



**Care Coordination Design Team
Submitted to the People First Waiver Steering Committee
August 24, 2011**

Team Meeting Dates:

- June 20, 2011
- July 13, 2011
- July 27, 2011
- August 10, 2011
- August 31, 2011

Contents

Executive Summary	2
Introduction	3
Team Recommendations	4
Follow-up Design Questions.....	10
Appendix A – List of Team Members.....	11
Appendix B – Team Charter.....	12
Appendix C – Resources Used by the Team.....	14
Appendix D – Essential Components of Care Coordination	15



Executive Summary

Through discussion, research, and analysis, the Care Coordination Design Team made recommendations for comprehensive care coordination within a care management environment for all people with developmental disabilities. The team looked for ways to ensure that individualized and person-centered principles are the primary focus of the coordinating entity and that individuals with developmental disabilities and their families have access to trained, competent professionals to guide them through multiple service options and systems in order to access supports that are streamlined and best meet their needs. The following is a short description of the team’s recommendations for care coordination. Please see Appendix D on page 15 for a more detailed list of recommendations.

Key Design Elements of Care Coordination:

Access to the System	Individuals must have access to the right level of care coordination which addresses individual needs and provides a consistent means to access coordinators when needed, including hours outside of regular business. Coordinators must have knowledge and expertise of service systems local to the individual.
Care Coordinator Qualifications	Each individual will have access to a core care coordination team with a designated team lead that has expertise in working with people who have developmental disabilities. In addition, the coordinating entity will recruit and hire a panel of professionals with different expertise and specialty backgrounds, i.e., nurse, education specialist, employment expert. These professionals will be available to participate on care coordination teams as dictated by the individual’s care plan. Each member of this team should know the individual.
Cross Systems Coordination	The care coordination panel of experts must maintain an understanding of other service systems that could assist in meeting the needs of individuals with developmental disabilities.
Person-centered Plans	True person-centered methodologies must be utilized when creating an individual’s plan. Policies, guidelines, and tools to create the person-centered plan must elicit individual goals and outcomes and incorporate benchmarks to ensure that progress is made in the achievement of these goals and outcomes. The individual service plan must articulate outcomes agreed upon by the individual, and the care coordination team.
Stable and Responsive Organizational Structure	Coordinating entities should have access to a stable and predictable reimbursement structure. The structure of the coordinating entity must be flexible and responsive to individual needs as they change over time.
Quality	Results of surveys should be transparent to individuals and families. Quality measures should look at culture change as well as achievement of individual’s goals. Benchmarks should be determined at the assessment level with outcome measures tracked within care coordination.
Advocacy	A separate advocacy arm is being recommended, but care coordinators, as MSCs do now, will continue to have to support an individual’s decisions and to campaign to get needed services.
Willowbrook	Members of the Willowbrook class must be kept in mind as there are specific rules and injunctions regarding this group.



Introduction

The care coordination design team took a collaborative approach to meet the identified goals in the charter and recommend essential components of care coordination. The group began by examining the current service system and how coordination of services is provided to people with developmental disabilities. The group then identified areas of needed improvement in the current system, which helped to provide a structural framework for elements in a future system. Some identified areas for improvement were:

- The need to access services proactively to avoid crisis situations
- Balance the right level of support with the needs of the individuals
- High caseloads and turnover rates for service coordinators
- Limited service coordinator education and awareness of issues specific to individuals' needs
- Difficulty in finding entities and service coordinators that really understand self-direction and self-determination
- Concern over potential conflict of interest when care coordination and direct service provision are provided by the same entity

After analyzing the current system, the group examined existing models of managed care in order to understand the impact of moving away from a fee-for-service system. Models examined and discussed include:

- Program for All Inclusive Care for the Elderly (PACE)
- Health Homes, particularly as detailed in the Department of Health State Plan Amendment
- Managed Long Term Care
- Systems in other states including Colorado, Wisconsin, Arizona, North Carolina, and Vermont
- The Social Work Leadership Institute

The group utilized this discussion to create a list of essential components for care coordination in a care management environment. The care coordination design team recognized the need to create a proactive frame of reference when designing a system for care coordination that connects individuals to all needed service systems as well as natural supports as individuals face changing needs in life. Major themes that emerged through discussion regarding essential components of care coordination were:

- Choice
- Independent advocacy
- Concern regarding conflict of interest
- Focus on local support
- Support for self-determination and individual budgets



Team Recommendations

- A. Charter Question 1: What is not working in the current service coordination model(s) for people with developmental disabilities?
- a. Succinct answer: Medicaid Service Coordinators (MSCs) do not have enough knowledge of available services or the expertise to know which services will best fit the needs of the individual. MSCs often do not have enough time to complete a plan that is person-centered because the person needs to have the services delivered immediately. There is a lack of continuity of care due to high turnover rates and lack of a backup when the regular MSC is unavailable.
- b. Expanded explanation: The current service coordination model currently operates in such a way that individuals enter the system when they are in an emergency situation and need services immediately. This type of entry into the system does not allow service coordinators to complete a plan using a person-centered methodology in a comprehensive manner. The care coordinator position needs to be defined by training, experience, and educational standards that recognize it as a professional level job. Care coordinators need to receive a level of compensation that is competitive so that staff choose the job as a career and not as entry into the system. Because the service coordinator position is often viewed as entry level, but can be very demanding, there is a lot of turnover that is not taken into account, leaving individuals without the continuity of care that is necessary for them. In addition, MSCs often do not have the tools, access, or training available to them to know which services and supports are available in a community or which of these services and supports will best meet the needs of the individuals they serve. While the present system expects the MSC to fill the role of advocate for the individual, often the MSC has limited authority and oversight to assure the services received are in fact appropriate for the individual they are supporting. The service system itself is fragmented, and there is little communication between an individual's current HCBS Waiver services, the State Plan services, or the medical services that an individual receives. This can result in redundancy in service delivery and oversight.
- c. Key issues: The design team felt that too much time was spent on compliance and not enough time was spent on planning for quality outcomes. In many areas of the MSC model, the program rules have become prescriptive as opposed to guiding, leading many MSCs, it was felt, to focus more on ensuring that paperwork and caseload levels are correct rather than on person-centered planning and ascertaining needed services. A care coordination program should deliver services based on the needs of the individual, and provide training to care coordinators so they are able to recognize the services and supports that would best fit an individual's needs. Care Coordination also needs to have guidelines and standards that are consistent throughout the state.



