Benefits and Services Design Team (BSDT)
Final Design Team Report for Steering Committee

Team Meeting Dates:
June 20, 2011
July 11, 2011
July 27, 2011
August 3, 2011
August 16, 2011
August 29, 2011 (cancelled due to Tropical Storm Irene)

I. Executive Summary

The Benefits and Services design team, hereafter referred to the BSDT, was charged with reform recommendations that promote person-centered delivery of supports to individuals with developmental disabilities in line with their needs and preferences and to look at options to increase the system's capacity to be person-centered. The team agreed that the ultimate goal is to serve people in the community setting most in-line with their interests and needs.

The BSDT embraced their articulated charge as follows: People with developmental disabilities must lead richer lives with a continued focus on choice – their choice, as vibrant members of their community. Four basic person-centered outcomes related to engaged community membership must be the center point of the People First Waiver. These four person-centered outcomes include: 1) living in the home of their choice within the community of their choice; 2) an ability to work in a job of their choice and engage in activities that result in active community membership; 3) developing and maintaining meaningful relationships with friends, family, neighbors, and others in their lives; and 4) maintaining good health. The People First Waiver must result in flexible support options that meet the needs and desires of the person with a disability at the right time and right place. The heart and center of service delivery must be the person being served. The People First Waiver and its new system of benefits and services must help people with developmental disabilities enjoy their rights as citizens of society – life, liberty, and the pursuit of happiness.

Through focused discussion, research and analysis, and the work of technical work groups, the BSDT identified areas where change or enhancement is needed to better serve individuals and where development of a broader array of support options could more effectively and efficiently meet individual's needs and interests in the most appropriate and least restrictive community settings.

While there was clear recognition of the diversity of individuals who are supported by our system, the BSDT focused on the following aspects of the population and the service system:

- ✓ First and foremost, the service system must support people over their entire lifetime.

- ✓ The need for the waiver to move away from narrow service definitions that create silos so that greater flexibility, capacity, and individually focused service delivery strategies can be possible across the entire service system. This includes:

    - Redefining the concept of family support;
    - The system to be responsive to those who are employed or want to seek employment; and
    - Services that are flexible and promote lifelong learning and movement, so that supports can be diminished as people gain independence and enhanced quickly and easily in response to an emergency or the increased needs of later life.

- ✓ The need to promote citizenship, inclusion, and full participation in an individuals' community by making true person-centered planning available for all individuals.

- ✓ Making self-directed services, already flourishing in parts of New York State, the default option for individuals transitioning into adult services and available to people already in the system who wish to access them.

- ✓ Establishing supports and services that can adequately respond to those with challenging behaviors and significant care and support needs as well as those who need less support.

- ✓ The complexities of ensuring health and safety while allowing individuals greater choice and independence.

II. Introduction

The BSDT met five times between June 20, 2011 and August 16, 2011, and completed many brainstorming and survey activities focused on addressing the assigned charter questions and related research areas. Specifically, the BSDT:

- ✓ Conducted exercises to prioritize areas that were identified by stakeholders and important to members of the BSDT.

- ✓ Researched other State initiatives and best practice standards and presented to its findings to the group for discussion and consensus building.

- ✓ Explored new service methodologies (e.g. new uses of technology) to enhance residential support, Key Ring concept supports, Shared Living, and adaptive housing options by viewing DVDs and hearing presentations on the concepts.

- ✓ Conducted surveys to build consensus from team members on priorities.
- ✓ Discussed the implementation of flexible models of support focused on meeting individuals' personal outcomes in various living options took place.
- ✓ Established technical workgroups that were charged with identifying more specific recommendations related to particular design areas. The workgroups addressed:
    - Developmental Center Transition;
    - Employment First within Managed Care;
    - Self Directed and Individualized Budgets within Managed Care; and
    - Behavioral Services and Supports within Managed Care.

III. Benefits and Services Design Team Recommendations

Charter Question #1 - Consider all the services and supports currently available through OPWDD's system and other systems for people with developmental disabilities:

A. What are the services/supports that are generally working well for people?

B. What are the services/supports that are not working that need to be simplified, enhanced, and/or redesigned?

C. What services/supports could people with developmental disabilities take advantage of from other systems if obstacles/barriers were addressed/eliminated (e.g., can only be in one waiver at a time; can only have one targeted case management service; etc.)?

The BSDT addressed charter question #1 (A-C) through discussions of the available and needed supports and services. Rather than defining services as working or not working, the BSDT focused on what is needed to establish the broadest possible range of supports, across the most broadly defined settings and delivered by the broadest range of people. The BSDT agreed that discussing which OPWDD services are working well and which are not working well would focus on the wrong question and not reveal what is really needed: a holistic approach to needs assessment. The BSDT agreed that answering the question as written would reinforce repacking the services we currently have which is what we do not want to happen in the People First Waiver.

The BSDT also reached the conclusion that the initial phrasing of question #1: *Consider all the services and supports currently available through OPWDD's system and other systems for people with developmental disabilities,* needed to be refined. The BSDT's answer to this question is that there is a broad range of services that work well for some people but not well for others. New York's menu can be comprehensive for some people, yet there are waiting lists and safety issues,

and it is hard to make other services work with each other. Further, there is inconsistency in the accuracy of the match between the service and the person.

Services

The BSDT agreed that the most broadly defined service categories would allow for the most flexibility in delivering supports and services most in line with individuals' interests and needs. The following list is meant to define the most comprehensive possible services that are approved by CMS. The categorizing of the services into service groups for billing purposes needs further exploration. These services include:

- ✓ Residential supports– in line with interest and need;
- ✓ Habilitative supports;
- ✓ Work/ Day support–implemented to achieve desired outcomes;
- ✓ Care Coordination;
- ✓ Medical and Dental services including nursing supports;
- ✓ Support in an individual's family home and to support the family as caregivers;
- ✓ Respite services;
- ✓ Crisis intervention services;
- ✓ Clinical services – related therapies (PT,OT, Speech), Social work, ABS;
- ✓ Environmental modifications;
- ✓ Adaptive devices;
- ✓ Technology supports;
- ✓ Meals;
- ✓ Recreation;
- ✓ State Plan Services (all), RN, PCA; and
- ✓ Intensive Behavioral Services.

Settings

Plans of care must be established based on individual's expressed interests and defined needs as determined through a person-centered planning process. The comprehensive assessment process discussed later in this report will drive the plan of care and the resource allocation available for the person receiving services. Through effective care coordination, the plan of care can be delivered in the setting of the individual's and family's choice. Specifically, the following settings were discussed as appropriate:

- ✓ Individual's uncertified living setting;
- ✓ Family home;
- ✓ Shared living setting; and
- ✓ Certified residential setting.

Community Based Clinical Supports

Supports must be delivered in line with identified need regardless of an individual's living setting and level of complexity. Clinical supports must be enhanced to ensure appropriate support for people who are leaving institutional settings. The effectiveness of the supports must be measured based on the outcome for the person, not on the delivery of the service. Areas of clinical support that require enhancement include:

- ✓ Behavioral supports that are integrated and responsive;
- ✓ Crisis supports to stabilize the person, and where relevant, the family, thus avoiding more restrictive placements;
- ✓ Primary and specialty medical care from providers with expertise in caring for individuals with developmental disabilities;
- ✓ Individual and group counseling focused on relapse prevention, anger management and evidence-based therapy models;
- ✓ Behavioral health/psychiatric treatment; and
- ✓ Effective therapies such as physical, occupational and speech.

The provision of effective clinical supports in line with identified needs through a care coordination model should support individuals with the least restrictive level of support that is possible.

Habilitative Supports

Habilitation is defined in the Home and Community Based Services waiver (HCBS) as "services that are provided in order to assist an individual to acquire a variety of skills, including self–help, socialization and adaptive skills. Habilitation is aimed at raising the level of physical, mental and social functioning of an individual."

Habilitative supports are critical to individuals with developmental disabilities, and the BSDT agreed that the types of supports included under the habilitative definition should be maximized so that the broadest possible array of supports can be provided to individuals regardless of their living setting. An expansive definition of habilitation will allow for the most innovative approach to the provision of supports to meet individuals' unique needs and interests. In the current model, habilitation is broken into day, residential, and community habilitation, depending on where one receives services. The BSDT recommends that habilitative supports be built into the lives of individuals based on expressed needs, interest and personal outcomes rather than the location where supports are provided. Accordingly, this recommended shift in the habilitative supports model will lead to greater use of the broader definition and increased flexibility which should result in a broader array of residential support for people seeking to and capable of living outside of congregate care settings.

Broader Residential Support Options

While the BSDT endorsed retaining traditional residential supports within the continuum of care, there was consensus that the system needed to be rebalanced to expand significantly the availability of community integrated, less intensive residential options. While some individuals require the level of support provided by traditional residential settings, a significant percentage of individuals are "over supported" with 24/7 supports and, more importantly, are seeking to be supported in non-certified community settings. Recommendations include:

- ✓ Ensure that people served in settings with heightened supports require that level of structure/supervision;
- ✓ Create partnerships within the broader community to develop affordable, accessible housing options; and
- ✓ Use existing infrastructure to meet the needs of individuals with high level of support need.

To allow increased options for residential supports, the following concepts are recommended for inclusion in the People First Waiver:

- ✓ Technology/smart home supports.

- ✓ Shared living opportunities.

