

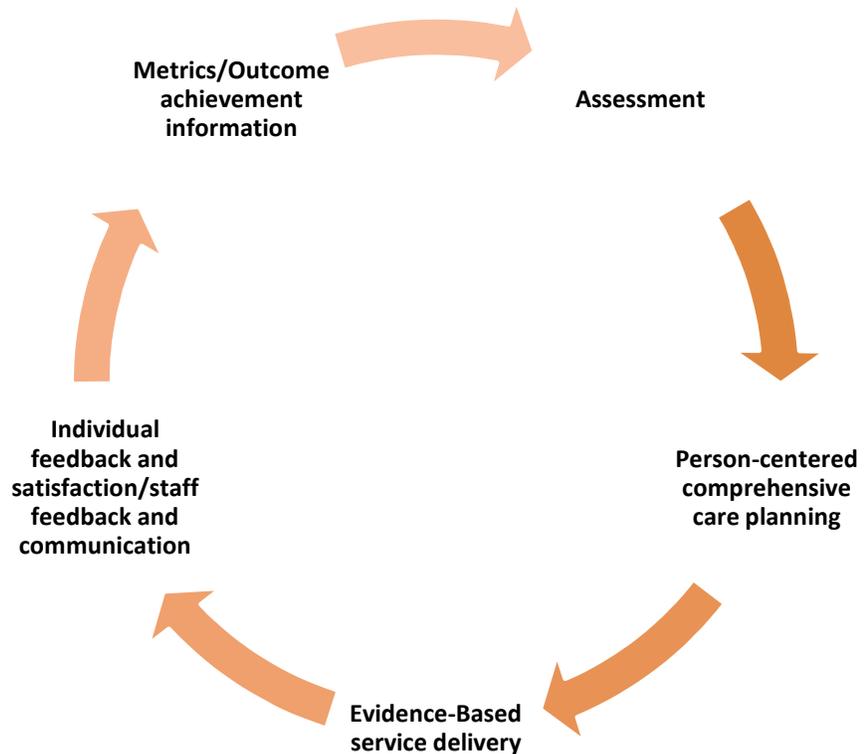
Section 2 — Care Coordination

Summary:

OPWDD’s intent in Section 2 of the Request for Information (RFI) was to seek broader input from the varied perspectives of stakeholders regarding the planning of the care coordination function within the People First Waiver.

Care coordination is a person-centered interdisciplinary approach to addressing the full range of a person’s needs, integrating habilitation, medical and behavioral health care and support services. The graphic below depicts a model developed by the care coordination design team during the summer of 2011, which illustrates that care coordination is not linear – there is a continuous feedback in the process to ensure that the individual’s needs and personal outcomes are being met:

Building on this model, care coordination will become comprehensive – allowing for the first time, within the five year span of the waiver agreement, a fully integrated system in which individuals with developmental disabilities can plan and access the full range of Medicaid services they need. This will support the planning and delivery of “whole person” care and enable people to receive the care and support they need. Primary functions that will be housed within the care coordination model of care delivery include ombudsman ship, encouraging active participation by individuals and families, advocacy, care planning, linkage and referral and on-going monitoring of care plans.



Quantitative Analysis:

The below tables represent the analysis of the responses to the Care Coordination section of the RFI which included a total of eight (8) questions.

OPWDD received a total of 251 separate responses from individuals who receive OPWDD services, providers, parents, advocates, self-advocates, associations, and other groups that wished to respond to the RFI. RFI responses were submitted by single persons or from groups of individuals. Therefore, when we refer to “responses” each “response” could represent the opinion of one individual or hundreds of individuals.