- B. Charter Question 2: What considerations should be integrated into any model of comprehensive care coordination/case management for people with developmental disabilities (and various subpopulations, e.g., children, aging, forensic/risk, medically involved, medically frail, etc.) in a care management environment?
- a. Succinct answer: The individual should continue to have a choice between care coordinators and care coordinating entities where available. Individuals should play the central role in choosing who should provide the services to them, and the care coordinating entity should attempt to honor that choice where possible. While some sort of advocacy needs to be a part of care coordination, it was felt that an independent advocacy arm is important to ensure that an individual is being heard throughout the process. There was also the belief that as the care coordinator will be arranging all of the services and supports, it is important for there to be a care coordinating team.
 - b. Expanded explanation: Although it is understood that choice is always limited, individuals should have a choice between providers where available. The team felt that this could be done by requiring managed care entities to have contracts with a certain number of providers based on the demographics of the area. In addition, the managed care entity should try to honor an individual's choice of provider as often as possible.

For the care coordination team, the coordinating entity will recruit and hire a panel of professionals with different expertise and specialty backgrounds, i.e., nurse, education specialist, employment expert. These professionals will be available to participate on care coordination teams as dictated by the individual's care plan. The care coordination panel of experts must maintain an understanding of other service systems that could assist in meeting the needs of individuals with developmental disabilities, for example Early Intervention (EI), Office of Mental Health (OMH), New York State Education Department (NYSED), Office of Children and Family Services (OCFS), etc. There must be a balance between mandating membership on a care coordination team and allowing the flexibility of having the team members there only when needed. The coordinating entity must allow individuals the ability to choose which experts participate on their care coordination team and to switch team members.

An advocacy body should be established that is separate from the Developmental Disabilities Individual Support and Care Organization (DISCO), care coordination entity, and service providers. However, in addition, the coordinating entity should have available representation from self-advocates, families of people with developmental disabilities, and experts in cultural diversity and language to provide expertise and advocacy as needed. Quality measures can be implemented that ensure a component of advocacy is in the care planning process.

- c. Key issues: There is a concern that requiring a team could become pro forma, so it is important to emphasize that the team should be flexible and that requirements do not become so rigid as to have team members that are not necessary for an individual's care.



- C. Charter Question 3: How should care coordination reimbursement be structured/compensated (e.g., provider-based regional care management/coordination models that specialize in the needs of people with developmental disabilities and take responsibility for managing care and are reimbursed on an individual budgeting, global budgeting, or capitation basis)? How could OPWDD establish pilots and demonstrations such as a Program for All-Inclusive Care for the Elderly (PACE) capitation model?
- a. Succinct answer: Reimbursement for care coordination does not necessarily have to be universally applied through the administrative cost, but should be based on the level of care coordination that a person needs. Reimbursement needs to ensure that outcomes are met and that this methodology does not penalize those with more complex care coordination needs.
 - b. Expanded explanation: The care coordination reimbursement should not be considered part of the administrative cost of the overall Per-Member-Per-Month reimbursement (PMPM). The reimbursement should be responsive to the level of care coordination that a person needs, and this level should be based on an assessment that outlines the level of care coordination a person might require. Reimbursement should also be responsive so that if a person's needs change, the care coordination entity is not penalized for providing more complex care coordination. The design team recognizes the importance of this issue and would like to see some pilot projects that provide for reimbursement of care coordination through different structures to see which ones ultimately provide for the best outcomes for an individual.
 - c. Key issues: Having care coordination considered an administrative cost gives it a "flat" reimbursement structure that does not provide any incentive for entities to ensure that individuals with more complex needs have the care coordination that they require. It also gives the appearance that care coordination is not as valuable as other supports and services. However, as care coordination is at the forefront of the process of accessing services and supports for an individual, the reimbursement methodology must recognize the importance of care coordination and have a structure that compensates for this vital component within a person's care.



- D. Charter Question 4: How can comprehensive care coordination enhance person-centered planning, individual responsibility, and self-determination (also relates to the Benefits Design Team)?
- a. Succinct answer: To achieve self-determination, all individuals must be offered self-determination as a choice. To enhance person-centered planning and individual responsibility, the assessment tool and other planning instruments must be completed prior to a plan being written and before services delivery begins so that a care coordinator and individual have the time to discuss and design the service package to meet the individual's needs and balance that with what the individual wants.
 - b. Expanded Explanation: To assist with better person-centered planning, screenings and assessments need to occur before a service is provided. If the assessment comes first and the plan is written based on this assessment, then care coordinators will have the time to properly create and write a plan using person-centered methodologies. Services will no longer be implemented before the plan is written, often times in a rushed state, to reflect those services. Policies, guidelines, and tools need to be created so that the person-centered plan elicits individual goals and outcomes and incorporates benchmarks to ensure that progress is made in the achievement of these goals and outcomes. Care coordinators and care coordination team members need to be trained and have ongoing training regarding how to carry out person-centered planning with an individual. Care coordinators should be required to have training on person-centered methodologies prior to beginning work. There should also be ongoing training to keep care coordinators' skill in person-centered planning up-to-date.

