral challenges, who are often not identified as requiring the level of support they do need.

State resources are valuable and limited. Some regions require educational support for community providers and families; other regions require intensive medical/ nursing/ therapy supports for the individuals themselves. The HRST system allows the state and provider administrative staff to view the state as a whole with appropriate allocation of resources based on an objective, comprehensive screening of individual needs. This decreases the waste of precious dollars by drilling down to actual needs per region.

Proactive Approach = Lower Morbidity = Reduced Cost

The HRST screens for health risks on a regular, routine and acute-event basis. The screenings detect health issues early before they develop into a health crisis, and thus reduce the incidence of morbidity and mortality. This in many instances avoids the extreme cost of additional medications, staffing, professional services, ER visits and hospital admissions.

Allowing an individual to destabilize for a period of time before treatment often results in the person requiring a higher level of health care at significantly increased cost. An example is a person who goes from eating by mouth to having a gastrostomy or jejunostomy tube. This increases the cost of eating to double or quadruple the costs of eating orally. In addition, the person's risk for GI bleeding increases substantially which increases the likelihood of requiring 24-hour nursing care.

Early identification of health risks + early intervention = improved outcomes for the individual + lower health care costs.

Federal Reimbursement

The Centers for Medicare & Medicaid Services (CMS) will reimburse 50% of the cost for the services that the HRST provides. CMS requires that systems be in place for monitoring the health and safety of individuals receiving services and the Health Risk Screening Tool (HRST) assists in fulfilling this requirement.

The State of Georgia is in its fifth year of using the web-based HRST with over 13,000 individuals in its system. The state has received a 50% CMS reimbursement for the HRST services each year. 

ATTACHMENT 3A

People First Waiver Commitments to Choice Worksheet

Summary: The following recommendations were compiled by the Access and Choice design team in response to the query – What components do we need to have in place to facilitate commitments to choice made by OPWDD? As this information represents the opinions of various team members, some statements may appear to contradict others.

COMMITMENT	WHAT COMPONENTS DO WE NEED TO HAVE IN PLACE TO FACILITATE THIS COMMITMENT?	RECOMMENDATIONS
<p>✓ Use of more flexible payment systems within care management environment that allows more individual control over choice of care and providers</p>	<p>I. Comprehensive, unbiased care coordination</p> <p>II. Ensure clarity and understanding</p> <p>III. Budget flexibility</p> <p>IV. Incentives to encourage conservative spending</p>	<p><u>I. Comprehensive, Unbiased Care Coordination</u></p> <ul style="list-style-type: none"> • The care coordinator job must be to help people explore a range of activities, including some that do not now exist • Separation of service provision and care coordination • Separation of housing and LTC support • Separation of housing and work • Establish the linkage between COS, PCP, PRA, etc. • Decision trees for care coordinators • Determination of needs/abilities/non-negotiables for individuals • Do not go to the lowest common denominator <p><u>II. Ensure Clarity and Understanding</u></p> <ul style="list-style-type: none"> • Clear, understandable systems • Transparent costs that are available ahead of time • Clear guidelines • Clear documents should be created to allow individuals to view this information AFTER initial conversation • Create other media for families – repetition, repetition, repetition will help families to understand what promises to be a very complex system • Educated case managers should meet with individuals and their families to initially describe the system • Have in place an accurate directory of service providers and services that are provided in the new system

ATTACHMENT 3A

		<p style="text-align: center;"><u>III. Budget Flexibility</u></p> <ul style="list-style-type: none">• Individualized budget linked to ISP• There should be flexibility to allow for increased funds when a person’s condition changes• Emergency fund pool with fast processing. Unused allocated resources could be put into the emergency fund. Each MCO could be required to contribute a small percentage of funds to form a pool. This pool of money could be held by the state to mitigate the risk of the high cost of serving difficult clients. The pool could also be the source of workman’s compensation• Flexible hours – An individual utilizing Employer Authority should have the ability to change the amount of time allotted to them for self-hires when their circumstances change• Provide ability to spend money on a range of things beyond certified programs (e.g., Stipend for respite care, etc. that does not have to be from a certified provider)• Establish mechanisms to ensure individuals will have supports and services when they travel• Develop a system of service provision that allows for bundled services among different providers (a la carte)• Providers should structure services in such a way that allows maximum choice in groupings of services and individual service• Funding methodologies should be applicable statewide
--	--	--