| Analysis of the Care Coordination Section of the RFI by Question Number | | | | | | |
|-------------------------------------------------------------------------|---------------------|--------------------------|---------------|--------------------|--------------|-------------------|
| Question Number | Number of Responses | % of Total RFI Responses | Yes Responses | % of Yes Responses | No Responses | % of No Responses |
| CC-1 | 186 | 74.1% | n/a | n/a | n/a | n/a |
| CC-2 | 181 | 72.11% | n/a | n/a | n/a | n/a |
| CC-2B | 191 | 76.10% | 83 | 43.46% | 108 | 56.54% |
| CC-3 | 160 | 63.75% | n/a | n/a | n/a | n/a |
| CC-3B | 180 | 71.71% | 86 | 47.78% | 94 | 52.22% |
| CC-4 | 159 | 63.35% | n/a | n/a | n/a | n/a |
| CC-5 | 182 | 72.51% | n/a | n/a | n/a | n/a |
| CC-6 | 158 | 62.95% | n/a | n/a | n/a | n/a |

| | Number of Responses | % of Total RFI Responses |
|---------------------------------------------------------------------------------------------------------------|---------------------|--------------------------|
| TOTAL RFI responses that answered all questions included in the care coordination section | 113 | 45.02 |
| TOTAL RFI responses that did not answer any question in the care coordination section | 38 | 15.14 |
| TOTAL RFI responses that answered one or more question but not all questions in the care coordination section | 100 | 39.84 |
| TOTAL Responses to RFI | 251 | 100.00% |

RFI Questions:

(CC-1) - As New York State transitions to a care management system, how would you recommend evaluating the expectation that a person-centered planning process is used effectively to develop supports for individuals?

| Number of Responses | % of Total RFI Responses | Yes Responses | % of Yes Responses | No Responses | % of No Responses |
|---------------------|--------------------------|---------------|--------------------|--------------|-------------------|
| 186 | 74.1% | n/a | n/a | n/a | n/a |

Evaluation Criteria — RFI respondents suggested a wide variety of criteria for evaluating the expectation that a person-centered process is used by individuals and their circle of support to effectively develop a personal support plan. One component that respondents said is essential is that circle or team meetings and the evaluation process focus on the participant. It was suggested that other stakeholders should be involved in the planning process as desired by the individual, and that all positive relationships and natural supports should be identified.

RFI respondents noted that plans should be evaluated on their use of least-restrictive approaches and the extent to which the individual participated, within their ability. It was suggested that documents and other materials related to the process should be focused primarily on providing supports to the individual and not on a program or site. It was also noted that evaluation involves assessing the consistency between an individual's goals and the supports provided to them. The use of plain language in plans was recommended.

RFI respondents suggested that criteria for evaluating the planning process should include that the planning process is based on a strong knowledge of the person, their needs, preferences and desires, is independent of cost containment pressures, and identifies and builds on a person's capacities. Another criterion suggested was that the planning team or circle of support must meet an appropriate number of times to address the individual's needs.

One way to evaluate the use of person-centered planning noted by respondents was to look for the existence of identical or "agency boilerplate" plans which are not truly person-centered. One suggestion from an RFI respondent said: "Look for patterns across plans. Agencies that are not person-centered use 'cookie cutter' valued outcomes. A truly person-centered plan will be specific to the individual and will not have the same wording as another plan. By measuring the number of plans with the same outcome you will see which agencies are person-centered and which are cookie cutter."

Commonly suggested measurements included progress towards goals identified in plan, progress towards self-sufficiency, and the use of measureable quality indicators and valued outcomes the individual chose.

See the table on the following page for more evaluation criteria suggested by RFI respondents.

Criteria for Evaluation Suggested By RFI Respondents

Individual Choice and Control

- Individuals goal's as expressed in their person-centered plan are reflected in their daily life
- Participant is the main focus of circles/team meetings
- Person's choices are favored over staff and institutional convenience (taking into account risk and safety)
- Day schedules are unique, and reflect the participants goals

"Nothing About Us Without Us!"

Face-to-Face Meetings for Plan Development

- Individual actively participated in the development of the plan
- Meetings included the participants the individual wanted in attendance
- Meeting took place at a time and location convenient for the individual
- Participants communicated effectively with the individual
- Plan accurately reflects the opinions the individual expressed at the meeting and thus the desired goals and action steps.

Plan and Implementation Criteria

- The plan is written using the individual's own words and not the service system's language. The plan includes the voices of those who care about the individual in the plan.
- An individual's goals are expressed as outcome-oriented rather than service-oriented.
- The plan changes as the individual changes.
- Care Coordinators and support staff demonstrate specific knowledge about the person.