- ✓ KeyRing Models of support currently being demonstrated in England (KeyRing's support is based on people living in their own homes but sharing their skills and talents with each other and with their communities. There is a volunteer in each Network. The volunteer sees Members regularly and helps the group work together. The volunteer is like a good neighbor who will help out if difficulties arise. Because the volunteer lives in the community, they know what is going on and are able to help Members make links. There are also Community Support Workers and Supported Living Managers who make sure that Members get the support they need. KeyRing believes that Community Connections are very important and encourages people with developmental disabilities to make good links in their neighborhood.

- ✓ Promise neighborhoods, established under the legislative authority of the Fund for the Improvement of Education Program (FIE), provides funding to support eligible entities, including (1) nonprofit organizations, which may include faith-based nonprofit organizations, (2) institutions of higher education, and (3) Indian tribes. The vision of the program is that all children and youth growing up in Promise Neighborhoods have access to great schools and strong systems of family and community support that will prepare them to attain an excellent education and successfully transition to college and a career. The purpose of Promise Neighborhoods is to significantly improve the educational and developmental outcomes of

children and youth in our most distressed communities, and to transform those communities by:

1. Identifying and increasing the capacity of eligible entities that are focused on achieving results for children and youth throughout an entire neighborhood;
2. Building a complete continuum of cradle-to-career solutions of both educational programs and family and community supports, with great schools at the center;
3. Integrating programs and breaking down agency "silos" so that solutions are implemented effectively and efficiently across agencies;
4. Developing the local infrastructure of systems and resources needed to sustain and scale up proven, effective solutions across the broader region beyond the initial neighborhood; and
5. Learning about the overall impact of the Promise Neighborhoods program and about the relationship between particular strategies in Promise Neighborhoods and student outcomes, including through a rigorous evaluation of the program.

The Promise Neighborhoods program has awarded one-year grants to support the development of a plan to implement a Promise Neighborhood that includes the core features described above. At the conclusion of the planning grant period, grantees should have a feasible plan to implement a continuum of solutions that will significantly improve results for children in the community being served.

- ✓ Family financial support; and
- ✓ Paid neighbor supports.

Providing residential supports through the broadest definition of habilitative and personal care supports will make it possible to better align supports with an individual's interests and needs.

Models of Family Support

Effective Family support is essential to helping families and individuals with developmental disabilities live with the greatest opportunity for full inclusion in the community. Often there are barriers to effective family supports, particularly for individuals with greater clinical complexity, and natural supports are not effectively pursued.

The amount of respite and habilitative supports available to families has not always been distributed consistently or equitably. Additionally, the opportunities available are often not able to support individuals with behavioral or significant health challenges due to the staffing levels required and the inability of staff to implement aspects of existing behavioral or medical support plans. Recommendations for enhancing family supports include:

- ✓ Broaden the scope and increase the quantity of available respite and habilitative services for families based on an equitable needs assessment process; and
- ✓ Develop capacity to provide appropriate behavioral and medical supports for individuals, including: increased staff training, family education, interdisciplinary clinical support, and enhanced staffing supports. Through the care coordination process, ensure that these supports are available with appropriate clinical monitoring.

Key Issues:

- ✓ To implement the proposed models of support, regulations need to be explored and revised to allow the delivery of services such as medication administration and behavioral supports in uncertified settings.
- ✓ To support the broader array of residential supports, OPWDD must develop additional support models such as the use of technology for monitoring/support and social/habilitative support settings that differ from traditional structures.

D. How can OPWDD build on the services that are working well by enhancing, consolidating, simplifying and/or clarifying services/service delivery to enhance value and quality? What changes in regulations and/or policies would be needed?

Because service delivery is categorized by funding source and location of service, a review of service delivery can fail to consider the experience of the whole person. Moreover, the methods of program delivery do not focus on a persons' abilities, but on a segment of their life or a part of their day.

Obtaining services is often complex and overwhelming. Currently, there is not a single point of entry through which a person defines and accesses the support they need to enhance their specific abilities. The system design focuses on disability, risk aversion and safety. The richness of each community is not considered when a person's life plan unfolds. Services do not support independence, but rather - dependence.

The overall service delivery must be simplified. This is true of all aspects of the current delivery model. Flexibility must be emphasized, with the needs and desires of the person and his or her family being the focal point of decision making and planning.

The current regulations are driven by risk aversion and safety. While these are critical elements of any person's life, these elements alone do not support citizenship or happiness. The regulations must take into consideration the dignity of risk and support decision making that have includes a margin for poor judgment.

Currently the regulations make living independently with severe disabilities impossible. Staff that can support people with medical conditions in a certified setting are unable to support a person in a non-certified setting.

Ideally, the regulatory structure will be developed "from the ground up" – rather than simply amending the current regulatory structure. A major issue identified throughout the team's deliberations were that current barriers to a person maximizing their independence – even in settings supposedly designed for independent living- were the vestiges of historical institutional or congregate care models.

E. How can needs assessment and resource allocation reform facilitate greater access to supports and services?

F. What role will needs assessment have in determining the types of supports and services that individuals have access to?

The BSDT merged its responses to these two charter questions. The Access and Choice Design Team examined reform options related to waiver and service access and eligibility. The BSDT did agree that the needs assessment tool needs to 1) be holistic; 2) permit the person being served to easily articulate his or her preferences and ideas for successfully living in the community; and 3) take into account a person's preferences and needs rather than solely assessing a person's eligibility for a specific program or service.

Through the use of a consistent and comprehensive needs assessment process individuals will have their interests, strengths and needs identified so that an appropriate plan of care can be developed and a level of need established. Also a consistent measureable process needs assessment process will support clearer determinations of resource allocation and greater equity of resource distribution. It is anticipated that the equitable resource allocation process will provide an incentive for providers to develop more innovative supports that better align with individuals' interests and needs.

Other BSDT recommendations regarding needs assessment and resource allocation include:

- ✓ Any assessment process must be flexible and simple.
- ✓ A review of assessment policies, practices, and instruments used by other States should be undertaken to identify best practices for the population served by OPWDD.
- ✓ Institutionalized individuals should be assessed to determine who could appropriately benefit from services and supports in a more integrated setting.
- ✓ Assessment processes should ensure that, for individuals who are appropriate for community-based services (excluding those committed in accordance with appropriate provisions of law), all such services and supports are pursued before an institutional placement is implemented.
- ✓ As part of the State's Single Point of Entry initiative, coordinated by the New York State Office for the Aging (NYSOFA) and Department of Health (DOH), OPWDD should look for a way to conduct assessments of individuals' service needs and to provide information on and referral to local community-based services and supports as an alternative to institutionalization.

- ✓ All of the general principles and guidelines specified above should be incorporated into OPWDD program specific assessment processes.

G. How can self-direction and self-determination be expanded and enhanced?

The Self-Direction and Individualized Budgets within a Managed Care System Workgroup (hereafter the Self-direction Workgroup) met twice in August 2011 to deliver specific recommendations to the BSDT for the preliminary report to the Steering Committee. The BSDT agreed with the recommendations set forth by the Self-direction Workgroup. The group's recommendations are summarized below and can be found in their entirety in *Appendix D (page 26)*.

Self-directed services, already flourishing in parts of New York State, should be the default option for all individuals transitioning into adult services, and should be made available to people already in the system who wish to access them. These services have been shown to be both life enhancing and cost effective.

Self-direction is the service delivery model that most closely adheres to the principles of self-determination. As per CMS, self-directed Medicaid services allow participants or their representatives, if applicable, to have "employer authority" (the authority to recruit, hire, train and supervise the individuals who furnish their services) and "budget authority," (decision-making authority over how Medicaid funds in their budget are spent). Each person's plan is unique because it is guided by a person-centered process that addresses each individual's preferences, choices, abilities, and support needs.

Recommendations:

- ✓ Person-centered planning should be required for everyone receiving services. It cannot be defined as a completed form, but as the guide for an action plan to enrich a life. Quality assessment must be based on meaningful outcomes for each individual.
- ✓ Make available the supports needed for self-direction: broker, FMS, help with logistics, and staff back-up. These are critical for full access to the program.
- ✓ Disseminate information about self-directed services broadly to families and members of care-coordination teams.
- ✓ Ensure availability of self-directed services throughout the state.
- ✓ Ensure independence for the role of broker.
- ✓ Streamline the budget process and reporting requirements.
- ✓ Allow family members or others to train support staff to administer medications.
- ✓ Money should be portable, so people can switch services when necessary.
- ✓ Communicate throughout the system the fact that self-direction is not required to live independently.

All of these recommendations are based on true person-centered planning as a cornerstone regardless of the level of independence and control the individual wishes or is capable of exercising over his or her service plan, or where the individual wishes to live or work.

Charter Question #2 - What specialized residential, community, and behavioral services (and cross systems supports) are needed for people leaving institutional settings (e.g., intensive and/or behavioral services) and how do these services differ from what is available today in the developmental disabilities system?

As individuals leave Developmental Centers (DC) it is imperative that they receive coordinated clinical supports to ensure their success in community-based settings. The need for true person-centered planning is especially important for people who have complex needs and the development of appropriate, individualized supports.