ATTACHMENT 3A

<p>✓ Reimbursement methodologies that ensure choice between plans and within plans choice of providers</p>	<p>I. Education</p> <p>II. Change in practice guidelines that promote person or member centered planning with the individuals and families at the center of a team process</p> <p>III. Flexible Funding</p>	<p><u>I. Education</u></p> <ul style="list-style-type: none"> • Create documents that clearly demonstrate the differentiation • Create frequently asked questions document • Encourage families to observe differences by visiting programs. Help them to create discussion questions. <p><u>III. Flexible Funding</u></p> <p>Funding must be portable so that it can move with the person being served</p>
<p>✓ Ample opportunity for self-direction including both employer and budget authority</p>	<p>I. Education</p> <p>II. Informed Choice within continuum of care</p> <p>III. Community integration</p> <p>IV. Support network</p> <p>V. Ability to avert and to prepare for emergencies</p> <p>VI. Advocacy</p> <p>VII. Strong needs assessment tool</p>	<p><u>I. Education Tools to Enhance Informed Choice</u></p> <ul style="list-style-type: none"> • Introduction to self direction training for everyone receiving or entering OPWDD services on what self-direction means and the responsibilities to all parties involved to help individuals and families • Training series developed on hiring staff, letting staff go, conflict resolution, incident reporting, documentation, etc. for those who choose to self-direct some or all of their supports and services – Could be offered online • Training and support for agencies that offer self-directed options • Ensure information is available in concise, easily understood language. • “Hot line” or “Help Desk” for questions • Use of accessible communication tools (translators, diagrams, pictures, demonstrations, etc.) • Provide navigation to and through “No Wrong Door” <p><u>II. Informed Choice within Continuum of Care</u></p> <ul style="list-style-type: none"> • A continuum of care will expand the opportunities with all levels of ability to self direct • OPWDD must demonstrate a visible commitment to self-direction in each DDSO region – Each DDSO should have at least one full-time point person designated to individualized and self-directed service initiatives • Incentivize self-direction

ATTACHMENT 3A

		<ul style="list-style-type: none">• Individuals should have the choice of provider organizations, and for individualized services• Employer and budget authority• Parent subsidies• If the new system is to provide innovations, choice needs to be able to include options that do not now exist <p style="text-align: center;"><u>III. Community Integration</u></p> <ul style="list-style-type: none">• Provide services that increase community integration• Mentorships, peer groups, internships etc. will expand opportunities for individuals and help them to become less reliant on the DD system• Families helping families work through the system <p style="text-align: center;"><u>IV. Support Network</u></p> <ul style="list-style-type: none">• Circle of support should not be mandated• Those who chose to have a circle of support should have control over membership <p style="text-align: center;"><u>V. Emergency Preparedness</u></p> <ul style="list-style-type: none">• Emergency assistance should be readily available• List of emergency contacts and employee registry to serve as a backup for last minute cancellations <p style="text-align: center;"><u>VI. Advocacy</u></p> <ul style="list-style-type: none">• Independent oversight must be in place to make sure people aren't persuaded• Create opportunities for independent paid advisor/advocates to supplant or supplement Medicaid Service Coordinator (MSC)• Individuals transitioning from institutional settings are used to structure. They will need time to get used to advocating for themselves• Provide training for self-advocates and advocates on making informed decisions <p style="text-align: center;"><u>VII. Strong Needs Assessment Tool</u></p>
--	--	---

ATTACHMENT 3A

		<ul style="list-style-type: none"> • Use a Strength Based Instrument (SIS)-like assessment tool that will be linked to personal resource allocation
<p>✓ Appropriate diversity of providers in line with individual interests in aligning their cultural, community, and family histories with a provider of choice</p>	<p>I. Network of providers: alignment of MCOs and provider agencies to multi-cultural agencies in their communities, development of networks that are culturally specific</p> <p>II. Contracted assurances that MCOs and providers meet the cultural needs of their members; language in contracts should specify requirements of meeting unique cultural, family and community needs</p> <p>III. Support existing multicultural agencies with provision of services</p> <p>IV. Cultural competence</p> <p>V. Incorporate aspects of culture into assessment tools</p>	<p><u>I. Network of Providers</u></p> <ul style="list-style-type: none"> • MCOs should be required to subcontract with other providers if they don't have services and supports in place that meet an individual's cultural expectations • A centralized, accessible system of minimally qualified individual service providers • Support partnerships with SANYS, Parent-to-Parent of NYS and others to conduct outreach and training activities <p><u>II. Contracted Assurances</u></p> <ul style="list-style-type: none"> • Agencies can have divisions that focus on specific areas to ensure cultural competency • Include in Individual Rights document the choice of utilizing services congruent to cultural community and family history • A provider agency does not have to be minority-based in order to be sensitive to diversity • Allow family members to be first choice advocates for individuals that require services <p><u>III. Support Existing Multicultural Agencies</u></p> <ul style="list-style-type: none"> • Create a system that continues the existence of small multicultural agencies <p><u>IV. Cultural Competence</u></p> <ul style="list-style-type: none"> • Ensure all agencies have training in cultural competence – Provide disability/cultural awareness training for all