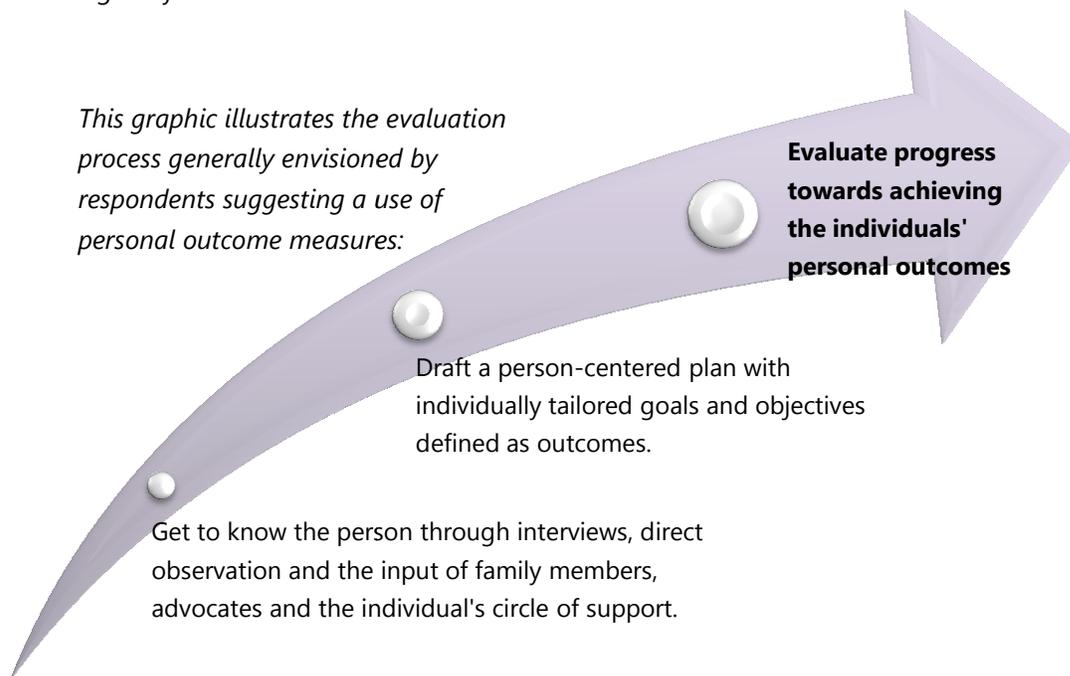
Evaluation Process and Method — Themes from the RFI responses included recommendations that a consistent standardized evaluation tool is used to evaluate the care planning process across providers. The evaluation tool should evaluate the degree to which care planning focuses on specific outcomes and the frequency of plan modifications and evaluations.

Some respondents suggested that provider agencies conduct the evaluation themselves or that agencies should provide the system or process they will use to collect information for the measurement of outcomes. However, a far greater number of respondents felt the evaluation should involve an independent entity to ensure objectivity.

A common evaluation method suggested by RFI respondents was the development and utilization of evaluation tools which are standardized and outcome-based. It was noted that desired outcomes, not satisfaction, should be measured to directly evaluate the efficacy of the person-centered plan devised for the individual. Many other respondents also suggested surveying satisfaction as well.

Formal assessments at specified intervals with close contact throughout the year were suggested. Use of an evaluation tool with minimum thresholds to be achieved for each criteria measured was suggested.

Personal Outcome Measures — Several respondents expressed their preference for using personalized metrics to evaluate very specific individual outcome measures, which are documented in the care plan and reviewed regularly.



System-Related Metrics — Other respondents focused attention on constructing an evaluation framework which could be applied to the person-centered planning process independent of the individual's goals or needs. This group of respondents suggested using practice standards as criteria for evaluation and developing metrics based on a defined expectation of person-centered planning. Respondents suggested that OPWDD set quality standards for person-centered planning and use standardized tools with standardized indicators.¹

Discussion — Some respondents suggested that the best way to evaluate person-centered planning is with face-to-face interviews and circle of support progress reviews. Some respondents also suggested that more than one group evaluate the plan to get the most accurate picture for the individual. It was noted that Medicaid Service Coordinators currently conduct a person-centered process of working cooperatively with family and care providers.

Quality Control — Respondents suggested audit or fidelity measures, including a review process and random audits to check the quality of person-centered planning. Furthermore, oversight bodies comprised of stakeholders and randomly determined direct observations of the life plan in action were suggested.