The following elements are critical to meeting the needs of people leaving DC settings:

- ✓ Clinical coordination to ensure that individuals receive needed supports outside of the highly structured DC setting. The coordination of behavioral health supports is critical to maintaining and ensuring clinical stability.
- ✓ Community-based group and individual counseling – many individuals transitioning from DCs to community settings need counseling services to prevent relapse and support successful anger management and coping strategies.
- ✓ Effective community crisis supports are needed to avoid reliance on DC models of support for people in community settings who experience behavioral crises. Needs for crisis supports exist across a variety of settings, including family settings, independent living settings and in certified settings.
- ✓ Broadening the supports that can be provided to people in non-certified settings. New clinical supports are needed to effectively support people across all community-based settings, including those that are non-certified. Consistent training to service providers and families is required.
- ✓ Person-centered planning should determine the appropriate residential supports for people who are transitioning out of Developmental Centers and for people who have been referred to DC settings historically. Determinations should be made about the appropriate residential support model based on the individuals' expressed interest and their identified risk management and clinical needs.

Charter Question #3 - What are the barriers for individuals with developmental disabilities to move into their own homes and apartments? What services and supports need to be created, strengthened, and/or enhanced in order for more individuals to transition from group homes and 24-hour staffing to their own homes and apartments with less than 24-hour support?

In response to this question, the BSDT agreed to the following recommendations:

- ✓ Establish a flexible funding mechanism that provides increased supports when needed and the ability to fade support when people are able to function more independently.
- ✓ Resource allocation must be tied to assessment.
- ✓ Disregard the "readiness" model; find people appropriate housing and then help them learn the skills they need to manage in their homes and/or supplement with supports.
- ✓ OPWDD should establish relationships with State/local housing developers/authorities to obtain set-asides for people with developmental disabilities or other arrangements to develop housing; create incentives for these kinds of organizations to work with us; and make the process simple and flexible. The ability to partner with others is particularly important when it comes to accessible housing.
- ✓ Offer assistance with financial planning for families/self-advocates around funding housing opportunities.
- ✓ Continue/expand Individualized Support Services-type rent subsidies.
- ✓ OPWDD needs to conduct thoughtful conversations about risk with all stakeholders; develop a set of guidelines and principles that reflect the balance between dignity of risk and the need for safeguards.
- ✓ Explore models that capitalize on natural supports and community membership.
- ✓ Give providers opportunities to learn about new approaches and practical assistance in developing them; establish "learning circles" to include families and self-advocates so that stakeholders are co-designing the new approaches.
- ✓ Reduce regulations; minimize compliance burden.
- ✓ Build the expertise of direct support professionals to support people at the community level; expand health care and other workforce enhancement programs.
- ✓ Co-design services/supports with individuals and families; make use of support circles and include circle members as part of the plan. Individuals should select staff and roommates and decide where they want to live.
- ✓ Make it a priority to the explore use of technology and "smart homes."
- ✓ These new options should not be limited to those who need minimal supports; even people who need 24-hour support should be able to have their own home.
- ✓ For areas where transportation is limited, have provider's pool existing resources.
- ✓ Be concerned about loneliness/isolation not only in person centered planning, but also in how our services and supports are designed.

Key issues:

- ✓ Expanding the social and habilitative supports that are available outside of certified settings would provide individuals greater opportunity for learning and establishing healthy relationships.

Charter Question #4 – What services/supports need to be created, strengthened and/or enhanced in order for children and other people with developmental disabilities to remain in the homes of their parents, family member and/or relatives longer, particularly when primary caregivers are aging? (A particular focus on the provision of behavioral supports in family settings from a challenges and solutions perspective is needed.)

The challenges faced in supporting people to live at home include providing far greater clinical assessment and person-centered planning by qualified staff. For individuals with behaviors at home which are disruptive to the family unit, the BSDT recommends:

1. Develop intensive in-home behavioral services for the family unit.
2. Increase the availability of habilitative supports for families; e.g. community habilitation and respite services.
3. Develop access to outpatient, community-based psychiatry for emergency and routine care and for medication management.
4. Develop twenty-four hour assistance for crisis management.
5. Increase provider payments for services for those with more complex behavioral issues and needs.
6. Make family counseling available to assist families to remain intact.
7. Provide assistive technology to meet both safety and communication needs.
8. When necessary, admit individual to a time-limited, intensive treatment program, with the goal of re-uniting the family as quickly as possible.

In regard to issues related to aging family members, the BSDT recommends:

1. Develop crisis placement options such as with other family members or staff known to individuals.
2. Increase the family's access to respite services, either in or out of the home, as needed.
3. Provide families with a certain amount of funds, annually, to be used, as needed. This can be utilized for additional respite, housekeeping services, emergency response systems, etc.

In regard to the isolation of families, the BSDT recommends:

1. Coordinate with agencies to extend natural connections and nurture relationships in the community.
2. Foster the ability of families to create networks with others within walking/driving distance to provide support to each other as well as respite.

In regard to individuals with "high needs" who are having difficulty accessing services such as respite or community habilitation, the BSDT recommends:

1. Provide specialized training for staff who serve individuals with high needs. Staff will need to be compensated for this additional training.
2. Provide service providers an enhanced rate to deliver services for those with high needs (based on established criteria).

Charter Question #5 – How can the People First Waiver better support and integrate services for children across systems (transition from early intervention to State Education services to adult services)?

To establish the flexibility of funding necessary to provide people with developmental disabilities integrated care, the BSDT agreed to the following recommendations:

- ✓ Develop a Life Transitions Model whereby care coordination ensures transitions and cross-system care over a lifetime as appropriate.
- ✓ Ensure access to the professional disciplines that can determine program eligibility in a timely manner.
- ✓ Create accountable and timely systems for service approvals within OPWDD and/or the Developmental Disabilities Individual Support and Care Coordination Organization (DISCO), ensuring smooth transitions.
- ✓ Provide access to consistent and accurate information from OPWDD and the DISCO for planning purposes.
- ✓ Ensure equal access and choice by centralizing opportunities for service. The DISCO and the flexible funding offered by a capitated payment structure will eliminate cross-system funding conflicts and facilitate more seamless transitions.
- ✓ Create cross system problem solving liaisons to assist families and children at specified times of transition.
- ✓ Create user-friendly means to access data and information about OPWDD and cross-system services. Include print, Web sites, and CDs that can be easily used by individuals, families, and care coordinators.
- ✓ Recognize the limited developmental disabilities workforce and make the field more attractive to potential employees.
- ✓ Cross-system care and funding mechanisms are needed to support transitions from one system to another, particularly those with dual diagnoses, autism spectrum disorders, and serious medical conditions.
- ✓ Enable behaviorists to work in and move between all environments and community settings. As an individual moves through different stages in their life, a consistent clinical infrastructure that

maintains continuity across the settings where services are provided will be most effective in ensuring smooth transition.

- ✓ Provide transitional housing for individuals who are improving behaviors and/or independence and for individuals/families who are homeless or in poverty and need to stabilize before moving to permanent housing.
- ✓ Transition supports should include assistance in cultivating support circles and accessing natural community supports and neighborhood resources.
- ✓ Start at an early age to support citizenship, community involvement and community membership.
- ✓ Adult transition supports for a self-determined life should include customized job supports, individualized home settings, life sharing, mentoring, and advocacy.
- ✓ Offer training and support to high school students with developmental disabilities, ages 14-21, and their parents, grandparents, caregivers, teachers and counselors. Incorporate assistive technology at the earliest age possible, assisting individuals at all developmental levels, i.e., for communication, travel training, "smart homes", medical needs, etc.

Charter Question #6 – How can the family support model be strengthened and enhanced in order to be a more viable option for more individuals with developmental disabilities as an alternative to group homes?

The BSDT discussed extensively how the People First Waiver needs to support and strengthen families across the individual's life regardless of where the person lives. Currently, the needs of individuals are greater than the grants available, and as a result, the BSDT agreed that the process should *not* be grant driven. Family support needs to be person-centered and needs to look more broadly at the role a family plays in a person's life and allow for family support funding to facilitate those roles and relationships. We should not think of family support as a separate model or grant service – we need to make sure funds follow the person. In addition, we do not need a funding source for Family Support as this will only create another "box." We do not want family support and family involvement to end when family members go into a group home or other living setting. We need to be flexible with resources so individuals are connected to their family.

Key Issues:

- ✓ Individuals should participate in programs of interest with people who have shared interests regardless of their living situation. The flexible funding anticipated through the Waiver will allow for program models that align with requested individual outcomes and are not funded based on where a person lives.
- ✓ Providing supports in uncertified settings requires evaluating and changing regulations that may currently limit the adequacy of supports provided. For example, being able to provide behavior

supports, based on individual's needs, in settings where other services are being provided can be critical to effectively meeting an individual's personal outcomes.

Charter Question #7 – How can the People First Waiver encourage and promote employment first opportunities for people with developmental disabilities?

The Employment First Services/Supports within a Managed Care System Workgroup (hereafter the Employment Workgroup) met twice in August 2011 to deliver specific recommendations to the BSDT for the preliminary report to the Steering Committee. The BSDT agreed with the recommendations set forth by the Employment Workgroup. See *Appendix E (page 33)* for the Employment Workgroup's recommendations.

While the work of the Employment Workgroup will continue, the Workgroup had the following preliminary recommendations for the BSDT:

- ✓ Some of the 1115 waiver demonstration projects should be related to employment.
- ✓ OPWDD should explore ways to blend funding for the entire day so individuals can seamlessly go from paid employment to volunteer opportunities, pre-voc opportunities, etc.
- ✓ Person-centered planning is key, along with portable budgets that enable individuals to be self-directing (hiring staff, etc).
- ✓ More resources need to be available for job coaching.
- ✓ There should still be a role for "agency of choice."
- ✓ Create better incentives (increase funding) for employment.
- ✓ We must remove the employment funding silos that currently exist within OPWDD.