ATTACHMENT 3A

		<p>generic community agencies and organizations</p> <ul style="list-style-type: none"> • Incentivize agencies to access their workforce’s cultural diversity, including language • Require online translation access • Contact faith based groups for cultural interaction • Open doors to family members, incentivize ongoing involvement • Use of existing best practices and ‘real’ examples to solicit and promote participation of all providers, associations, etc. • Use of variety in media promotions <p><u>V. Culturally Sensitive Assessment Tools</u></p> <ul style="list-style-type: none"> • Ensure multicultural/family history needs are identified and expressed at the time of assessment
<p>✓ person-centered principles and person-centered systems of care</p>	<p>I. Person centered planning</p> <p>II. Outcome measures</p> <p>III. Ongoing Education</p>	<p><u>I. Person Centered Planning</u></p> <ul style="list-style-type: none"> • Person centered has to be the main theme or principle for service delivery • Provide training on the philosophy of person-centered practices for ALL staff working with MCOs or service providers <p><u>II. Outcome Measures</u></p> <ul style="list-style-type: none"> • Create outcomes and measures that objectively measure and assess an organization’s abilities. • Employ satisfaction surveys that allow individuals and their families to identify the positives and negatives of each organization. • Establish a committee of consumers/recipients to develop an evaluation/assessment tool to rate providers of services <p><u>III. Ongoing Education</u></p> <ul style="list-style-type: none"> • Require ongoing education for direct support professionals (DSPs) and for all levels of management • Create online interactive training course

ATTACHMENT 3A

<p>✓ Provider network standards that ensure individuals can exercise choice among services and service providers, recognition of culturally and linguistically relevant supports, adequate medical/dental specialties</p>	<p>I. Implementation of criteria standards with the choice of at least two providers within geographic proximity</p> <p>II. Outcome Measures</p> <p>III. Contract language with MCOs and providers should reflect these standards</p>	<p><u>I. Implementation of Criteria Standards</u></p> <ul style="list-style-type: none"> • Develop standardized job descriptions that include minimum qualifications • Require all service providers to drive service delivery based on established valued outcomes. This includes culturally and linguistically relevant supports and adequate medical/dental specialties • Decisive action for agencies that continuously fail in customer satisfaction <p><u>II. Outcome Measures</u></p> <ul style="list-style-type: none"> • Develop a rating system of service providers • Study disproportionality and its effects. We need to know the economic effect of cultural bias. • Self assessments • Transparent publication of customer report cards – allow reporters to remain anonymous <p><u>III. Reflection of Standards in MCO Contracts</u></p> <ul style="list-style-type: none"> • Develop measures to ensure that MCOs do not form contracts with internal providers
--	---	---

ATTACHMENT 3B

What Are the Essential Aspects of Individual Choice That Should be Incorporated in the 1115 Waiver?

CHOICE OF:	CURRENT BARRIERS AND POTENTIAL SYSTEM CHALLENGES TO BE ADDRESSED IN 1115 WAIVER	DESIRED CHARACTERISTICS	RECOMMENDATIONS FOR CHOICE WHAT DO WE NEED TO HAVE IN MCO CONTRACTS TO ENSURE INDIVIDUALS HAVE CHOICE?
<p>Care Management/Managed Care Organization</p>	<ul style="list-style-type: none"> • Information on differences between care management entities (i.e., service providers not readily available). • No reliable/independent information available to compare quality between providers to make an informed choice. • Managed Care Organization rules (e.g., reserves) may prevent desirable providers from becoming a managed care organization. 	<ul style="list-style-type: none"> • Individuals should have choice of care management entities in the geographic regions where they live. • Individuals need to be able to distinguish between the advantages and disadvantages of their choices—i.e. informed choice of care management entities. • There needs to be reliable and transparent information available for individuals to make an informed choice between care management entities. • Individuals must have portability—ability to change care management entities. 	<ul style="list-style-type: none"> • Ensure informed choice within a continuum of self-directed options • Create a ratio number of individuals/number of agencies and make sense of the ratio • MCOs must establish and update complete directories of all service providers available to them • A rating system must be established and assigned to service providers that is fair, unbiased and balanced that will give service providers and individuals the ability to examine quality • MCOs must establish measures to ensure employee competence. The performance criteria should emphasize diversity and individual choice