¹ The following specific instruments were suggested by a respondent:

The Person-Centered Quality of Life Indicators (Holburn, Pfadt, Vietze, Schwartz, Jacobson, 1996)

Person-Centered Organizational Capacity Indicators (Holburn, Vietze, Jacobson, Gordon, 2003)

Person-Centered Organizational Climate Survey (Holburn, Vietze, Jacobson, Gordon, 2003)

Quantitative and Qualitative Research Methods

RFI Respondents suggested both quantitative and qualitative methods of analysis:

Quantitative research refers to the systematic empirical investigation of social phenomena via statistical, mathematical or computational techniques. Quantitative data is any data that is in numerical form such as statistics or percentages.

The following model using metrics to evaluate the effectiveness of person-centered planning was submitted by an RFI respondent:

- Clearly establish phase gates within the process - which specific criteria must be met to move to the next phase. These criteria should include relevant service quality benchmarks.
- Gather metrics on each individual as they go through the process so that you can assess the number of individuals in each process stages, as well as the time that each individual spends in the phase.
- Establish service quality benchmarks

Metrics to measure:

1. Percentage of service population that is engaged in the process
2. Progress participants through the process phases
3. Quality of service levels obtained by participants

Qualitative research aims to gather an in-depth understanding of human behavior and the factors that govern it. The qualitative method investigates the why and how of decision making. Forms of data collected can include interviews, group discussion and document review.

The following model for a review of written plans was submitted by an RFI respondent:

The evaluation of the effectiveness of a person-centered plan developed using appropriate guidelines should include a review of a sample of written plans to ensure that they:

- Reference how the person and all key people were involved and contributed to the plan development
- Cite source documents reviewed
- Connect key information provided by the person and/or their parent/guardian/advocate to various components of the plan
- Connect key information obtained from documents reviewed to the various components of the plan
- Clearly articulate differing opinions and if/how negotiation led to consensus or not (it should be allowable to table some issues for further consideration)

Other Quantitative Measures:

- Number of meetings/decisions that occur with the individual present
- How long someone has worked on a particular outcome or goal
- Interval at which plan is updated

Other Qualitative Measures:

- Day schedules are unique and reflect the participants goals
- Person-centered language is used in all materials
- Strength-based plan is produced

Considerations for Evaluation — Many respondents submitted comments which inform proper evaluation of person-centered planning and provide a contextual backdrop to evaluation. It was noted

that care coordinators should be trained in the philosophy of person-centered planning and planning competencies and be able to facilitate discussion between the individual and his or her circle of support. It was suggested that there be an expectation of person-centered planning for all individuals. It was suggested that providers should be required to certify they are hiring quality brokers and make training on person-centered planning available to all participants. Medicaid Service Coordinators were noted as having the specialized knowledge of the individuals they serve and the service system that is needed to effectively evaluate person-centeredness.

It was noted that clear documentation of the supports provided is necessary to evaluate the effectiveness with which the plan is carried out, and that there should be ongoing communication for feedback. It was recommended there be clear lines of responsibility and accountability including an established list of who does what for the plan. A web-based application to gather data was also recommended.

Surveys — Respondents commonly suggested surveys be used to measure the effectiveness of person-centered planning as part of the care coordination process in a variety of ways. The majority of respondents suggested surveying individual and family satisfaction related to the person-centeredness of their plan and supports. Others suggested surveying to more objectively determine the suitability of the plan and the extent to which it is person-centered. A system of surveys conducted at regular intervals was suggested, these surveys could potentially be anonymous or reviewed by an independent entity.