The care coordination team must have an understanding of self-determination in the developmental disabilities system. All individuals must be offered the choice of self-directing services. It would then be the responsibility of the care coordinator and care coordination team to find the best way to honor that choice. It is understood that the extent that an individual directs his/her services will vary. To ensure that self-determination is being offered, self-advocacy and self-determination training should be required for care coordination team members

- c. Key issues: Requiring that self-determination be offered to all individuals would be new, and the managed care entity, care coordination entity, and direct service providers would need training on how self-determination for an individual works. The process for writing the plan will change as it will start with an assessment that identifies the unmet needs of the person and then identify the services and supports that will be put into place after that. Care coordinators will need additional training to understand how to determine that an individual is receiving the right amount and type of services. It will be absolutely imperative for care coordinators to know or have access to experts who know all of the types and services and supports available.



- E. Charter Question 5: How can we better incorporate the strengths of the family in the development of the comprehensive care plan?
- a. Succinct answer: Families need to be part of the care planning process from the beginning. Family members may be part of the individual's team and have the option of being on the panel of experts so that they can assist other families and individuals in the care coordination process. Care coordination needs to engage families in person-centered planning early in someone's life before there is an emergency. Families, who are in a crisis, may find it more difficult to see how their strengths can help to support an individual. In addition, care coordinators need to find the services that will maintain and buttress those natural supports, instead of finding services that replace the natural supports already in place.
 - b. Expanded Explanation: The coordinating entity should have available representation from self-advocates, families of people with developmental disabilities, and experts in cultural diversity and language to provide expertise and advocacy as needed. These types of representatives allow for a care coordinator to be better informed about the individual's life and how his/her family play a role in that life. These representatives will give assistance in understanding the diverse population of individuals being served.

In addition, individuals need to be identified before the need for formal services becomes critical. A care coordination entity should complete outreach to other systems serving individuals with developmental disabilities, such as schools and Early Intervention, prior to individuals leaving those systems to ensure continuity of care. This will allow for care coordinators to know the needs of the individual before other services are discontinued.

Finally, after an assessment identifies an individual's needs, the care coordinator needs to use a strengths-based approach to identify where those needs are already being met. Such an approach will help to assure that natural supports are being integrated into the plan, and services are not being put into place that would replace a family's or community's involvement.

- c. Key issues: Currently MSCs do not have available a state-wide tool that would assist them with clearly identifying where natural supports, such as families, are already meeting an individual's needs. This type of tool would need to be developed and made accessible to care coordinators. In addition, the relationships between the developmental disabilities service system, schools and Early Intervention are often not in place and would need to be cultivated to ensure that care coordination entities are aware of individuals as they leave these systems, so that individuals and their families are not left without any services or support.



- F. Charter Question 6: What are quality and individual outcome measures that could be used to demonstrate effective comprehensive care coordination (also relates to the Quality Design Team)?
- a. Succinct answer: The plan of care is developed based on an individual's assessed and desired health, functional and personal outcomes; it is delivered through a comprehensive care coordination approach with the ultimate goal of improving the quality of life for the person receiving supports. Measurable benchmarks will be established based on the Essential Components Chart in Appendix D.
 - b. Expanded Explanation: Quality measures that are based on outcomes will help to guarantee that caseload levels are kept at a manageable level, that coordinators know what services are available and have accessed them for the individual, that person-centered methodologies are being used, and that opportunities for individuals to maintain and establish relationships are supported and nurtured. Quality measures will include the care coordination entity's ability to access and utilize natural supports, offer and implement self-direction/self-determination for individuals, and the policies and procedures in place to address an individual's complaints, grievances, and changing needs. Quality outcomes may be gathered through surveys and the results of surveys should be transparent to individuals and families. Quality measures should look at culture change as well as achievement of each individual's goals, for example, moving all individuals to the least restrictive setting. Measurable benchmarks developed at the assessment and level-of-need determination should drive the tracking of personal outcomes.
 - c. Key issues: Measurable outcomes that reviewers can also use will need to be developed and put into place so that it can be clear if person-centered methodologies are being used. A quality scale for the DISCO and care coordinating entity will need to be developed in the same format as the Quality Scale for service providers as created by the Quality Design Team.



Follow-up Design Questions

Design Questions

The Care Coordination Design team listed the following questions/issues that need to be answered as OPWDD defines the next steps in furthering the final design of this aspect of the waiver.

- How will assessment information be gathered and made available for the care coordination team?
- What connections will need to be made to ensure that, as an individual's needs change, a new assessment is completed, and changes are reflected in an individual care plan?
- Should the care coordinating entity be able to provide services and coordinate care for the same people?
- How does the system ensure that service delivery is not impacted when there is an increased need for care coordination?
- How will the system ensure a smooth transition to coordinating care for medical needs?
- How will the system ensure that an individual has a choice of provider, particularly in areas of the state where there is limited choice?
- How will self-determination be assured in the People First Waiver?

Recommended pilots

The Care Coordination Team recommends that OPWDD consider the following pilots projects to address design questions raised by the design team.

- *Design Question:* How does the system ensure that service delivery is not impacted when there is an increased need for care coordination?
- *Recommended Pilot Structure:* Develop two methods of paying for care coordination:
 - Reimbursement for care coordination is included in the PMPM capitated payment to the coordinating entity. This rate is inclusive of care coordination and service provision.
 - Reimbursement for care coordination is exclusive of service provision and is not impacted as an individual's service needs change over time.
- *Hypothesis:* The pilot structure with an exclusive reimbursement for care coordination will allow for greater flexibility and advocacy in the coordination of services and will protect dollars needed for service provision.
- *Possible pitfalls:* The pilot structure with an exclusive reimbursement for care coordination may:
 - Limit the care coordination made available for people who have very expensive or extensive needs for care coordination, or
 - Mean that resources are tied up in care coordination for people who don't need a lot of care coordination support and would rather have those resources directed to other services.



