



## Design Team Meeting Summary

**Benefits and Services Design Team**

**August 16, 2011**

**Present:**

Pat Dowse, Susan Platkin, Sharon Rockwell Linne, Pasquale Ginese, Karen Gillette, Max Donatelli, Amy Cohen Anneling, Suzanne Sennett, Joann Dolan, Kate Bishop, Laurie Kelley, Angela Lauria-Gunnink, Myrta Cuadra-Lash, Debra Bojarski, Margaret Mikol

**Absent:**

Diana McCourt, Fredda Rosen

**Discussion Topics**

**Summary of Main Discussion Points, Considerations, Recommendations, Next Steps, etc.**

**Review and approve Design Team summaries from July 27, 2011 and August 3, 2011 meetings**

The team approved the design team summaries from the July 27, 2011 and August 3, 2011 meetings.

**Review and discuss Employment First Services/Supports Technical Workgroup Recommendations**

Ceylaine Meyers-Ruff (OPWDD Workgroup facilitator) presented the workgroup outcomes with the Benefits and Services Team. This workgroup assisted the Benefits and Services Team in answering Charter Question #7. *See Employment First Preliminary Workgroup Report for full details.*

Preliminary recommendations on employment to the Benefits and Services Design Team included:

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





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	<ul style="list-style-type: none"> <li>○ There should still be a role for “agency of choice”.</li> <li>○ Create better incentives (Increase funding) for employment.</li> <li>○ We must remove the employment funding silos that currently exist within OPWDD.</li> </ul> <p>Comments and further recommendations from the Benefits and Services Design Team included:</p> <p>The Team discussed all of the above recommendations and had a discussion on the ITNAmerica senior transportation model in Maine and how this program can be coupled 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's 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.</p> <p>The Team also discussed capping volunteer/internship hours to address Department of Labor concerns without limiting opportunities for individuals with developmental disabilities.</p> <p>There was discussion on Pennsylvania and how the State is paying families the current IRS rates for transportation to and from work.</p> <p>The Team discussed how there needs to be clarification of what “Agency of Choice” means as it relates to employment. The Team also discussed the need to find a way for a person to decide how much "hands on" an individual wants to be doing on the accounting side vs. the design and control of the services side. There also needs to be a range of options for the fiscal management for those people that want to self-direct.</p>
<p><b>Review and discuss Self-Direction and Individualized Budgets within Managed Care Technical Workgroup recommendations</b></p>	<p>The Self-Direction workgroup was lead by Suzanne Sennett. This workgroup assisted the Benefits and Services Team in answering Charter Question #1: <i>How can self-direction and self-determination be expanded and enhanced? See Self-Direction and Individualized Budgets</i></p>





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*Workgroup Preliminary Report for full details.*

The Self-Direction Workgroup spoke with Michael Head, Director (retired), Mental Health & Substance Abuse Administration. Michigan's services for people with 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 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 it appeared that this competition element increased customer satisfaction with supports and services.

Preliminary recommendations on self-direction to the Benefits and Services Design Team included:

- Ensure that person-centered plans address the entire lifespan of the individual, including future planning for what happens after the individual's parents die, as well as contingency planning.
- Every MCO must offer self-direction as an option and actively promote it so that no individual is excluded based on their MCO.
- Programs should not make individuals "prove" themselves before being afforded the opportunity to transition into more independent settings.
- Housing and self-direction must be linked.





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	<p>Team discussion included how the mechanical part of the self-direction has to be better defined and that the design and architecture (“bricks and mortar”) have to be better studied so that agencies cannot force individuals into self-direction. The mechanical design has to be succinct and there needs to be a better understanding on how individuals get a specific service from Agency A and another service from Agency B. OPWDD needs to create the infrastructure to allow this to work. Also, future providers need specific expectations so they will know what is expected and can’t circumvent the system. OPWDD needs to be clear as to what can and cannot happen from the start.</p> <p>Other areas of discussion included:</p> <ul style="list-style-type: none"> <li>○ There is a need for a reliable toll-free phone number to call for assistance.</li> <li>○ NYSARC system should be looked at.</li> <li>○ We need to define and measure quality but don’t “teach to the test”.</li> <li>○ Give providers an incentive innovation to provide self-direction.</li> </ul>
<p><b>Review and discuss Behavioral Supports and Services Technical Workgroup Recommendations</b></p>	<p>The Behavioral Supports and Services Workgroup was lead by Jill Pettinger. This workgroup assisted the Benefits and Services Team in answering Charter Question #8. <i>See Behavioral Supports and Services Preliminary Workgroup Report for full details.</i></p> <p>Workgroup Preliminary recommendations on behavioral supports and services to the Benefits and Services Design Team included:</p> <ul style="list-style-type: none"> <li>○ The People First Waiver presents a strategic opportunity to provide a continuum of behavioral supports and crisis services to people with DD/ID, the available behavioral support options must be expanded.</li> <li>○ The use of structured, individualized assessment and planning standards is essential to determining the most appropriate course of treatment and intervention for individuals.</li> <li>○ Behavioral support capacity within all service settings as well as for individuals who self direct, must be available</li> </ul>