Involvement of the Individual and

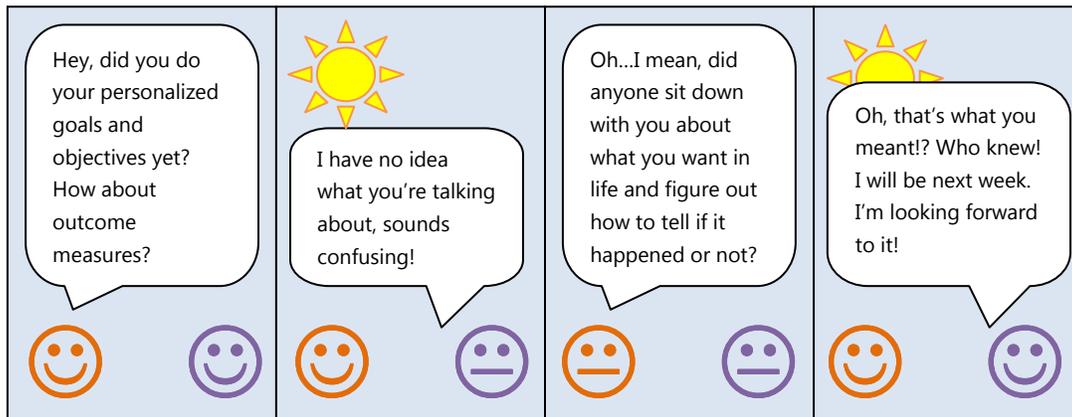
Stakeholders — Respondents commonly insisted that individuals with disabilities be involved in the assessment process, along with their family, friends, circle of support and other relevant people in the individual's life. This involvement is seen as essential to educate and inform participants in the person-centered planning process, as well as a way to seek feedback from people and their advocates. It was suggested that either the individual or family should have the final say on the person-centered plan produced, taking into account risk and safety.



Independent Evaluations — Suggestions for independent evaluations took a few forms. One idea is to have a designated Independent Advocate be responsible for monitoring to ensure the person-centered planning has been effective. Other respondents suggested that independence stems from having an outside entity conduct the evaluation, instead of the agency providing and funding supports. It was suggested that Developmental Disabilities Individual Support and Care Coordination Organizations (DISCOs) subcontract with a Quality Measuring Organization (QMO) to ensure independent evaluations. Other suggestions included the use of separate advocates to interview the individual and see if their needs are being met properly.

Say (and Evaluate) What? — Respondents noted as a final aspect of evaluation, that what is to be evaluated (in terms of the effectiveness of person-centered planning) must be clearly defined in plain language, and expectations and parameters must be communicated. It was suggested OPWDD develop Guiding Principles or a minimal set of guidelines to define a set of core criteria for evaluation. By disseminating a definition of what person-centered planning means, OPWDD can clarify the process and standardize expectations and processes. It was also noted that the Person Centered Plan needs to be clearly defined so that everyone who is collaborating to support the individual in developing his or her life plan will have detailed information and training.

System jargon can make things seem more complicated than they are...



...but person-centered planning uses plain language that is easy to understand!

(CC-2) - What would you envision as the most effective system to ensure that there is a comprehensive clinical team of experts available to develop a plan of care in line with an individual's expressed interests and needs?

| Number of Responses | % of Total RFI Responses | Yes Responses | % of Yes Responses | No Responses | % of No Responses |
|---------------------|--------------------------|---------------|--------------------|--------------|-------------------|
| 181 | 72.11% | n/a | n/a | n/a | n/a |

Desired Traits of the Clinical Team — Respondents described their ideal clinical expert as one who is trained, caring, well-seasoned and has a shared vision for serving the individual with disabilities in a person-centered way. Multiple respondents recommended that clinicians must have experience in the developmental disability field and be well-educated about the needs of individuals with developmental disabilities. These clinicians should be held to baseline credentials, ideally have years of experience, and know of the changes to the service system over time. It was suggested that clinicians should be clearly identified for their specialty and be available for consultation and final review of a plan, and that they should be hired as contractors independent from the funding organization. Respondents commonly held the view that clinical supports are intended to help people achieve community membership rather than

seeing them as interventions to change a person. The clinician should have good information about and know the person being served.

It was noted that the availability of suitable clinicians is largely a function of the medical marketplace, and that scarcity in rural areas and smaller cities is a hindrance. A respondent suggested that full-time clinicians employed by an agency grow relationships with individuals and provide training to direct care staff, and that clinicians be co-located with care coordinators to allow for greater communication and quicker response. Higher salaries for clinicians were also recommended.

Role of the Clinician and Clinical Team — A common view held by RFI respondents regarding the role of clinicians is that they should be available as a group of experts in many disciplines to assist in care coordination. Respondents suggested that these professionals be available as part of the individual's planning team to offer their advice and expertise, and that specialty clinical resources should be accessed based on an individual's specific needs. To this end, the clinical team should be comprised of people able to address issues identified from assessment results and the person-centered planning process.