Appendix A – List of Team Members

- **Jill Gentile**, Associate Commissioner, OPWDD Team Leader
- **Robert Budd**, Executive Director, Family Residences and Essential Enterprises (FREE), Co-facilitator
- **Maria Bediako**, Deputy Director NYCRO, OPWDD
- **William Bird**, CNY DDSO, Director of Community Support, OPWDD
- **Jane Davis-Bunt**, Vice President/Chief Operating Officer, Ability Beyond Disability
- **Nick Capoletti**, Executive Director, NYS Mental Retardation and Developmental Disabilities Advisory Council (MRDDAC)
- **Donna Colonna**, Executive Director, Services for the Underserved
- **Patrick Dollard**, Executive Director, Center for Discovery
- **Marcia Heckel**, Developmental Disability Program Specialist, OPWDD
- **Maggie Hoffman**, Parent
- **Paloma Hernandez**, President and CEO, Urban Health Plan
- **Michael Kennedy**, Self Advocacy Association of New York State
- **Hope Levy**, Assistant Executive Director for Workforce Development, Interagency Council of Developmental Disabilities Agencies, Inc
- **Robert Lopez**, Deputy Director of Community Services, OPWDD
- **Michael Mascari**, Executive Director, AHRC, Nassau County Chapter
- **Michael Northrop**, Self Advocate, Self Advocacy Association of New York State
- **Eric Pasternak**, Statewide MSC Coordinator, OPWDD
- **Carol Rodat**, New York Policy Director, Paraprofessional Healthcare Institute
- **Anne Swartwout**, People First Waiver Team Member, OPWDD
- **Jeff Wise**, Chief Executive Officer, New York State Rehabilitation Association, Inc.
- **Susan Wanamaker**, Parent, Speech Pathologist, Broome DDSO
- **Sheryl White Scott**, Medical Director, Brooklyn DDSO, OPWDD



Appendix B – Team Charter

Care Coordination: The purpose of the Care Coordination Design Team is to make reform recommendations that will result in comprehensive care coordination within a care management environment for all people with developmental disabilities. The recommendations of this team will ensure that individualized and person-centered principles (goals, choice, rights, self-determination) direct how Medicaid and non-Medicaid primary and acute health care, behavioral health care, and long-term care services will be planned and coordinated between multiple service systems through “No Wrong Door” and with an effective and flexible comprehensive written care plan to coordinate and monitor quality of services.

1. What is not working in the current service coordination model(s) for people with developmental disabilities?
2. Under the People First Waiver the current service coordination model will be transitioned to one or more comprehensive care coordination/case management models in a care management environment. What considerations should be integrated into any model of comprehensive care coordination/case management for people with developmental disabilities (and various subpopulations, e.g., children, aging, forensic/risk, medically involved, medically frail, etc.) in a care management environment?
 - Consider whether the person’s needs assessment should correlate to the type/intensity/level/model of comprehensive care coordination.
 - What choices should the individual have (e.g., choice of care coordination providers; choice of services provided under the care coordination model; choice of health, behavioral health and/or long-term service providers; and choice of specific services and resulting outcomes to be delivered through the People First Waiver)?
 - Consider roles and responsibilities of the care coordination provider and person(s) delivering the service (must address assurance and monitoring of health and safety (a component of the HCBS quality framework)).
 - What are the components of the system that should be independent from comprehensive care coordination (e.g., service authorization, resource allocation, service delivery, etc.)?
 - Given that advocacy is an important component of the current service coordination model, how should this function be addressed in a comprehensive care coordination model?
3. In conjunction with the Fiscal Sustainability Design Team, how should care coordination reimbursement be structured/compensated (e.g., provider based regional care management/coordination models that specialize in the needs of people with developmental



disabilities and take responsibility for managing care and are reimbursed on an individual budgeting, global budgeting, or capitation basis)? How could OPWDD establish pilots and demonstrations such as a Program for All-Inclusive Care for the Elderly (PACE) capitation model?

4. How can comprehensive care coordination enhance person-centered planning, individual responsibility, and self-determination (also relates to the Benefits Design Team)?
5. How can we better incorporate the strengths of the family in the development of the comprehensive care plan?
6. What are quality and individual outcome measures that could be used to demonstrate effective comprehensive care coordination (also relates to the Quality Design Team)? What are quality and individual outcome measures that could be used to demonstrate effective comprehensive care coordination (also relates to the Quality Design Team)?