ATTACHMENT 3B

			<ul style="list-style-type: none"> • MCOs need to have user friendly outreach and appeals processes. Individual authority (both budget and employer) must be protected in this contract. MCOs will have to provide information re: other MCOs. • Ensure that the firewall between MCOs and providers does not limit choice, especially in underserved areas.
<p>Service Provider</p>	<ul style="list-style-type: none"> • Individuals and families are challenged in determining which provider(s) in their region would best support their needs. • Many primary and specialty providers choose not to provide services to those w/intellectual disabilities or developmental disabilities due to the low Medicaid reimbursement rates. • Providers with all specialties and/or cultural diversities are not available in each region. 	<ul style="list-style-type: none"> • Individuals and families should have choice over which qualified agency (ies) provide their needed supports and services. • There should be an adequate number of primary and specialty providers in all geographic areas for individuals and families to choose from. • Individuals and families should be able to choose from a diverse provider base which aligns with the individual's interests and their cultural, community, and families histories. 	<ul style="list-style-type: none"> • Create tools and requirements to ensure informed choice. In addition, a system must be established to allow individuals to provide feedback • Providers must be mandated to provide a full array of services to individuals in their geographic area. This includes individuals who receive lower Medicaid reimbursement rates • Incentives should be established to allow providers to expand coverage to underserved regions • A system should be established to allow providers to hire individuals and family members to work in their catchment areas • An open enrollment season should be

ATTACHMENT 3B

	<ul style="list-style-type: none"> • Many providers do not offer, support or encourage individuals and families to self-hire their staff. Agencies in particular are concerned about liability of staff they may not directly control. • Current provider and OPWDD administrative practices often limit portability. • Lack of portability often limits the individual's choices of providers and service options. 	<ul style="list-style-type: none"> • Individuals should be able to self-hire neighbors, relatives, friends, and other individuals to deliver some or all of their services to them (i.e., employer authority). • Individuals should be able to easily and seamlessly change service providers if they want to access alternative services. 	<p>established to allow individuals the opportunity to change providers based on their choice or needs</p> <ul style="list-style-type: none"> • Eliminate the artificial barriers to choice presented by DDSO regions. People should be able to live in a house or go to a day program because it works for them, not because it is in some artificial region • Service innovation and creativity should be incentivized • Establish measures to decrease dependence on services and increase the individual's responsibility for achieving their goals • Ensure regulations from DOL, OPWDD and the IRS are consistent and congruent with this purpose • The care coordinator or MCO should be involved in creating/implementing a back-up plan for self hires who cancel • Establish an accessible career ladder and provide higher pay for more experienced workers • Provide performance-based incentives
--	--	--	--

ATTACHMENT 3B

			<ul style="list-style-type: none"> • MCO contracts need to allow use of self hire and non-certified (friends and family) personnel
<p>Services/Supports That Best Meet the Person’s Needs</p>	<ul style="list-style-type: none"> • The breadth of available service options varies by geographic location. • The resources available for approved supports and services is frequently less than the service needs identified. • Not all services are promoted in each DDSO district. • Priority needs are not consistently managed across DDSO districts which results in varying availability and access of services. • Choice of services is often restricted to available 	<ul style="list-style-type: none"> • A full array of services should be available in all geographic areas. • Services should adapt to the individual rather than having individuals adapt to existing services. • Specific services that best meet the person’s needs should be based on assessment, service planning and the individual’s life goals • Service coordinators, front-line responders, and other providers/ MCO representatives (?) should be well versed regarding the variety of service options available within the OPWDD, 	<ul style="list-style-type: none"> • In order to adapt to the individual, the function of DDSOs may have to change. People are more mobile and should not be restricted within DDSO geographical regions. Instead, DDSOs can function as Aging and Development Resource Centers or Disability Development Resource Centers • Establish a web presence for the promotion of services in each district. Create a search engine to allow individuals to find services in the areas where they live. Allow providers to generate electronic responses to help individuals find what they need • Create opportunities for neighboring counties to increase service delivery • Ensure that the discussion of goals is relevant and not demeaning. Service