Charter Question #8 – What, if any, crisis intervention/stabilization services should be made available under the People First Waiver for people with developmental disabilities? What are the circumstances under which these services could be accessed?

The Behavioral Supports and Services within a Managed Care System Workgroup (hereafter the Behavioral Workgroup) delivered specific recommendations to the BSDT for the preliminary report to the Steering Committee. The BSDT agreed with the recommendations set forth by the Behavioral Workgroup. See *Appendix F (page 39*) for the Behavioral Workgroup's recommendations.

Crisis intervention services need to be accessible when a person with developmental disabilities is in jeopardy of losing any placement, to avoid admission into a high level of care such as a DC or acute hospital setting or when there is an immediate concern for the safety of the individual and/or

caregivers. Some of the following services are available in some areas, but need to be expanded or enhanced to reach more of the population:

- ✓ Parents require supports and training to respond to behavioral challenges in a best practice, treatment focused manner and provides guidance for times of crisis that could require physical intervention.
- ✓ Trained behavioral specialists and psychiatric and/or psychological supports need to be available for consult in all home and day environments in a timely way (including foster homes, school, day treatment, respite, and community habilitation) to help prevent a full-blown crisis from occurring.
- ✓ OPWDD and OMH need to work together to determine which existing OMH programs can be modified to support people with developmental disabilities. The goal should be for the access afforded through the 1115 waiver to obviate the need for duplication of services across systems.
- ✓ Trained staff (including behavioral and psychiatric consultants) need to be available 24/7/365 to assist.
- ✓ Emergency respite or crisis diversion beds available on a timely basis to prevent an in-patient admission when appropriate.
- ✓ People who have behavioral challenges need strong support both at home (whether it is an IRA or other living arrangement) and for day supports.
- ✓ Emergency respite not only to prevent hospitalization, but in cases of suspected abuse/neglect/risk of homelessness.
- ✓ Increased community access to psychiatrists, psychologists, and other relevant practitioners with expertise in developmental disabilities and mental illness. Improve recruitment and retention strategies for practitioners listed above.

Charter Question #9 – What are the circumstances under which cost-sharing arrangements should be considered/implemented for People First Waiver services/supports for people with developmental disabilities (e.g., parental deeming; adaptive and environmental modifications, etc.

The BSDT had a very thoughtful discussion regarding cost-sharing and recognized the importance of discussing this topic with the Fiscal Sustainability Team. The crucial role of Medicaid and SSI as funding streams requires strict compliance with fiscal eligibility rules defined by the federal government. Imposing State level rules related to required family contribution could undermine the definition of “case unit” that is used to define eligibility. In addition, there was a concern that a family’s ability to participate financially might change significantly over time and any earlier fiscal participation might somehow evolve into a permanent “maintenance of effort” requirement.

It was noted in discussion that the shift in person-centered approach to service planning envisioned by BSDT might obviate some of the concerns related to this issue. In particular, the movement away from a rate-based or fee-for-services approach toward the allocation of resources in response to an individualized needs assessment would at least allow a person to explore and bring to the table other resources that would offset the need for public expenditures.

IV: Follow-up Design Questions

In reviewing the entirety of its deliberations, BSDT is cognizant of the enormity of the work plan that emerges. To maintain the momentum of its work, the BSDT recommends the following as a way to shape ongoing design discussions:

- ✓ While the Waiver has the ability to revolutionize service delivery for people with developmental disabilities, the evolution must occur strategically and over a period of no less than five years. All parties want this to succeed, but to be successful, carefully planned transitions of legacy services must occur.
- ✓ Initial focus and energies are best spent in actualizing true person centered planning, rather than focusing on detailed definitions of services.
- ✓ Multiple opportunities for creativity and pilot projects should be provided throughout the People First Waiver period.
- ✓ Immediate relief from the current complexities of the current CSS process must be provided to expand the viability of self-directed budgeting and service delivery. The development and approval of initial and revised budgets and rates is cumbersome and requires more levels of review, with less automated support than traditional services, creating significant disincentives.
- ✓ A comprehensive review of cross-systems regulations and laws must be undertaken. Areas of immediate interest should be:
    - Department of Labor rules related to innovative support models and employment.
    - Barriers to behavioral supports being delivered in uncertified settings.
    - Reexamination of the Nurse Practices Act as it pertains to people residing and working in community integrated, non-certified settings.
    - Barriers to using technology supports to provide safety and oversight.
    - The ambiguity and overlap between OPWDD and ACCES-VR and key aspects of special education must be examined and realigned.

Questions remain about how we can we move from a system that operates with program silos to one that provides supports and services seamlessly across the person's life. Even in the midst of transition the question should no longer be "in what program do we place this person?" Rather, we should immediately start asking: what supports does the person need to achieve his/her goals? How many hours of service does he/she need? Where should the service be provided?

APPENDIX A

Benefits and Services Design Team Members

- **Suzanne Zafonte Sennett**, OPWDD Deputy Commissioner, Policy and Enterprise Solutions, Team Leader
- **Laurie A. Kelley**, Executive Director, ARC of Ulster-Greene County, Co-facilitator
- **Kate Bishop**, People First Waiver Unit, OPWDD
- **Debra Bojarski**, Treatment Team Leader Office of Community Support, CNYDSO
- **Amy Cohen Anneling**, Licensed Psychologist, OPWDD, Bureau of Behavioral and Clinical Solutions
- **Myrta Cuadra-Lash**, Executive Director, Sinergia
- **Joann Dolan**, Parent, The Big Tent
- **Patricia Dowse**, Chief Operating Officer, New York State Rehabilitation
- Association, Inc.
- **Max Donatelli**, Parent, Department Head, Bridges to Health and Family Engagement, Baker Victory Services
- **Karen Gillette**, Self Advocate
- **Pasquale Ginese**, Self Advocate, Self Advocacy Association of New York
- **Richard Iannello**, Executive Director, Albany Guardian Society
- **Angela Lauria-Gunnink**, Program Research Specialist, OPWDD
- **Diana McCourt**, Parent, The Big Tent, Board Member, Job Path, Inc.
- **Margaret Mikol**, Executive Director, SKIP of New York
- **Susan Platkin**, Parent
- **Sharon Rockwell Linne**, Parent
- **Fredda Rosen**, Executive Director, Job Path, Inc.

APPENDIX B

Benefits and Services Design Team Charter

The purpose of the Benefits and Services Design Team is to make service and supports reform recommendations that enhance person-centered planning and service delivery, as well as to increase the system's capacity to serve people in the most appropriate community setting with an equitable level of resources based on the needs assessment process. The Benefits Design Team will focus in particular on the following:

- ✓ Residential services, community and behavioral supports for individuals with developmental disabilities transitioning from institutional settings;
- ✓ Reforms in services and supports for subpopulations with developmental disabilities;
- ✓ Enhancing supports for families; and
- ✓ Employment first services/supports

Through its work, the Benefits and Services Design Team will answer the following questions:

1. Consider all the services and supports currently available through OPWDD's system and other systems for people with developmental disabilities:

A. What are the services/supports that are generally working well for people?
B. What are the services/supports that are not working that need to be simplified, enhanced, and/or redesigned?
C. What services/supports could people with developmental disabilities take advantage of from other systems if obstacles/barriers were addressed/eliminated (e.g., can only be in one waiver at a time; can only have one targeted case management service; etc.)?
D. How can OPWDD build on the services that are working well by enhancing, consolidating, simplifying and/or clarifying services/service delivery to enhance value and quality? What changes in regulations and/or policies would be needed?
E. How can needs assessment and resource allocation reform facilitate greater access to supports and services?
F. What role will needs assessment have in determining the types of supports and services that individuals have access to?
G. How can self-direction and self-determination be expanded and enhanced?

2. What specialized residential, community, and behavioral services (and cross systems supports) are needed for people leaving institutional settings (e.g., intensive and/or crisis behavioral services) and

how do these services differ from what is available today in the developmental disabilities service system?

3. What are the barriers for individuals with developmental disabilities to move in to their own homes and apartments? What services and supports need to be created, strengthened, and/or enhanced in order for more individuals to transition from group homes with 24-hour staffing to their own homes and apartments with less than 24-hour support?

4. What services/supports need to be created, strengthened and/or enhanced in order for children and other people with developmental disabilities to remain in the homes of their parents, family members and/or relatives longer, particularly when primary caregivers are aging (particular focus on the provision of behavioral supports in family settings from a challenges and solutions perspective is needed)?

5. How can the People First Waiver better support and integrate services for children across systems (transition from early intervention to State Education services to adult services)?

6. How can the Family Support model be strengthened and enhanced in order to be a more viable option for more individuals with developmental disabilities as an alternative to group homes?

7. How can the People First Waiver encourage and promote employment first opportunities for people with developmental disabilities?

8. What, if any, crisis intervention/stabilization services should be made available under the People First Waiver for people with developmental disabilities? What are the circumstances under which these services could be accessed?

9. What are the circumstances under which cost-sharing arrangements should be considered/implemented for People First Waiver services/supports for people with developmental disabilities (e.g., parental deeming; adaptive and environmental modifications, etc.