Appendix C – Resources Used by the Team

- Social Work Leadership Institute, Division of the New York Academy of Medicine. (2008, October). *Toward the Development of Care Coordination Standards: An analysis of Care coordination in Programs for Older Adults and People with Disabilities*. Prepared for NYS Department of Health and the NYS Office for the Aging. October 2008. Retrieved from <http://www.searchedac.org/resources/NYS%20DOH%20SOFA%20Care%20Coordination%20Report.pdf>
- Colorado Department of Public Health and Environment. (August 2010). *HCP Care Coordination Policies and Guidelines*. Retrieved from <http://www.cdphe.state.co.us/ps/hcp/form/carecoordination/HCP%20Care%20Coordination%20Forms%202010/6-1-10%20HCP%20CC%20Policy%20and%20Guideline.pdf>
- New York State Department of Health. (2011, July 30). *Draft NYS Health Home State Plan Amendment for Individuals with Chronic Conditions*. Retrieved from http://www.health.state.ny.us/health_care/medicaid/program/medicaid_health_homes/docs/nys_health_home_spa_draft.pdf
- Journal of Ambulatory Care Management. (date). *Independence Care System: A Disability Care Coordination Organization in New York City*. Retrieved from http://www.icsny.org/in_the_news_01.pdf
- Kaiser Foundation. (date). *Medicaid's New Health Home Option*. Retrieved from <http://www.kff.org/medicaid/8136.cfm>
- CHCS Centers for Health Care Strategies, Inc. (date). *Care Management Definition and Framework*. Retrieved from http://www.chcs.org/usr_doc/Care_Management_Framework.pdf
- Medical Care Research and Review. (date). *The Cost-Effectiveness of Noninstitutional Long-Term Care Services: Review and Synthesis of the Most Recent Evidence*. Retrieved from <http://www.npaonline.org/website/download.asp?id=1656>
- The Millbank Quarterly. (date). *Program Characteristics and Enrollees' Outcomes in the Program of All-Inclusive Care for the Elderly (PACE)*. Retrieved from <http://www.npaonline.org/website/download.asp?id=2109>



Appendix D – Essential Components of Care Coordination

Essential Components of Care Coordination	Recommended OPWDD Policies	Quality Metrics*
Access to the System		
Care Coordinator has expertise and knowledge of services and the community in which the individual lives.	<ul style="list-style-type: none"> • There should be a regional component to the structure of the coordinating entity to assure that the care coordination team understands local issues important to individuals such as transportation, availability of providers, Willowbrook entitlements for services, etc. • Care Coordinating entities should have procedures and methodologies in place to assist care coordinators in finding and developing neighborhood resources. 	<ul style="list-style-type: none"> • Does the coordinating entity have a presence in the local communities of the individuals it serves? • Does the coordinating entity have policies and procedures to address local issues important to individuals? • Does the coordinating entity have policies and procedures in place to assist care coordinators in finding and developing neighborhood resources? • How does the coordinating entity measure demonstrated participation in community events?
Individuals gain access prior to crises occurring.	<ul style="list-style-type: none"> • To ensure continuity of care, care coordination entity will complete outreach to other systems serving individuals with developmental disabilities, such as NYSED and Early Intervention, prior to individuals leaving those systems. 	<ul style="list-style-type: none"> • Does the coordinating entity have policies and procedures in place to conduct outreach efforts to and within other systems? • Does the coordinating entity measure the number of crises that occur and the number of successful outcomes?
Individuals need to receive the right amount of service (not too much or too little).	<ul style="list-style-type: none"> • There should be a balance between mandating membership on a care coordination team with allowing the flexibility of having the team members there only when you need them. • The coordinating entity must allow individuals the ability (1) to choose which experts participate on their care coordination team and (2) to switch team 	<ul style="list-style-type: none"> • Does the coordinating entity have policies and procedures in place to: • Allow the individuals to choose coordination team members? • Switch team members?



Final Care Coordination Design Team Recommendations

	<p>members.</p> <ul style="list-style-type: none"> • The level of care coordination provided should be based on the level of need identified in the assessment and the person’s need at the time of coordination. • Care coordinating entities will need to ensure that any court ordered entitlements are met and provided to the individual. 	<ul style="list-style-type: none"> • Match assessed need with level of care coordination? • Utilize independent advocacy to address areas of concern with service planning? • Address and resolve issues when an individual is unsatisfied with the amount of service? • Does the coordinating entity have a review and appeals process? Does this process allow individual to exercise freedom of choice?
<p>Care coordinators need to be available in a timely manner and must provide backup when the regular coordinator is not available.</p>	<ul style="list-style-type: none"> • Each individual will have access to a core care coordination team with a designated team lead that has expertise in working with people who have developmental disabilities. Each member of this team should meet/know the individual. • Care coordinating entities need to have back-up plans and crisis response protocols developed to have a coordinator available 24 hours a day and procedures to access services in emergency situations. Care coordinating entities will determine when emergency services are necessary and then determine where those services can be accessed. 	<ul style="list-style-type: none"> • Have all members of the care coordination team met and gotten to know the individuals that they serve? • Do coordinating entities have a back-up plan and crisis responses developed? Is a coordinator available 24 hours a day? Are all members of the team familiar with and ready to implement individualized back-up plans and crisis responses? • Does the coordinating entity have policies and procedures in place to determine individual indicators of when emergency services are necessary and then determine what those services are and where they can be accessed? • Does the coordinating entity have an independent advocate available to audit back-up plans and crisis responses?