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	<p>and delivered as needed based on a consistent individual assessment.</p> <ul style="list-style-type: none"> <li>○ There must be increased community access to psychiatrists, psychologists, and other relevant practitioners with expertise in developmental disabilities. Partnerships must be created with behavioral health agencies and OMH to most effectively meet individual needs.</li> </ul>
<p><b>Presentation and Discussion of Charter Questions as Selected by Team Members</b></p>	<p>Each Team member selected a Benefits and Services Design Team Charter Question. Each Charter question was answered based on all of the research and conversations the Team has had in their five previous meetings.</p> <p><b><u>Charter Question 1- Presented by Laurie Kelley, Pat Dowse, and Myrta Cuadra-Lash:</u></b></p> <p><i>Consider all the services and supports currently available through OPWDD’s system and other systems for people with developmental disabilities:</i></p> <ul style="list-style-type: none"> <li>• <i>What are the services/supports that are generally working well for people?</i></li> <li>• <i>What are the services/supports that are not working that need to be simplified, enhanced, and/or redesigned?</i></li> <li>• <i>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.)?</i></li> <li>• <i>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?</i></li> <li>• <i>How can needs assessment and resource allocation reform facilitate greater access to supports and services?</i></li> <li>• <i>What role will needs assessment have in determining the types of supports and services that individuals have access to?</i></li> <li>• <i>How can self-direction and self-determination be expanded and enhanced?</i></li> </ul> <p>The Team discussed how the question <i>Consider all the</i></p>





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*services and supports currently available through OPWDD's system and other systems for people with developmental disabilities* is the wrong question to ask. The Teams' 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, safety issues, and it is hard to make other services work with each other.

It is misleading to present these services as working well – as a result this is not the right question to ask. The Team flipped the question – it is not an option of listing a service as “good” or “bad” it is the architecture and the holistic approach that are absent. The thinking of the Team has evolved beyond this question, and answering this question as it is written would reinforce repacking the services we have which is what we don't want to happen in the 1115 Waiver.

Other Team discussion in regard to barriers included:

- The methods of program delivery do not focus on persons' abilities but on a segment of their life or part of their day.
- Obtaining services is complex and overwhelming.
- Service delivery must be simplified.
- Regulations make living independently with severe disabilities impossible.

In regard to *what role will needs assessment have in determining the types of supports and services that individuals have access to*, the Team discussed:

- How the MISCC Assessment Committee reviewed assessment processes currently used in the state, evaluated their strengths and weaknesses, and developed specific recommendations to ensure that assessment processes promote “most integrated setting outcomes”;
- Assessments need to permit the person to easily articulate his or her preferences and ideas for successfully living in the community; and
- Assessments need to take into account a person's preferences and needs rather than solely assessing a





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person’s eligibility for a specific program or service.

**Charter Question #2 - Presented by Kate Bishop:**

*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?*

As individuals leave Developmental Centers (DC) the need for coordinated clinical supports is imperative to ensure they are successful in community based settings. The need for true person centered planning is especially important for people who have complex needs and should be at the core of the development of appropriate supports. The following areas are critical to meet the needs of people leaving DC settings:

**Care Coordination**

Effective coordination of care, in a person centered manner is critical to ensuring that complex needs are met.

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- Clinical coordination 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.
- Community based group and individual counseling – many individuals transitioning from DCs and those served in community settings rather than a DC, have a need for counseling opportunities to maintain a focus on relapse prevention, anger management and coping strategies

**Crisis 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 present with behavioral crises. Needs for crisis supports exist across a variety of settings, including family settings, independent living settings and in certified





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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 creating linkages for the ongoing provision of supports in line with the person’s needs.

**Behavioral supports**

The development of effective behavioral supports requires changes in practices to broaden the support to people in non-certified settings. Clinical supports need to facilitate the implementation of a plan across settings and provide consistent training to service providers and families. For behavior supports to be productive they need to be implemented consistently and monitored for effectiveness to achieve the desired personal outcomes for individuals and families.

**Residential Supports**

Person Centered Planning should drive the appropriate residential supports for people who are transitioning out of Developmental Centers and for people who are at risk of having 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 models of support and appropriate community based clinical supports individuals can be safely supported outside of segregated settings.