APPENDIX C

Title and Publication Date	Author	Link
Host-Home Living Services. Retrieved June 18, 2011.	The Mentor Network	http://thementornetwork.com/standard/services.aspx?guid=7d873200-00ce-4928-ae7c-c169475fa3e2
Keeping the Promise: Self Advocates Defining the Meaning of Community Living. March 2011.	The Autistic Self Advocacy Network	http://www.autisticadvocacy.org/documents/KeepingthePromise-SelfAdvocatesDefiningtheMeaningofCommunity.pdf
Living the Smart Life (DVD). 2008.	Ablelink Technologies	https://store.ablelinktech.com/store.php?action=show_detail&crn=200&rn=372
Making Homes That Work: A Resource Guide for Families Living with Autism Spectrum Disorder + Co-occurring Behaviors. 2011.	George Braddock, Creative Housing Solutions LLC John Rowell, Rowell Brokaw Architects, PC	Link not available. Distribution with written permission from authors.
NCI Consumer Outcomes, Phase XII Final Report, 2009-10. March 2011.	Human Services Research Institute, NASDDDS	http://www2.hsri.org/docs/NCI%20CS%2009-10%20FINAL%20Report.pdf
NCI Data Brief: What does NCI tell us about people with autism? – An update. April 2011.	Human Services Research Institute, NASDDDS	http://www.hsri.org/publication/nci-data-brief-autism/

NCI Data Brief: What does NCI tell us about people with dual diagnosis? April 2011.	Human Services Research Institute, NASDDDS	http://www.hsri.org/publication/nci-data-brief-what-does-nci-tell-us-about-people-with-dual-diagnosis/
NCI Data Brief: What does NCI tell us about people who self-direct? April 2011.	Human Services Research Institute, NASDDDS	http://www.hsri.org/publications/download/nci-data-brief-what-does-nci-tell-us-about-people-who-self-direct
NCI New York State Report, 2009-2010. No publication date.	Human Services Research Institute, NASDDDS	http://www2.hsri.org/nci/docs/state-reports/2009-10%20NCI%20State%20Report-%20New%20York.pdf
The NYSACRA Learning Institute: Evolving System for Persons with Developmental Disabilities. October 1, 2009.	NYSACRA	http://www.opwdd.ny.gov/2011_waiver/images/benefits_and_services_071111_innovation.pdf
The NYSACRA Learning Institute: Examples of Excellence in Prototype Development that Supports one if not all Eight of the Values Social Roles. October 1, 2009.	NYSACRA	http://www.opwdd.ny.gov/2011_waiver/images/benefits_and_services_071111_innovation.pdf
The NYSACRA Learning Institute: Framework for Person Centered Impact. October 1, 2009.	NYSACRA	http://www.opwdd.ny.gov/2011_waiver/images/benefits_and_services_071111_innovation.pdf

The NYSACRA Learning Institute: Framework for Person Centered Outcomes. October 1, 2009.	NYSACRA	http://www.opwdd.ny.gov/2011_waiver/images/benefits_and_services_071111_innovation.pdf
The NYSACRA Learning Institute: How Individualized is the Support of Service? October 1, 2009.	NYSACRA	http://www.opwdd.ny.gov/2011_waiver/images/benefits_and_services_071111_innovation.pdf
The NYSACRA Learning Institute: Wheel of Power. October 1, 2009.	NYSACRA	http://www.opwdd.ny.gov/2011_waiver/images/benefits_and_services_071111_wheel_power.pdf
New York State Health Home Federal Rules and Potential Models. July 12, 2011.	New York State Department of Health	http://www.health.state.ny.us/health_care/medicaid/redesign/behavioral_health_reform.htm
Rest Assured (DVD). No publication date.	Rest Assured	http://www.restassuredsystem.com
Shared Living Guide. May 2011.	NASDDDS	http://www.nasddds.org/Publications/special_pubs.shtml
Using the Resource Allocation Decision Method. May 2008.	Wisconsin Department of Health	http://www.dhs.wisconsin.gov/ltcare/pdf/RADinformational.pdf

APPENDIX D

Technical Workgroup on Self-Direction and Individualized Budgets within Managed Care Recommendations

Workgroup Meeting Dates:
August 5, 2011
August 10, 2011

Self-Direction and Individualized Budgets Workgroup Members:

Members:	**Representing:**
Suzanne Sennett	OPWDD, Deputy Commissioner, Workgroup Facilitator
Angela Lauria-Gunnink	OPWDD, People First Waiver Design Team
Kris Freitag	Parent
Max Donatelli	Benefits and Services Team
Maria Dibble	New York Association On Independent Living
Karen Gillette	Benefits and Services Team
Robin Hickey	Quality Team
John Maltby	Access and Choice Team
Dr. Keith McGriff	Fiscal Sustainability Team
Susan Platkin	Benefits and Services Team
Kathleen Quinn	Care Coordination Team
Doris Moore	OPWDD, CSS
Don Moffit	OPWDD, Rate Setting

Purpose and Scope:

The proposed scope and charge of the Self-Direction and Individualized Budgets Technical Workgroup is to:

1) Investigate how other States have designed and implemented self-direction and individualized budgets within the State's managed care organization model for people with developmental disabilities. (Michigan and Tennessee are two examples.)

"Michigan's Transformation Process for Excellent Consumer Outcomes"
Workgroup discussion with Michael Head, Director (retired), Mental Health & Substance Abuse Administration, August 10, 2011:

Michigan Department of Community Health (MDCH), Behavioral Health and Developmental Disabilities Administration:
1997 – Self-Determination Initiative for people with developmental disabilities (DD)
1998 – 1915(b) Managed Care Waiver – covers all Medicaid specialty mental health, substance abuse and DD services – allows managed care, capitation, risk-sharing (State & counties share risk for overspent budgets)

Michigan's services for people with developmental disabilities (DD) are based on 1915(b) & (c) authority; CMS allows Michigan to operate the two waivers "concurrently." Services are entitlements, are not setting based, and "medical necessity" is redefined to include community inclusion, integration, participation and/or productive activity. Goals moving forward are to support maximum consumer choice and control, and expand opportunity for integrated employment.

Michigan **requires** person-centered planning (*PCP is a statutory requirement for all people receiving and eligible to receive services*), self-determination, and care management, and uses an external quality review organization to monitor health plan compliance. Individuals are interviewed (without providers present) to assess satisfaction. Michigan noted that providers became a lot more person-centered when this change was put in place and therefore, many individuals receiving services stayed with their present providers after the statutory requirement went into effect. In the one county where people were not happy with their services, a second MCO was established, and that this competition seemed to increase customer satisfaction with supports and services.

People with mental illness (MI) and people with DD in Michigan are served through the same county-based community mental health services programs (CMHSPs) (public entities). DD services totaled $971 million in 2007 and served +/- 37,700 individuals (80% Medicaid eligible): 12% living in their own home, 46% living with relatives, 42% living in licensed community residences; 4,500 people self-determining with individual budgets. Anyone can access self-determination in Michigan; Michigan's self-determination program is part of its waiver in accordance with an agreement with CMS. People with individual budgets are allowed/encouraged to build savings into the budget for anticipated and unanticipated future needs.

CMHSPs make up the 18 sole-source Prepaid Inpatient Health Plans (PIHPs or PHPs) and share risk with the State. Ten (10) PHPs were formed through affiliation of two or more CMHSPs. Eight (8) PHPs were each a single CMHSP, but in several cases represent more than one county. Michigan executed Medicaid contracts with the 18 PHPs, but executed general funds contracts with all 46 CMHSPs (serving 83 counties.) Each region is required to have an extensive array of services that allows for maximizing choice and control on the part of individuals in need of service. Individual plans of service are developed using a person-centered planning process for adults and a person-centered process and family-centered, "family directed" care for children.

Michigan takes all of the funding in the system and pushes it out to the counties for services: the (b) waiver uses PEPM (per eligible per month), the (c) waiver uses PMPM (per member per month). Michigan's self-directed option primarily offers individuals budget authority, and when people have an individual budget they also control scheduling and who to hire. For those who want employer authority and the ability to self-hire their staff, MCOs must offer an Agency with Choice option. The State monitors the services people are getting, but they allow people to make mistakes; they do not expect perfection. Agencies are held accountable for quality requirements. Michigan promotes and people actually use the Medicaid fair hearing process to address complaints/grievances.

Issue areas include the need for a better uniform needs assessment tool, achieving administrative efficiencies, developing and maintaining a competent workforce, assessing needs and managing demand, coordinating and managing care and improving quality of supports and services. Regarding self-determination, Michael indicated that everyone has access to self-directing their services, but "some localities do it better than others." Michael also noted the importance of training for individuals and families: "If you want this stuff to work you don't train providers, you train individuals and their families…otherwise they don't know how things should be, what they should expect and what to complain about."

The Workgroup was unable to speak with a representative from Tennessee before the August 12, 2011 deadline.

Purpose and Scope:

2) Based on the research and the work of the design teams and technical workgroups, recommend design features and parameters for self-direction and individualized budgets within the managed care organization model of the People First Waiver that OPWDD should consider piloting.

Self-Direction Workgroup Recommendations:

Recognizing that there is much work to do, the Self-Direction Workgroup has identified the following as design features and parameters that should be incorporated into the People First Waiver:

- This is an opportunity to ensure that the regulatory structure supporting services for people with developmental disabilities is driven by the principles and priorities of individualized services and community integration. New York State should not start from its current regulatory framework which is still heavily steeped in historical institutional and "care-taking" approaches. Instead, everything should begin with the Person-centered Plan (PCP), and use the PCP for everyone. While this work team was charged with focusing on self–direction, the basic tenets of person-centered and self-determination should not be limited to those who seek to have greater fiscal and administrative control over their supports.