Final Care Coordination Design Team Recommendations

Care Coordinator Qualifications		
<p>Consistency in care (e.g. care coordinator's not keep changing).</p>	<ul style="list-style-type: none"> • Each individual will have access to a core care coordination team with a designated team lead that has expertise in working with people who have developmental disabilities. Each member of this team should meet/know the individual. • The designated team lead should not be considered an entry-level position. • The coordinating entity will recruit and hire a panel of professionals with different expertise and specialty backgrounds, (i.e., nurse, education specialist, employment expert). These professionals will be available to participate on care coordination teams as dictated by the individual's care plan. • The coordinating entity should have available representation from self-advocates, families of people with developmental disabilities (this would include families and individuals who are actually being served by the care coordinating entity), and experts in cultural diversity and language to provide expertise and advocacy as needed. • Mandating membership on a care coordination team should be balanced with the flexibility of having the team members there only when needed. • The coordinating entity must allow individuals the ability to (1)choose which experts participate on their care coordination team and (2)to switch team members. 	<ul style="list-style-type: none"> • Do the qualifications of the designated team lead show that he/she has a bachelor's degree and a history of working with people with developmental disabilities? • Does the coordinating entity have a panel of experts on staff and available to participate on care coordination teams as determined necessary by individuals' assessed need? • Does the coordinating entity have available representation from self-advocates, families of people with developmental disabilities, including families and individuals who are actually being served by the care coordinating entity? • Does the coordinating entity have available representation from experts in cultural diversity and language to provide expertise and advocacy as needed? • Does the coordinating entity have policies and procedures in place to determine when membership by experts on the coordinating team is necessary?
<p>Ability to manage caseloads effectively.</p>	<ul style="list-style-type: none"> • The coordinating entity will manage caseloads by allowing flexibility of the teams. Caseloads should be related to the intensity of individuals' needs. The coordinating entity will be responsible to balance care coordination resources, e.g. the higher the care coordination need, the lower the caseload. • Holding care coordination entities responsible for supporting individuals to meet their individual outcomes (i.e. quality) will help entities to keep case load levels reasonable. 	<ul style="list-style-type: none"> • Does the coordinating entity have policies and procedures in place to balance care coordination caseloads? • Does the coordinating entity have a method to measure and improve individual satisfaction with level of coordination received from the coordinating entity?



Final Care Coordination Design Team Recommendations

<p>Education and awareness of the individual’s needs, cultural background and the OPWDD population.</p>	<ul style="list-style-type: none"> • The designated care coordination team lead cannot be an entry level position. It is recommended that this individual have a bachelor’s degree or have a certain number of years of experience in the field and a demonstrated capacity to complete necessary care coordination tasks. The lead must meet this requirement, other team members cannot “make up” this experience & education. • Licensed professional on the care coordination team will be held to their professional licensing standards. • Team members have to meet regularly and everyone has to know the individual. 	<ul style="list-style-type: none"> • Do all licensed professional members of the care coordination team meet their professional licensing standards? • Does the coordinating entity have policies and procedures in place to assure that the coordinating team meets regularly? • Does the coordinating entity have an assessment of cultural competency?
<p>Ongoing training for coordinators.</p>	<ul style="list-style-type: none"> • Members of the care coordination team must receive continuing education as defined by OPWDD. Training topical areas should include person-centered methodologies, available services, and the needs of the DD population. • Licensed professionals on the care coordination team will be held to their professional licensing standards for continuing education and should not be restricted from assisting an individual if they have met their licensing standards. • There should be a central educational repository with a listing of all available trainings and a record of courses completed. • Standards for continuing education should not be prohibitive to implementation. • Ongoing training should include training that is specific to an individual’s needs (e.g. Ticket to Work, psychiatric-dual diagnoses). • Training shall include as appropriate information on the Willowbrook entitlements for services. 	<ul style="list-style-type: none"> • Does the coordinating entity have policies and procedures in place to assure that care coordination team receives continuing education as defined by OPWDD? •
<p>Understanding of self-direction.</p>	<ul style="list-style-type: none"> • The care coordination team must have an understanding of self-direction in the DD system. • Individuals must be offered the choice of self-directing services. If an individual chooses this option, the coordinating entity and individual must work together to determine the most appropriate way to support this 	<ul style="list-style-type: none"> • Does the coordinating entity have policies and procedures in place to assure that: <ul style="list-style-type: none"> ○ Care coordination team has an understanding of self-direction in the DD system?



Final Care Coordination Design Team Recommendations

	<p>choice.</p> <ul style="list-style-type: none"> • Require self-advocacy and self-determination training for care coordination team members, including individuals. • Care coordination entities should demonstrate that they have specific procedures for ensuring self-direction. 	<ul style="list-style-type: none"> ○ Individuals are offered the choice of self-directing services ○ Ensure self-direction • Does the coordinating entity provide or contract for the provision of self-advocacy and self-determination training for care coordination team members, including individuals?
<p>Standardized guidelines of care coordination for the individual.</p>	<ul style="list-style-type: none"> • Policies, guidelines, and tools used to develop, gather feedback on, and implement individual care plans should have some level of statewide standardization. • If a standard changes, care coordination entities and individuals must be made aware of the change. • Policies, guidelines, and tools should be available on the internet. • Tools should allow for a balance in spending time with the person and completing necessary paperwork. • Allow for methods and approaches to be flexible and not prescriptive so that innovative and effective approaches can be used to meet the needs of the individuals. 	<ul style="list-style-type: none"> • Does the coordinating entity utilize standardized policies, guidelines, and tools to develop, gather feedback on, and implement individual care plans? • Does the coordinating entity allow for methods and approaches to be flexible and not prescriptive so that innovative and effective approaches can be used to meet the needs of the individuals?
<p>Cross System Coordination</p>		
<p>There is no conflict of interest between coordination and service delivery.</p>	<ul style="list-style-type: none"> • There must be a firewall between the coordinating entity and the direct provider of services to avoid self-referrals and potential conflicts of interest. • The oversight entity must monitor the coordination of services and provision of services to ensure that conflict of interest is limited. • For areas where there are potential conflicts of interest, entities need to have processes in place for appeals, grievances, and training of individuals on these processes. 	<ul style="list-style-type: none"> • Does the coordinating entity have a firewall between the coordinating entity and the direct provider of services to avoid self-referrals and potential conflicts of interest? • For areas where there are potential conflicts of interest, does the coordinating entity have processes in place for appeals, grievances, and training of individuals on these processes? • How does the care coordination entity