The Team discussed the above and made the following conclusions:

- It was recommended that there be standardized assessment of risk to determine the most appropriate level of support for individuals.
- While the concept paper identifies that the institutional capacity will be reduced to 300 opportunities, the team challenged the OPWDD to not set an arbitrary number and to focus on strategies to lessen the number of people in the highest level of support.
- The team recommended that there be a focus on





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building “bridges” in the transition from institutional to community focused supports and that the bridges seek to maximize continuity of clinical supports. Any movement needs to have a coordinated Team that involves community stakeholders.

**Charter Question #3 - Presented by Max Donatelli, Pasquale Ginese, and Fredda Rosen:**

*What are the barriers for individuals with developmental disabilities to move 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?*

Team discussion included:

- Lack of flexible funding; current funding is not responsive to changing needs and is tied to program “silos”.
- Access to decent, affordable housing in some areas of the state; OPWDD guidelines do not reflect actual costs in these areas; there is a particular need for housing that is accessible (all areas of the state).
- Concern about loneliness, isolation, vulnerability.
- Lack of thoughtful conversation around dignity of risk; the current environment is risk averse; there needs to be a way to balance safeguards vs. opportunity.
- Provider expertise limited to IRA model.
- IRA funding is richer.
- IRA model enables individual to receive congregate-care level SSI.
- Questions/concerns about how to do this for people who require nursing care or significant medical/behavioral supports.
- Large numbers on the wait list who need immediate placement; how to respond to need in an expeditious, thoughtful way
- Lack of connection to local resources that can be a source of support and relationships.





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Recommendations included:

- 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; individuals should be able to stay in their homes throughout their lives.
- 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/other arrangements to develop housing; create incentives to work with us and make the process simple and flexible; this issue is particularly important when it comes to accessible housing.
- Financial planning with families/self-advocates around funding housing opportunities.
- Continue/expand ISS-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 need for safeguards
- Explore models that capitalize on natural and community membership (key rings; Big Tent; neighborhood-based clusters).
- 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.

**Charter Question #4 - Presented by Karen Gillette and Deb Bojarski:**

*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)?*





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Team discussion focused on the current service system and how it is not designed to provide more generous funding for persons not living with families; e.g. residential schools and certified sites. Recommendations included:

- Develop a tool that adequately assesses need and the allocation of service dollars, which encourages 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.

In addition, the Team discussed Individuals with behaviors at home, which are disruptive to the family unit.

Recommendations included:

- Develop intensive in-home behavioral services for family unit.
- When necessary, admit individual to a time-limited intensive treatment program, with the goal of re-uniting the family as quickly as possible.
- Increase the availability of Habilitative supports for families; e.g. Community Hab 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 available family counseling to assist families remain intact.
- Provide assistive technology to meet both safety and communication needs.

Another topic was the isolation of families.

Recommendations included:

- Coordinate with agencies to extend natural connections





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- and nurture relationships in the community.
- Develop ability for families to create networks with others within walking/driving distance to provide support to each other as well as respite.

**Charter Question #5 - Presented by Margaret Mikol and Joann Dolan:**

*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)?*

Team discussion and recommendations included the following:

- Develop Life Transitions Model whereby case management coordinates transitions and cross-system care over a lifetime as appropriate.
- Ensure access to the professional disciplines that can satisfy program eligibility in a timely manner.
- Create accountable timely systems for approvals within OPWDD, ensuring smooth transitions that are not held up.
- Provide help line at central office level to assure information is consistent.
- Ensure equal access and choice by centralizing opportunities for service. Eliminate agency based allocations.
- Create problem solving liaisons between systems that families and children encounter at specified times of transition.
- Create understanding and knowledge base with OPWDD system so information is consistent.
- Create user-friendly access to data and information about OPWDD and Cross- Services. Include print, web site, CDs. that can easily be used by individuals, families, MSC coordinators.
- Recognize limited specialized workforce and make the field more attractive and employment opportunities available.
- Cross-service care and funding mechanisms support transitions, particularly those with dual diagnosis, ASD, and serious medical conditions. Waiver must be