- Ensure that PCPs address the entire lifespan of the individual, including future planning for what happens after the individual's parents die, as well as contingency planning, including backup arrangements for staff and planning to address socialization needs, including arrangements to enable people with developmental disabilities to get to know people with similar interests who are not paid to serve them and who may take a long-term interest in assisting them.

- Create an all-encompassing budget tool that is easy to understand for families and individuals.

- Need to better define and measure quality.

- Allow money to follow the person and not the provider.

- Services and supports cannot be an unfunded mandate.

- Every Managed Care Organization (MCO) must offer self-direction as an option and actively promote it so that no individual is excluded based on their MCO.

- Create a needs assessment methodology that is holistic, accurately assesses individuals' functional level, and recognizes that needs change over time (for both the individual and family).

- OPWDD needs to simplify the reporting format by revisiting regulations.

- OPWDD needs to partner with providers to leverage community resources for individuals beyond just those services reimbursed through Medicaid.

- Demedicalize scope of use by not using rigid medical interpretation but still encompassing medical services. A strong potential is to build on how Michigan defined medical necessity. Michigan adopted an expansive definition of medical necessity, which is as follows: *Determination that a specific service is medically (clinically) appropriate, necessary to meet needs, consistent with the person's diagnosis, symptomatology and functional impairments, is the most cost-effective option in the least restrictive environment, and is consistent with clinical standards of care. Medical necessity of a service shall be documented in the individual plan of services* (Michigan Department of Community Health, Medicaid Provider Manual, October 1, 2009). This would encompass any direct services or supports and clerical or administrative support necessary to ensure effective procurement and provision of such direct services and supports, that have the demonstrable effect of maintaining or improving an individual's inclusion or participation in society, employment or productivity, independence in any life activity, or recovery from any medical, psychiatric, or psychological condition.

- Allow individuals to make mistakes and recognize that skill acquisition happens best in the environment in which skills will be used. Thus, programs should not make individuals "prove" themselves before being afforded the opportunity to transition into more independent settings.

- Individualized budgets, and the use of funds within those budgets, should be subjected to levels of oversight and approval consistent with other program rates.

- Availability and use of technology to improve access to self-direction and greater individual choice.

- Community integration must be a core expectation – and activities that support a person's community involvement should not have to be justified on the basis of "medical necessity."

- There must be technical expertise and advocacy accessible outside of, and not accountable to the MCO.

- Housing and self-direction must be linked. In traditional congregate settings, the setting of a home takes into account safety, the richness of community resources, and maintaining personal affiliations. These are values that have been acceptable counterbalances to cost. However, when a person seeks to live independently, the fiscal model defaults exclusively to one of poverty and or low income housing parameters, such as Section 8 Housing. These fiscal ceilings are typically insufficient to accommodate unique physical plant needs of the person, let alone allowing for an assessment of community resources.

- People can work. The Self-Direction Workgroup strongly endorses OPWDD's current policy initiative of "Employment First." The person-centered planning should start from the presumption of a goal of employment and/or community engagement, rather than the current default of enrollment in a day program.

- OPWDD should devote an unprecedented level of resources to training people about the new waiver, including an emphasis on best-practice principles of self-determination, individual budgets, person-centered planning, and self-direction.

- Create a self-hire registry (such as in VT).

- Recognition of the need for guardianship and succession planning for guardians, particularly when there are no natural successors and OPWDD or a provider/subcontractor/lawyer may be asked to stand in.

- Separate advocacy from the provider of services. Individuals whose job it is to advocate for people with developmental disabilities in the broadest sense must not be employed by entities that provide, or are in a position to provide, direct services to the person being advocated for.

- There should be a Statewide governing council that includes a majority of people receiving self-directed services, and that will review waiver outcome data and problem reports.

While the Self-Direction Workgroup debated what exactly the managed care organization model will look like and how it may be premature to select pilot projects without this information, the Workgroup did identify the following as potential pilot project subjects with the understanding that there will be sufficient resources to manage and evaluate the pilot(s):

- Moving from certified sites and group homes to individual apartments.

- Using the PCP through a capitated model.

- Collaboration with OMH to ensure service access during crisis.

- Look at the Regional Resource Development Centers (RRDC) model to target the DD population involved in self-determination.

- Medication administration – especially in rural areas.

- Look at other States' risk assessment models (health and safety) and pilot.

- Partner with the State Education Department to support children ages 14-21 with OPWDD services and ACCES-VR supports.

- Allow individuals to keep everything from childhood into adulthood (job, etc).

- Pilot paying families (focus on cost-savings).

- Pilot an all-encompassing budget.

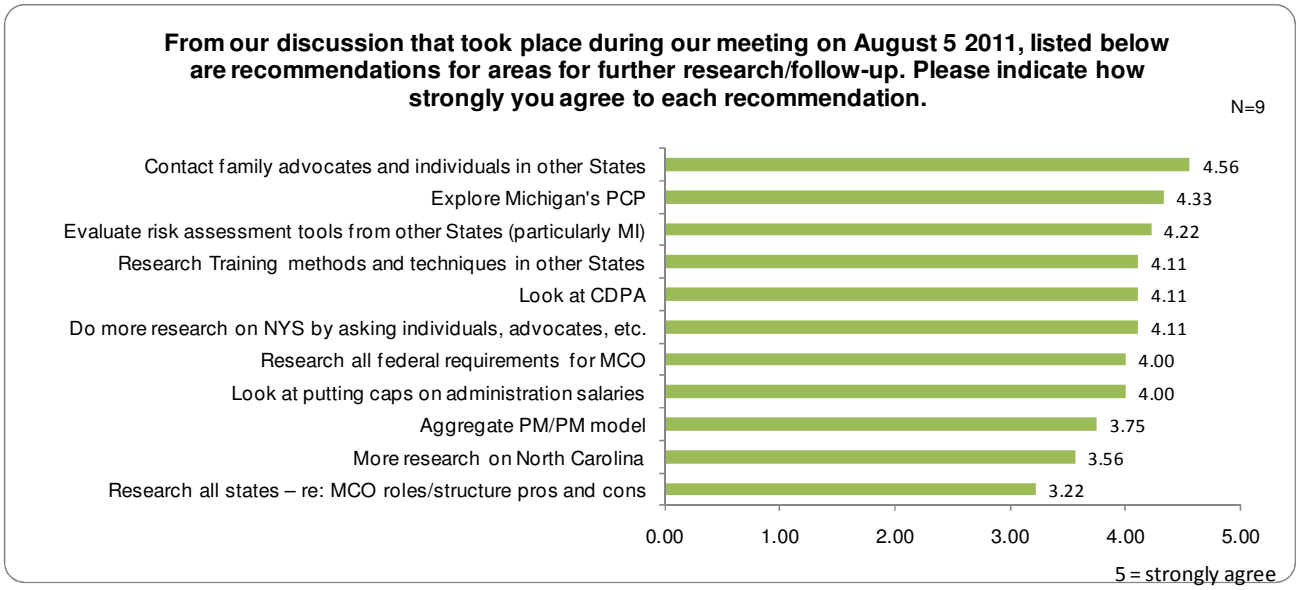
- Allow individuals to have more adaptive equipment and define adaptive equipment more broadly/flexibly.

- Develop an on-line headquarters for linking with such resources as the Regional Resource Directory Councils supported by the Nursing Home Transition and Diversion (NHTD) Medicaid Waiver program.

- Create an administrative template to build administrative and regulatory compliance across the State.
- Focus on cultural drivers in the system to understand how best to help people handle system change and manage expectations.
- Look at both public and private MCOs.

Further Research:

The Self-Direction Workgroup also identified areas for further research:



Conclusion:

The Workgroup members were clearly very passionate about the recommendations they generated. They agreed on the need to maximize individual independence by tying the design, frequency, intensity and valued outcomes of all direct services and supports, whether integrated or segregated, to a true person-centered planning process. In addition, they agreed that regardless of the level of independence and control the individual wishes to exercise over his or her service plan, or of where the individual wishes to live or work, everyone should have a person-centered plan that drives an individual budget. Person-centered planning and maximizing an individual's independence boils down to one word: citizenship.

APPENDIX E

Employment First Technical Workgroup Recommendations

Workgroup Meeting Dates:

August 2, 2011
August 9, 2011

Employment Workgroup Members:

Pat Dowse	NYSRA
Fredda Rosen	Job Path
Steve Towler	AHRC
Maggie Hoffman	Self-Determination Coalition
Wendy Quarles	Heritage Christian
Ceylane Meyers-Ruff	OPWDD (facilitator)
Joanne Bushart	OPWDD
Lynne Thibdeau	OPWDD

Scope and Charge:

The proposed scope and charge of the Employment First Technical Workgroup is to:

1. Outline recommendations made by NYS's Most Integrated Setting Coordinating Council (MISCC) Employment Committee which strategized ways to support a Statewide, cross system employment agenda promoting employment for all individuals with developmental disabilities.

   - These activities are on-going.

2. Research Wisconsin's Pathways to Independence initiative, which is designed to provide person-centered employment first services and supports within a managed care environment.