Final Care Coordination Design Team Recommendations

		resolve conflicts of interest?
Holistic and comprehensive approach to services (i.e. services need to intersect and meet all parts of an individual's life.)	<ul style="list-style-type: none"> The coordinating entity will recruit and hire a panel of professionals with different expertise and specialty backgrounds, e.g., nurse, education specialist, employment expert. These professionals will be available to participate on care coordination teams as dictated by the individual's care plan. Respond to individuals as their needs change and be able to access and provide services as needs change (e.g. aging). Reevaluation of services based on a change in needs. 	<ul style="list-style-type: none"> Does the coordinating entity have policies and procedures in place to respond to individuals through life change such as (list is not comprehensive) <ul style="list-style-type: none"> Transition into school Transition out of school Residential changes Changing medical needs Aging Does the coordinating entity have policies and procedures in place to trigger a reassessment due to a change in needs?
Reduce the redundancies of oversight by other systems.	<ul style="list-style-type: none"> The care coordination panel of experts must maintain an understanding of other service systems that could assist in meeting the needs of individuals with developmental disabilities, for example Early Intervention, DOH, OMH, NYSED, NYSOFA, OCFS, etc. There needs to be access to all service systems to meet the needs of the individual and reduce redundancy. 	<ul style="list-style-type: none"> Does the coordinating entity have policies and procedures in place to ensure that the care coordination panel of experts maintains an understanding of other service systems that could assist in meeting the needs of individuals with developmental disabilities?
Care coordinators provide information on medical providers.	<ul style="list-style-type: none"> The coordinating entity will recruit and hire a professional with expertise in the medical needs of individuals with developmental disabilities and knowledge of medical providers in the region. This medical professional will participate in the panel of experts on the care coordination team as needed based on individual service plans. 	<ul style="list-style-type: none"> Does the coordinating entity have methods in place to recruit and retain professionals with expertise in the medical needs of individuals with developmental disabilities and knowledge of medical providers in the region?
Care Coordinators assist in locating and accessing natural and community resources.	<ul style="list-style-type: none"> A "community expert" could provide this portion of care coordination as a member of the care coordination team. Individuals should have a community inclusion strategy based on his or her 	<ul style="list-style-type: none"> Does the coordinating entity have procedures and methodologies in place to assist care coordinators in finding and



Final Care Coordination Design Team Recommendations

	<p>interests, preferences and need; person-centered frequency and variety; and documentation to confirm implementation.</p> <ul style="list-style-type: none"> • Care coordinating entities should have procedures and methodologies in place to assist care coordinators in finding and developing neighborhood resources. 	<p>developing neighborhood resources that allow for expanded participation and enhance individual quality of life?</p>
Care Coordinators assist the person in forming and sustaining relationships.	<ul style="list-style-type: none"> • Care coordination entities need to provide policies and strategies to care coordinators to assist them in helping individuals to develop and maintain relationships with families, friends, and others. 	<ul style="list-style-type: none"> • Does the coordinating entity have policies and procedures in place to assist the coordination team and the individual to create links for forming and sustaining relationships?
Availability of cross-system experts to assist the care coordinator.	<ul style="list-style-type: none"> • The coordinating entity will recruit and hire a panel of professionals with different expertise and specialty backgrounds, i.e., nurse, education specialist, employment expert. These professionals will be available to participate on care coordination teams as dictated by the individual’s care plan. 	<ul style="list-style-type: none"> • Does the coordinating entity have policies and procedures in place to ensure that the care coordination panel of experts maintains an understanding of other service systems that could assist in meeting the needs of individuals with developmental disabilities?
Person-centered Plan		
Tools and time to complete a plan using a person-centered plan.	<ul style="list-style-type: none"> • The person and family members must be essential and contributing members to the development of the care plan. • Screening and the assessment occur before a service is provided. The assessment comes first, and the plan is written prior to any services. Having the service does not drive the rush to complete the plan, i.e. to protect billing the ISP is written to “authorize” the service. • Need to have a process for a person-centered plan. • Reaching out to the person first and then planning for the services, will allow for the time and thoughtful completion of a plan. • Working with people before there is a crisis or emergency. 	<ul style="list-style-type: none"> • Are individuals, family members, and/or advocates included as an integral part of the coordination team when developing the person-centered plan? • If no existing family or advocacy support is available, does the coordinating entity <ul style="list-style-type: none"> ○ identify there is a need for that support? ○ assist the individual to access needed advocacy support? • Does the coordinating entity follow State guidelines for the completion of a person-centered plan?



Final Care Coordination Design Team Recommendations

<p>Individualized benchmarks to ensure that the plan meets the individual's outcomes.</p>	<ul style="list-style-type: none"> • True person-centered methodology is being utilized. • Policies, guidelines, and tools to create the person-centered plan must elicit individual goals and outcomes and incorporate benchmarks to ensure that progress is made in the achievement of these goals and outcomes. • Identified outcomes and benchmarks must be measurable. • The coordinating entity should put supports and services in place to achieve individual outcomes. • Outcomes need to be written that acknowledge the risk that an individual accepts when self-directing his or her own services. 	<ul style="list-style-type: none"> • Do plans reflect an accurate representation of individual goals and outcomes? • Do plans include benchmarks to measure outcomes? • Does the coordinating entity utilize the benchmarks to evaluate progress and performance? • Does the coordinating entity have policies and methodologies to evaluate the balance between the risk an individual accepts and the entity's responsibility to meet health and safety?
<p>Incentives to ensure that care coordinators deliver on outcomes.</p>	<ul style="list-style-type: none"> • There needs to be choice of care coordinators so that coordinating entities want to improve on outcomes so they don't lose out on serving individuals. • The individual service plan must articulate outcomes agreed upon by the individual and the care coordination team. • Results of surveys should be transparent to individuals and families. • Acceptable performance standards for the coordinating entity must be made available. • If performance measures are not met, monthly payments and/or operating licenses could be at risk. • Incentives should be provided when benchmarks and outcomes are met. 	<ul style="list-style-type: none"> • Are results of surveys transparent to individuals and families? • Does coordinating entity meet performance standards determined by the state?
<p>Choice needs to be available and the spectrum of choice is flexible based on the needs of the individual, including care coordination.</p>	<ul style="list-style-type: none"> • A core value of the DISCO and any coordinating entity should be to offer choice and make a reasonable effort to meet the individual's choice of service provider or care coordinator and/or delivery of services. • Coordinating entities must attempt to have a range of providers available to promote choice and allow for self-directions as often as possible. • The DISCO should be required to contract with a certain number of providers based on the demographics of the area. Individuals should be able to choose a functionally independent care coordinator if such a person is available. 	<ul style="list-style-type: none"> • Does the coordinating entity offer choice and make a reasonable effort to meet the individual's choice of service provider, care coordinator, and/or delivery of service? Can the entity provide proof of these efforts? • Does the coordinating entity contract with the minimum required number of providers for the demographic area?