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	<p>dynamic and change with the needs of the child and family.</p> <ul style="list-style-type: none"> <li>○ Enable behavioralists of choice to work between all environments and community settings.</li> <li>○ Provide transitional housing for individualized environments that improve behaviors and/or independence; and for individuals/families that are homeless or in poverty that may need to stabilize before moving to permanent housing.</li> <li>○ Transition supports should include cultivation of support circles, natural community supports, and neighborhood resources. Start at an early age to support citizenship, community involvement and community membership.</li> <li>○ Adult transition supports for a self-determined life should include customized job supports, individualized home settings, life sharing, mentoring, and advocacy.</li> <li>○ Offer training and support to high school students with DD, ages 14-21, and their parents, grandparents, caregivers, teachers and counselors. Information should provide clear and simple ways to explore options.</li> <li>○ Make transition choices more flexible for easier change.</li> <li>○ Incorporate assistive technology at earliest age possible with continuum to assist on different developmental levels. i.e., for communication, travel training, “smart homes”, medical needs, etc.</li> <li>○ Look at OMH’s Supportive Education Model (job coaching).</li> </ul> <p><b><u>Charter Question #6 - Presented by Rick Ianello and Susan Platkin:</u></b></p> <p><i>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?</i></p> <p>A better rewrite of the question is: <i>How can family support be strengthened to strengthen families?</i></p> <p>The Team discussed how the 1115 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 Team discussed in-depth and agreed that the</p>
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process should *not* be grant driven. Families need to be a part of the individuals’ life, no matter where the individual lives. Family support needs to be person-centered and needs to look at the whole continuum of services. We should not think of family support as a separate model or grant service – we need to make sure funds follow the person. Also, we don’t 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 they go into a group home or setting. We need to be flexible with resources so individuals are connected to their family.

**Charter Question #7 - Presented by Ceylane Meyers-Ruff:**

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

**See above Employment First Services/Supports Technical Workgroup Recommendations.**

**Charter Question #8 - Presented by Amy Anneling and Sharon Rockwell Linne:**

*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?*

**See above Behavioral Supports and Services Technical Workgroup Recommendations.**

Crisis intervention services need to be accessible when a person with developmental disabilities is in jeopardy of losing any placement (home, residential, school, or day treatment) or when there is an immediate concern for safety of the individual and/or caregivers. The Team discussed the following:

- Enhanced respite - This requires relief from current regulations.





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- Enhanced community habilitation services should be staffed with employees who have received specialized training in managing challenging behaviors and crisis prevention and intervention.
- Mobile crisis supports are needed with trained staff (including behavioral and psychiatric consultants) and need to be available 24/7/365 to assist.
- Emergency respite or crisis diversion beds on a timely basis to prevent an in-patient admission when appropriate.
- Incentives for providers to develop programs for the hard-to-serve population. People who have behavioral challenges need strong support both at home (whether it's an IRA or other living arrangement) and for day programs.

**Charter Question #9 - Presented by Suzanne Sennett:**

*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 Team had a very thoughtful discussion regarding cost-sharing and recognizes the importance of discussing this topic with the Fiscal Sustainability Team.

Cost-sharing is a slippery slope for parents. There are parents who could afford to contribute but should that be incumbent upon these parents vs. parents who do not have a child with DD? This needs to be looked at very carefully and thoughtfully as the 1115 Waiver is submitted to CMS.

To some extent, is it possible that the structure of the 1115 Waiver will obviate this issue? Instead of cost-sharing from the concept of shared billing, start from the person-centered approach, as families/natural supports can help more and do not have to budget for specific services.

Team discussion also included:

- Cost-sharing will require changing the infrastructure





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	<p>of SSI.</p> <ul style="list-style-type: none"> <li>○ Who is going to regulate this cost-sharing arrangement?</li> <li>○ If there is cost-sharing, we will end up with a two tiered system (for those who can contribute and those who cannot).</li> <li>○ For the parents who have the ability, there should be a way for parents to contribute. The problem is that this contribution will be unearned income. The 1115 Waiver needs to waive this and allow individuals/families to contribute without getting penalized.</li> </ul>	
<p><b>Discuss Design Team Preliminary Recommendations to Steering Committee Report</b></p>	<p>The Team discussed the draft Preliminary Report to the Steering Committee. The Team had a few minor revisions.</p>	
<p><b>Next Steps</b></p>	<p>The team will reconvene on 08/29/11 to discuss feedback from the steering committee.</p>	
<p><b>Action Items</b></p>		
<p style="text-align: center;"><u><b>Action Item</b></u></p>	<p style="text-align: center;"><u><b>Owner</b></u></p>	<p style="text-align: center;"><u><b>Due Date</b></u></p>
<p>Send out final Preliminary Steering Committee Report to Team</p>	<p>Angela Lauria-Gunnink</p>	<p>08/23/11</p>
<p>Send out all relevant meeting materials, including 08/16/11 meeting summary, prior to August 29 meeting to Team</p>	<p>Angela Lauria-Gunnink</p>	<p>08/25/11</p>
<p><b>Additional Documents of Reference</b></p>		
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**Upcoming Team Meetings:**

August 29, 2011    OPWDD Room 4B