ATTACHMENT 3B

	<p>options.</p> <ul style="list-style-type: none"> • Not all service options are known by service coordinators and other front-line staff. • Seeking/Receiving services offered beyond those provided by the agency primary supporting an individual or family are often not promoted or encouraged. • It is difficult to access appropriate cross system supports. • Many generic community supports and services are not known to service coordinators and others. • Communities and community organizations are not well versed on how to support individuals with disabilities. 	<p>across other service systems, and within the generic community. [No Wrong Door].</p> <ul style="list-style-type: none"> • Individuals and families should have more control and self-direction over the supports and services they choose to meet their needs. 	<p>delivery should be cognizant of diverse levels of intellectual capacity</p> <ul style="list-style-type: none"> • Although services are partially based on goals, providers must be aware that goals are fluid. Providers should not impose a structure on an individual's goals • Ensure dollars are available • Quality check for DDSO if they are still responsible is critical. If it is an MCO/ACO, ensure the list of services is listed in the language of the contract • Knowledge is critical. Pre-test/post-test for care coordinators must be available. Care coordinators must have knowledge to retain position • Although services should adapt to the individual rather than having individuals adapt to existing services, a spirit of teamwork should still be maintained within the realm of service provision • Develop a case management/advocacy function and require MCOs to deliver services based on the individual plan developed
--	--	--	--

ATTACHMENT 3B

			<ul style="list-style-type: none"> • MCOs must provide information about the array of services in an open and transparent manner • At minimum, MCOs should provide subsidized housing information. Ideally, MCOs and care coordinators will bear the responsibility of helping individuals search for housing and provide moving assistance
<p>Initial and On-Going Person-Centered Planning</p>	<ul style="list-style-type: none"> • There is a lack of qualified person centered planning facilitators statewide. • Some agencies see person centered planning as a separate and distinct process that is too time intensive and not compensated for in their rates. • The person centered planning process should be easily folded into the service plan or be used as the individual’s service plan. 	<ul style="list-style-type: none"> • All individuals served should have the option of a person-centered life plan that is developed in conjunction with the person and others they may choose. • The person centered life plan should be reviewed regularly and revised appropriately based on the needs and goals of the individual. 	<ul style="list-style-type: none"> • The term “person-centered planning” may not be appropriate. Some believe that the term imposes a negative spotlight by conveying the message that individuals with developmental disabilities are weak and vulnerable. This is reminiscent of institutional stigmas. A new term should be created that affords individuals a sense of strength and equality, e.g., “Individual Achievement Plan” or “Opportunity Plan” • All MCOs should be required to have qualified person-centered planning facilitators in their regions to meet the needs of individuals. • Initiate and incentivize process of becoming and keeping facilitators. Provide training and mentoring opportunities

ATTACHMENT 3B

			<ul style="list-style-type: none"> • Determine outcomes/measure outcomes • Criteria should be established to ensure that the appropriate level of training/resources are committed to this crucial phase • Host inter-agency person centered planning workshops in different geographical regions to facilitate dialogue and share best practices
<p>Self-Direction via Personal Resource Allocations/Individualized Budgets</p>	<ul style="list-style-type: none"> • We do not currently have a standardized needs assessment instrument and/or assessment tool that is consistently applied to all people we serve. • The payment systems and funding are largely committed to institutional, more traditional, services rather than to flexible service options. • Many services have different funding (fee) 	<ul style="list-style-type: none"> • A standardized assessment tool should be developed that can be used to determine equitable personal resource allocations statewide. • Each person should have an individualized personal resource allocation. • The personal resource allocation level should be known to each individual and/or their representatives. • Individuals and families should be able to choose the 	<ul style="list-style-type: none"> • MCO contracts need to support consumer and family authority • An assessment tool should be utilized for all individuals who are currently receiving residential services to determine whether certain individuals are qualified to transition to a less restrictive environment. The individual may choose to stay in a more restrictive setting with cost sharing, or to move to a less restrictive environment • Implement a payment system that is based on the level/intensity of the service provided