Final Care Coordination Design Team Recommendations

		<ul style="list-style-type: none"> • Are individuals able to choose a functionally independent care coordination team lead?
Organizational		
Stable and predictable reimbursement structure.	<ul style="list-style-type: none"> • Reimbursement should be flexible and responsive to the individuals’ needs, so that if a person’s needs change, the care coordination entity is not penalized for providing more complex care coordination. • Reimbursement for care coordination should consider training as one of the elements included. • The assessment should impact the reimbursement that is received. 	<ul style="list-style-type: none"> • Does the care coordinating entity have fiscal viability?
Flexible and responsive to individual’s needs.	<ul style="list-style-type: none"> • Care coordination is reflective of an individual’s needs as they change over time. This means that, in a managed care environment, access to direct care and services is not impacted by whether a person needs more or less care coordination. • Technology needs to be in place so that a care coordinator can access and share medical records and planning records for better coordination and delivery of services. 	<ul style="list-style-type: none"> • Does the coordinating entity have policies and procedures in place to assure that coordination is reflective of individual’s needs as they change over time? What triggers are in place to indicate a change in need? • Does the coordinating entity have access to technology which allows for the: <ul style="list-style-type: none"> • Analysis of costs • Sharing of medical and planning records?
Quality		
Realistic and Measurable Outcomes.	<ul style="list-style-type: none"> • Policies, guidelines, and tools to create the person-centered plan must elicit individual goals and outcomes and incorporate benchmarks to ensure that progress is made in the achievement of these goals and outcomes. • Identified outcomes and benchmarks must be measurable. • Acceptable performance standards for the coordinating entity must be made available. • If performance measures are not met, monthly payments and/or operating licenses could be at risk. 	<ul style="list-style-type: none"> • Does the coordinating entity have policies and procedures in place to assure that the person-centered plan elicits individual goals and outcomes and incorporate benchmarks to ensure that progress is made in the achievement of these goals and outcomes?



Final Care Coordination Design Team Recommendations

<p>Focus on quality and less on compliance.</p>	<ul style="list-style-type: none"> • The individual service plan must articulate outcomes agreed upon by the individual and the care coordination team. • Results of surveys should be transparent to individuals and families. • Quality measures should look at culture change as well as the achievement of an individual’s goals, for example, moving all individuals to the least restrictive setting. • Outcomes need to be written that acknowledge the risk that an individual accepts when self-directing his or her own services. 	<ul style="list-style-type: none"> • Does the coordinating entity assist the individual to write outcomes that acknowledge the risk that an individual accepts when self-directing his or her own services?
<p>Advocacy</p>		
<p>Independent Advocacy</p>	<ul style="list-style-type: none"> • An advocacy body should be established that is separate from the care coordination entity, and service providers. 	<ul style="list-style-type: none"> • Does the coordinating entity consult with an independent advocacy body?
<p>Internal Advocacy</p>	<ul style="list-style-type: none"> • The coordinating entity should have available representation from self-advocates, families of people with developmental disabilities, and experts in cultural diversity and language to provide expertise and advocacy as needed. • Quality measures can be implemented that ensure a component of advocacy is in the care planning process. 	
<p>Willowbrook</p>		
<p>Compliance with expectations for services as stipulated by the Willowbrook Permanent Injunction and subsequent court orders.</p>	<ul style="list-style-type: none"> • Care coordination for Willowbrook class members will include an annual plan of services based on current assessments. • Team reviews will be convened on a semi-annual basis or more often as needed. • The care coordination team will include a designated Willowbrook care coordination entity at a ratio equivalent no greater than 1:20 who is a Qualified Mental Retardation Professional (QMRP) not employed by an agency that provides residential or day services to the class member unless the class member or the class member’s advocate chooses a functionally independent QMRP, if such a person is available. • A class member will have a community inclusion strategy based on his or her interests, preferences and needs; person-centered frequency and variety; 	



Final Care Coordination Design Team Recommendations

- and documentation to confirm implementation.
- The designated Willowbrook care coordination entity will:
 - provide monitoring and follow up to ensure the plan of services is developed, implemented and reassessed appropriately;
 - take an active role in advocating for the implementation of the class member’s rights and entitlements for services as well as those per class membership, including but not limited to Safety and Physical Environment, Staffing, Active Representation, Active Treatment, Appropriate Services, Community Inclusion, Informed Consent, and Protection from Harm;
 - make face to face visits at least monthly; and
 - proactively advocate for the class member and be actively involved in notification to Willowbrook interested parties, including preparation of due process notices.

*The Quality Metrics for care coordination will be drafted into a format similar to the Quality Scale developed by the Quality Design Team.