   - In Wisconsin, they used their Medicaid Infrastructure Grant to focus on Employment First. While the impact was larger than individuals with DD, there has been an impact on such individuals.

   - We are obtaining additional information on Wisconsin's experience.

3. Research strategies used to support Washington State's Working Age Adult Policy (WAAP), which legislatively integrated employment at living wages for individuals with developmental disabilities.

- Outreach was done to Washington State regarding their school-to-work model, with a specific focus on Kings County where representatives from the adult service system work at the high schools. They also use a customized employment model and Project Search. Washington has been working on this issue since the 1970s when it first focused on values clarification. More recently, the legislature and executive branch have worked together to promote an Employment First Agenda. In 2004, individuals with DD were given two years to transition from day habilitation to employment. The State also made a strategic decision for services to be provided by the counties, which created more flexibility. The counties were also able to address the transportation needs of individuals. Feedback from Washington indicated that focusing on students transitioning out of school really made a difference in moving people with DD into employment. During their transition phase, the State implemented pilots projects to measure success.

- There was consensus that we need more information about Washington's experience, particularly about the challenges encountered and the outcomes for individuals who were not able to transition into employment (did anyone get left behind, what happened to them?). We are also interested in getting feedback from parents who were involved in this process. We need the complete picture of what happened and the concerns raised along the way to reform.

4. Recommend design features and parameters for pilot/demonstration projects for employment first within a managed care framework under the People First Waiver that refocuses the choice of traditional day service options to a directed employment planning process that encourages choice of employment based on an individual's interests and strengths.

- The following aspects of CSS and the blended model developed under OPWDD's OPTS program should be a part of any pilots or demos: flexibility, ability to respond quickly to changes in an individual's life and to make the changes in a seamless fashion, individualized planning, self-determination and blending volunteer and paid employment.

- We should encourage pilot projects that are based on agency-with-choice, an "enhanced" CSS-like program where families or circle of support members may "purchase" a more muscular Fiscal Management Services package (with back up from fiscal management service agency). This menu option reflects a structure that is between the blended OPTS approach and CSS.

- We need to identify what is working and could be improved as it relates to current employment initiatives like SEMP, E-SEMP and OPWDD's Employment and Training Program. However, it is important to stress that we need to move away from program titles that keep us in silos instead of focusing funding on what a person needs for the whole day.

- We should also focus on youth transitioning from school to work. We should build on the expectation of families who want more than day habilitation for their loved ones.

- Volunteerism is also important, not only as a way to develop job skills as a person transitions to employment, but the value of volunteerism on its own, especially given efforts to decrease participation in day hab. Volunteerism is an excellent way to integrate individuals into their community. Recent changes in federal Department of Labor policies have the potential to limit volunteer opportunities. We will review this further and reach out to the State Department of Labor about how to work on these issues.

- There was also a lengthy discussion about the role of the Vocational Rehabilitation system and how any OPWDD changes related to employment must be mindful of the current ACCES-VR process. While this group can't impact ACCES-VR policies, it may be necessary to recommend the need for OPWDD to dialogue with ACCES-VR regarding ways for individuals with developmental disabilities to take advantage of both ACCES-VR and OPWDD services and the importance of including individuals with developmental disabilities in ACCES-VR vocational training programs.

- It was agreed that providers and parents should be surveyed about what they like or feel needs to be changed about CSS and OPTS blended contracts. Results of the surveys are as follows:

Survey Results

- The Workgroup surveyed 100 parents of individuals receiving CSS on what they liked or felt needed to be changed in the CSS program. Twenty-nine people responded in just four days. Feedback on what works about CSS and should be included in the 1115 waiver included the following:
  - Person-centered planning.
  - CSS costs 15% less than traditional services because there is more flexibility. People are able to spend what they need. Less money is spent on overhead and transportation.
  - Direct support staff can be paid higher wages, reducing staff turnover.
  - Funding for training and availability of good job coaches.
  - Having job coaches provide support on the work-site.

- Suggested improvements included more training of job coaches, seamless transition from work to other day activities and more hours for job coaching.

- Based on this feedback it was suggested that a demonstration should be done to evaluate and analyze the cost benefits of CSS to see how much Medicaid savings it truly generates and how the savings can be used to create more employment opportunities for individuals.

- Given the very short turn around on the survey and the fact that it was limited to Long Island, we will reach out to Central NY DDSO to also survey parents.

  - NYSRA and NYSARC also sent a survey to providers. There were 22 responses which are still being analyzed. Some of feedback included the following:
    - On-the-job support is important.
    - Need to fund the entire day, blending models (employment and day habilitation).
    - Need to fund the seamless transition from employment to day services.
    - Do not forget to fund "soft skills" that help individuals to retain employment.
    - Transportation has to be addressed.
    - For students transitioning out of school, establish eligibility prior to High School graduation.
    - Increase funding for employment.
    - Reduce paperwork.
    - Better coordination with ACCES-VR
    - Expand the E-SEMP model.

- We will be reaching out to IAC to survey its members also.

5. Preliminary Recommendations to the Design Team:

While the work of the Employment First Workgroup will continue, the Workgroup offers the following preliminary recommendations for the Design Team:

✓ Some of the 1115 waiver demonstration projects should be related to employment.
✓ Explore ways to blend funding for the entire day so individuals can seamlessly go from paid employment, to volunteer opportunities, pre-voc opportunities, etc
✓ Person-centered planning is key, along with portable budgets that enable individuals to be self-directing (hiring staff, etc)

- ✓ More resources are needed for job coaching.
- ✓ There should still be a role for "agency of choice."
- ✓ Create better incentives (Increase funding) for employment.
- ✓ We must remove the employment funding silos that currently exist within OPWDD.

Addendum:

Comments and further recommendations from the Benefits and Services Design Team (August 16, 2011):

The BSDT discussed all of the above recommendations and had a discussion on the ITNAmerica senior transportation model in Maine and how this program can be adapted to support with people with developmental disabilities. The Independent Transportation Network (ITN) provides rides with door-to-door, arm-through-arm service to thousands of seniors nationwide. It is a truly innovative solution with unique programs that allow older people to trade their own cars to pay for rides, and enable volunteer drivers to store transportation credits for their own future transportation needs.

The BSDT also discussed capping volunteer/internship hours to address Department of Labor concerns without limiting opportunities for individuals with developmental disabilities.

There was discussion of Pennsylvania's experience and how that State is paying families the current IRS rates for transportation to and from work.

The BSDT discussed the need to clarify what "Agency with Choice" means as it relates to employment. We need to find a way for a person to decide how much hands-on management he/she wants to do on the accounting side vs. the design and control of the services side. There needs to be a range of options for managing the fiscal aspects of services and a way to aggregate accounting responsibilities without aggregating the level of control over services.

The BSDT also discussed how DD officials in Washington State, where employment rates among transitioning youth has increased from 14% to 60%, affirm that it wasn't until the DD system structured a mechanism for provider organizations to work with students in their last year of school that they were able to have an impact on employment rates. OPWDD's Pathways to Employment waiver provides this structure. This feature should be part of the 1115 waiver and should be implemented as soon as possible.

Other important lessons from Washington State include their belief in piloting employment efforts and collecting data on outcomes. In addition, Washington emphasizes the importance of training and technical assistance.

The BSDT agreed that OPWDD needs to move away from a system where employment programs are for only the most capable people to a system that supports employment for all. We should support models that have been effective in enabling people with the most severe disabilities to enter the workforce (for example, customized employment and microenterprise). The “blended” OPTS structure has provided a vehicle for people with significant support needs to work part-time and participate in other community activities during the rest of their week.

Real working partnerships with the NYS Education Department and ACCES VR are essential.

APPENDIX F

Behavioral Supports and Services within a Managed Care Workgroup Recommendations

Behavioral supports and services must be easily accessible and responsive to a broad range of individuals: adults living, or seeking to live independently; children and young adults supported within the context of their family; those in intermittent crises and those with ongoing behavior management and support needs. The following chart highlights some key recommendations for better serving some of these groups. This is an initial set of recommendations relating to better serving those sub-populations with which the Workgroup was most fluent. A more comprehensive assessment of the gaps and best practices for other groups must be undertaken.

Family

	Challenges	Solutions
1	Current service system is designed to provide more generous funding for persons not living with families; e.g. residential schools and certified sites.	-Develop a tool that adequately assesses need and develops an allocation of service dollars that will encourage families to remain intact. -Rebalance service dollars to enable families to care for individuals at home. -Consider family as paid supports in specific circumstances. -Amend individualized services to provide more services to individuals living with families (instead of less), as well as simplify. -Provide families with a certain amount of funds, annually, to be used, as needed.
2	Individuals with behaviors at home which are disruptive to the family unit	-Develop intensive in-home behavioral services for family units. -Increase the availability of Habilitative supports for families; e.g. Community Habilitation and Respite Services. -Develop access to psychiatry for medication management. -Develop twenty-four hour assistance for crisis management. -Increase provider payments for services for those deemed

		"hard-to-serve" (based on established criteria). -Make family counseling available to assist families to remain intact. -Provide assistive technology to meet both safety and communication needs. -When necessary, admit individual to a time-limited intensive treatment program, with the goal of re-uniting the family as quickly as possible.
3	Isolation of Families	-Coordinate with agencies to extend natural connections and nurture relationships in the community. -Assist families to create networks with others within walking/driving distance to provide support to each other as well as respite.
4	Issues related to aging family members	-Develop crisis placement options such as staying with other family members or staff known to individuals -Increase the family's access to respite services, either in or out of the home, as needed. -Provide families with a certain amount of funds, annually, to be used, as needed. Allow this money to be utilized for additional respite, housekeeping services, emergency response systems, etc.
5	Individuals with "high needs" have difficulty accessing services such as respite or community Habilitation	-Staff requires specialized training to serve those with high needs and must be compensated for this additional training. -Providers will need an enhanced rate to provide services to those with high needs (based on an established criteria).
	There are "Sub-Groups" within the persons served that need to considered: 1. Children with autism (a growing population); 2. Parents with Special Needs;	-Services must be flexible and responsive to unique needs. -Our service responses must remain current through strong linkages with best practices and new research.