ATTACHMENT 3B

	<p>structures – even within a given agency.</p> <ul style="list-style-type: none"> • Resource availability for approved supports and services is frequently less than the service demand. • Ensure that individualized service options are easier to access. • The infrastructure to support more individualized service options is not well developed and differs geographically. 	<p>level of responsibility they want related to hiring their own staff (employer authority) and/or managing their individualized budget/resource allocation (employer authority).</p> <ul style="list-style-type: none"> • Portability of resource allocations should be seamless and easily accomplished 	<ul style="list-style-type: none"> • Create regionalized rates for the array of services to be provided within the categories for people. If agencies have significant differences among the initial rates, competition and choice will be affected • Provide financial information to individuals and families so that they will have a general idea of what things cost prior to budget allocation. Financial Planners should also be available for individuals and families • For emergency situations such as a car accident requiring a higher level of service, individuals should have the opportunity to choose same service providers when using no-fault insurance, workers compensation, and foster care. MCOs should negotiate with no-fault insurance providers to ensure that no-fault will cover the staff that they used prior to emergency situations • Individuals should have the opportunity to make out of pocket contributions. Though the expectation is not that individuals will pay in full, some people still want a sense of ownership and responsibility
--	---	--	---

ATTACHMENT 3B

			<ul style="list-style-type: none"> • All MCOs should have 24/7 customer service hotlines • Homemaking support • A comprehensive information packet should be given to individuals who are transitioning into less restricted settings. The packet should include information about insurance, medical needs, locations of grocery stores and other vital resources • Emphasize quality of life decisions
<p>Independent Advocacy</p>	<ul style="list-style-type: none"> • In current system, Medicaid Service Coordinators (MSCs) are charged with independent advocacy, however, service coordinators often feel compromised between advocating for the person served and sense of commitment to the purse strings of the agency they work for. 	<ul style="list-style-type: none"> • Individuals and families should have choice of an independent advocate/advocacy organization • Individuals should have the ability to choose an independent advocate to help them navigate their choices and options. 	<ul style="list-style-type: none"> • Each MCO must commit to ensuring that each person has the opportunity to enjoy an interesting and meaningful day • A system should be established that will allow and fund independent advocacy agencies as well as allowing parents, relatives and friends to advocate for individuals who receive services. This should be tied in to how agencies/individuals are rated for the services that they provide to individuals. • Programs to enhance skills of care coordinators/service coordinators must be developed.

ATTACHMENT 3B

			<ul style="list-style-type: none"> • MCOs/providers/non-profits should be aware of OPWDDs supports /services services and vice-versa. Information sharing will improve the likelihood that individuals encounter well-informed staff • Individual advocacy should come from a variety of sources. Ombudsmen should have clout so MCOs will listen
<p>Employment/Meaningful Activities</p>	<ul style="list-style-type: none"> • Presently OPWDD serves over 45,000 people in various day habilitation programs and only 9,000 people in supported employment (SEMP). • There are few if any incentives for agencies to support people to utilize SEMP vs. day programs options. • Community businesses and organizations need to become more versed regarding the mutual benefits of supporting people with disabilities in work and volunteer opportunities. 	<ul style="list-style-type: none"> • Each individual should have a choice of whether they want to be employed and what kind of work they want to do. • For individuals who want to be employed, access to adequate employment related services should be provided to support them. • Appropriate supports should be available to assist people to volunteer or participate in communities in other. meaningful, productive ways. • Build greater partnerships and utilization of community and natural supports. 	<ul style="list-style-type: none"> • Every MCO should have a comprehensive employment program. These programs should be compatible with the diverse range of abilities, needs, and expectations of the population we serve. Vocational rehab should not be seen as a universal answer • MCOs should develop guidelines regarding meaningful activities. Adjust the reimbursement methodology for day habilitation to support the implementation of these guidelines • Requests for Proposals (RFPs) should be sent out to the service provider community, seeking creative ways to integrate more DD individuals in the business community. These RFPs should be designed to encourage the creation of social entrepreneurial initiatives to

ATTACHMENT 3B

			<p>provide employment/volunteerism to individuals with developmental disabilities.</p> <ul style="list-style-type: none">• MCOs should form partnerships with companies to create opportunities that can lead to employment (e.g., internships, job shadowing, workshops, training programs and apprenticeships)• Some individuals are afraid that they will lose their benefits when they start working. MCOs must ensure that benefits will be available immediately should an individual lose their job. This concept must be conveyed clearly to individuals• Recognize the limitations set by ACCES-VR. Their outcomes truly look towards working with those individuals who will succeed in a short time frame. It does not encourage risk taking for agencies• Identify methodology to incorporate an adult PROJECT SEARCH. This program has proven its success with high school students. It has been replicated in other states for adults. Find ways to ensure its achievement in other forums
--	--	--	---

ATTACHMENT 3B

<p>Living Arrangement</p>	<ul style="list-style-type: none"> • Many people reside in our system based on what choices were available at the time they came into the system versus where they wanted to. • Many people residing in supervised residences have the same developmental profiles as those living in supported residential sites or living on their own in the community with intermittent supports. • Creative options such as live-in caregivers, companions, etc. need to be developed that will enable people to live in their communities of support with less costly and formal supports. 	<ul style="list-style-type: none"> • Each individual should have the choice of where they live and who they live with. • Support the right of individuals to live in the most appropriate and restrictive community setting with an equitable level of resources and services as appropriate for their individual needs. • Use of assistive technology and environmental modifications to support individuals to live more independently in their communities of choice 	<ul style="list-style-type: none"> • The new system must be more responsive to non-institutional care models and provide the proper tools for individuals and organizations to make it work • Ensure new assessment tools truly measures the right needs and skills. The current DDP 2 doesn't measure an individual's abilities to be safe in their own home • The new assessment tool should look at people in their current living arrangement and determine who is ready to move to a less restrictive setting. This will make more resources available for individuals with more acute needs. • The state's entire family care program should be revised and utilized in a way that will create a whole new living option for individuals with developmental disabilities. A state-wide model could be developed to reduce costs where appropriate. • MCO contracts should support expanded and flexible family support services for individuals that live at home
----------------------------------	---	--	--

ATTACHMENT 3B

			<ul style="list-style-type: none"> • Use smart technology in our current homes and in new homes that will allow people have more independence • MCOs should provide crisis management training/referrals to families and ensure that families develop plans for emergencies • Individuals should have assistance with finding a desired home/neighborhood/residential setting, and moving assistance once they find a location • Information about renting/home ownership and transportation logistics should be provided in advance • Cost-benefit analyses should be used to help individuals make the best decision • In state and out of state contacts should be available for individuals who travel • Compile a database using information from other individuals who have successfully navigated the system
<p>Choice of Community</p>	<ul style="list-style-type: none"> • Staffing considerations 	<ul style="list-style-type: none"> • Individuals should have the 	<ul style="list-style-type: none"> • Align regulations with this desire. New

ATTACHMENT 3B

<p>Integration Activities and Choice of How to Spend Free Time.</p>	<p>often prohibit the ability of individuals we serve to participate in activities that are meaningful to them or to become regulars in places that match their interests.</p> <ul style="list-style-type: none"> • Administrative practices often discourage independence. • The use of community supports have not been strongly encouraged, largely due to fear and liability issues. 	<p>choice of what activities they want to participate in that are meaningful to them.</p> <ul style="list-style-type: none"> • Where appropriate, the person centered planning process would be used to help determine areas of interest for individuals we serve. • Appropriate supports should be made available to support people in meaningful community activities. • Appropriate supports should be made available to support people to build and sustain meaningful relationships. • More focus placed on building greater partnerships within communities and utilizing community and natural supports to support people we serve. • Use of more generic transportation options. 	<p>regulations as a result of the NY Times article will decrease the likelihood of this happening as the desire for less risk taking will occur</p> <ul style="list-style-type: none"> • A system needs to be devised that will provide incentives to create different family care models for individuals to live in the community. The best way to have an individual become part of the community is to help them to become part of a family. Our current family care program is one dimensional. • Individuals must be apprised of options before they can make choices. MCOs should have the responsibility of compiling and synthesizing information so that it can be presented to individuals • MCOs should negotiate discounted membership rates for recreational facilities such as the YMCA • Foster relationships with local firefighters, police officers, veterans • Facilitate partnerships with students who have an interest in disability law, support service provision, communications, social work, advocacy, etc.
--	--	---	---

ATTACHMENT 3B

			<ul style="list-style-type: none">• Host community activities for recipients of developmental disability/mental health services
OTHER			<ul style="list-style-type: none">• It is about the relationships that are created between individuals and the employees who support them. All systems must be consistent with that• “The quality of life for a person with developmental disabilities is only as strong as the weakest link within attendant care” – Wendy and Mike Orzel