	3. Homeless Persons; and 4.Those dually diagnosed with mental illness, substance abusers, those who are aging, medically frail, adjudicated, etc.	
	Challenges	**Solutions**
1	Concerns with behaviors Sensory needs unmet Issues with siblings Family issues may lead to requests for placement	-See number 2 above. -Assess use of ABA techniques for use on a wider scale.
2	Maintaining custody of children Ensuring adequacy of care provided to children Housing/ financial/child care concerns	-Comprehensive assessment to look at the needs of both the child and the parents. -Holistic person-centered planning process that is family-centered as well as culturally and linguistically sensitive. -Interagency collaboration with agencies such as DSS and legal services.
3	Lack of stability as well as concern over safety Locating permanent housing	-Provide stabilization and permanent housing through creation of transitional housing program. -Education and support to ensure long-term success.
4	Lack of services leads to crisis and requests for placement	-Increase Habilitative supports for those with specialized needs. -Pay particular attention to Respite and use of Family Supports funds. -Staff requires specialized training to serve those with high needs. Staff needs to be compensated for this additional training.

Community Behavioral Supports

	Challenges	Solutions
1	Individuals and their families have reported a variety of problematic experiences with accessing supports and services for their loved ones with ID/DD and co-occurring mental health and/or behavior disorders.	A number of federal and state disability agencies believe that children with ID/DD and co-occurring mental health and/or behavior disorders are best served within a "System of Care" approach (i.e. with services and supports that are individualized, community-based, child-centered, family-driven, culturally competent, comprehensive, integrated, and that foster the development of meaningful relationships between the child, the care provider, and the family). The goal of the System of Care approach is to decrease existing barriers by addressing eligibility and financing problems and by increasing access for families to non-clinical support systems such as in-home supports and respite care, thus providing a seamless set of services that are accessible and available to all children with ID/DD and co-occurring mental health and/or behavior disorders. Expanding our repertoire beyond the traditional services delivered by the State and voluntary providers is critical now more than ever because of the new challenges presented by younger clients, aging clients and individuals with increasingly complex and specialized needs such as autism spectrum disorders and dual diagnoses. The 1115 Waiver presents a strategic opportunity to build the capacity to provide a continuum of behavioral supports and services and a crisis support model to people with ID/DD.
2	Fragmentation of responsibility between the developmental disability, mental health and local education systems; Limited availability of mental health and developmental disability providers with expertise in treating individuals with dual diagnosis or complex behavior disorders;	New York needs access to a residential facility to provide a comprehensive, assessment program for children and adults with very challenging behaviors. The facility would be equipped with highly trained staff capable of assessing and creating plans that would effectively manage complex needs and behaviors. The treatment model is short-term (maximum of six months) and would be available only for individuals with the most complex behavioral needs. The program would also be able to effect a smooth transition back home with appropriate follow-up services.

		Cross-systems meetings between OPWDD and the children and adult mental health systems should be initiated and/or continued to increase a sense of shared responsibility. Collaboration needs to be initiated at the top level. Need to distinguish between individuals with dual diagnoses and those with developmental disabilities and severe and complex behavior disorders. The challenge is making an accurate assessment, but doing so results in more targeted and appropriate treatment and intervention. Additional costs (e.g. more intensive staffing) for providing specialized supports for individuals with dual diagnosis and complex behavior disorders should be factored into service rates. Supports for people who have high behavioral needs may need to be delivered in settings that allow for adequate staffing patterns and safety; this may not be in the family home. Regulations that drive defined staffing patterns may need reconsideration.
3	The use of structured, individualized assessment and planning standards is essential to determining the most appropriate course of treatment and intervention for individuals with ID/DD and co-occurring mental health and/or behavior disorders.	-Provide behavior plan development/implementation in family homes/structured residential/day program settings as well as for individuals who self-direct their services. Ongoing support is needed, as behavior plans need to be adjusted as a person's needs change. -Services could be provided by "Integrated Behavioral Health Service Delivery Teams" consisting of a mental health practitioner, a behavior specialist, and a health care manager with 24/7 responsiveness. -Intensive in-home Applied Behavioral Analysis (ABA)/Positive Behavior Supports (PBS) Services delivered by behavior specialists intervening in the community (home and/or program) to support caregivers in reducing challenging behavior. Parents/caregivers need to be trained in ABA and PBS techniques. -In-home behavioral Telehealth services for families supporting individuals with ID/DD and co-occurring mental health and/or behavior disorders; Psychiatric, behavioral and other professional services can be delivered via direct intervention in the home through Telehealth software/technology that brings the family and professionals together.

		-Psychologists and/or Behavior Specialists should be: ▪ Available in staff positions in residential settings; ▪ Available in network arrangements for groups of small providers/skilled home-based providers; ▪ Included on integrated teams; ▪ Able to link with Service Coordinators, Health Care Managers and/or Care Managers; ▪ Providing training in positive behavior supports to staff and families; and ▪ Training staff and families in data collection, analysis and development, implementation and monitoring of behavior plans.
4	A broader array of respite services and more availability in geographically remote areas is needed to support families who are caring for their loved ones with ID/DD and co-occurring mental health and/or behavior disorders at home.	Behavioral support capacity within all service settings (e.g. residential services, supported employment, family homes, respite etc.) as well as for individuals who self-direct their services. The addition of time-limited intensive services and staff support to facilitate transitions from the hospital or inpatient setting to home or other living arrangement should be considered to prevent the regression that often occurs during these transitional periods. Family/Caregiver education and support, including support through professionals and through family and peer run organizations; Family/Caregiver Education and Support should include teaching self-advocates and families in the use of effective behavioral management. Develop a continuum of crisis response services including: -An array of supportive resources for individuals and families to allow plan implementation based on identified needs at assessment and prior to the need for crisis intervention; -Mobile response with a clinical outreach capacity; -Short-term emergency treatment (both in home and site-based); -Crisis respite beds; and -Acute partial hospital programs that have an expertise in supporting individuals with DD.

	Developmental Center Transition	
	Challenges	**Solutions**
1	As individuals leave Developmental Centers (DCs) providing coordinated clinical supports is imperative to ensure they are successful in community-based settings.	Community based group and individual counseling - individuals transitioning from DCs and those served in community settings rather than a DC, need counseling opportunities to maintain a focus on relapse prevention, anger management and coping strategies. These counseling opportunities provide an opportunity for clinical monitoring and assessment and to respond proactively to potential clinical challenges. The most effective models have trained psychologists and social workers providing the counseling and oversight. In NYS, the expertise in serving individuals with offender histories has been in State-operated programs. It is recommended that consideration be given to joint clinical supports; the State-operation experts can serve as mentors for partner agencies. Clinical coordination of all needed supports to ensure that individuals are provided with the needed supports outside of the highly structured DC setting. The coordination of behavioral health supports is critical to maintaining and ensuring clinical stability. The clinical supports needed must be provided across settings.
2	Person Centered Planning should drive the appropriate residential supports for people who are transitioning out of Developmental Centers and for people who have been referred to DC settings historically. Determinations should be made about the appropriate residential support model based on the individuals' expressed interest and their identified risk management and clinical needs. The management of risk needs to be looked at differently than it has been historically. By utilizing innovative	Residential supports with appropriate supervision, monitoring and life skill building are essential to maintain safety and support individuals to make good decisions. Step-Down Facilities (SF) for use with individuals who have been stabilized at the emergency room or in a DC support setting and require more long-term stabilization before returning to the community residence or family home. SF would allow for more consistent staffing and implementation of interventions to ensure the correct plans are in place before reintegration into the community. Increased community placement options for persons with intense behavioral issues who historically have not been able to reside in a community setting (i.e., people who are placed in DCs because even an IRA placement is difficult to obtain due to

	models of support and appropriate community-based clinical supports, individuals can be safely supported outside of segregated settings.	behaviors). We cannot look at everyone as being able to step down to a lower level of support. For some, intense behavioral issues are the baseline. For individuals with these identified long-term needs, a highly staffed residential setting will most appropriately meet their needs. To allow increased options for residential supports, the following concepts are recommended for inclusion in the waiver: -Technology/smart home supports; -Shared living opportunities; -KeyRing Models of support; -Promise neighborhoods; -Family financial support; and -Paid neighbor supports, Effective community crisis supports are needed to transition individuals out of DC settings and to avoid the reliance on DC models of support for people in community settings who experience behavioral crises. Needs for crisis supports exist across a variety of settings, including family settings, independent living settings and in certified settings. Crisis services focus on an immediate response to a crisis event, assessment of ongoing need and related plan development, implementation of the care plan, and the ongoing provision of supports to meet the person's needs.