Other RFI respondents viewed the clinical team as more central to the planning process, as opposed to the previous view which integrates clinician assistance as needed. It was suggested that clinicians should be embedded in service delivery and serve as a key resource for care coordination, but the system should still be structured according to the individualized needs of a person. It was suggested that clinicians be part of the care coordination team, including recommendations that a physician should be an integral part of the review of assessments to ensure decisions are made with appropriate clinical input. It was suggested a multidisciplinary team would be ideal, but that is not practical for all (and especially smaller) agencies. Respondents suggested that the clinical team be an independent entity making independent decisions and should rely on its own independent medical reports.

Some respondents, especially those from rural areas, noted that clinical experts should be available in the individual's geographic area to develop the plan. This may include travel to homes or programs and other natural support settings to collaborate directly with the persons served.

Clinical Process — Respondents addressed the process clinicians will use to help individuals develop a plan in line with their goals and interests from many different levels and perspectives. A primary quality suggested by respondents was for the system to allow the free flow of providers between and among DISCOs, described by one respondent as a shared operational model combining the full range of clinical resources and expertise to create a single well coordinated multidisciplinary team. It was noted that the array of clinical providers should reflect the expertise needed to serve the comprehensive needs of the individual. It was recommended OPWDD utilize an assessment that accounts for medical needs.

In addition to suggesting the use of in-house clinicians, respondents also suggested using multiple providers and experts to allow a consultative approach to development of the plan, partnering with a healthcare system and creating a directory of community clinical professionals indicating their areas of training and expertise.

Another group of RFI respondents replied to the question, saying that successful person-centered planning often does not involve many clinicians. An approach offering differing levels of clinical support was recommended as many individuals do not require a team of experts in their planning. Follow-up monitoring and support for individuals who need more support, like those moving from institutions to the community, were also suggested. Some respondents noted that the dominance of clinicians in the planning process is reminiscent of the medical model, and that the individual needs to make the final call in determining the necessity of clinicians. It was also suggested that self-advocates have a say in clinical decisions and be empowered to act as advisors to individuals with similar challenges.

Respondents wrote about the importance of data and the use of technology to improve process. It was noted that a system must be in place so that direct care providers can get information from a database. Electronic Health Records were suggested as a way people can review documents remotely, but it was noted that clinicians must use the same or compatible system to allow communication between clinicians, providers and the individual being supported. Frequent and consistent data collection was noted as necessary. Use of other technologies such as teleconferencing to meet remotely and the use of telemedicine were also suggested.

Evaluations of clinical supports at regular intervals were recommended, and it was noted that the efficacy of the team can be measured through an annual survey of individuals and families and review of identified outcomes.

RFI respondents' ideas for an effective system to ensure that there is a comprehensive clinical team of experts available to develop a plan in line with an individual's expressed interests and needs:

One respondent recommended a system of care coordination that is overseen by a Licensed Clinical Social Worker (LCSW) and made of teams that are comprised of service coordinators, clinical specialties, (therapists, counselors) with medical support for day-to-day care and ongoing out-patient treatment. The Medical Support team would be comprised of Physician Assistants or Nurse Practitioners under the supervision of a Physician acting as Medical Director. On the other hand, when a medical admission becomes necessary, the Medical Support team would take the lead until the time of discharge, at which time primary responsibility would revert to the Community Support team. Both teams would work in concert with one another to ensure a holistic approach to the coordination of the consumer's overall care.

Another respondent recommended that the care coordination entity could establish and maintain a comprehensive clinical team of experts by:

1. Identifying the professionals who need to be on the clinical team through analysis of data from assessments.
2. Obtaining the services of these professionals from each identified area by hiring, contracting, or developing associations with individuals or affiliate groups to perform the role of clinical team participant.
3. Establishing affiliations with other experts or providers who may participate in the clinical team on an ongoing or as-needed basis.
4. Providing comprehensive, ongoing training for care coordinators regarding the availability of services and providers.
5. The expert clinical team must work in concert with self-advocates, families and others to assure that clinical team members are selected as appropriate, neither too many nor too few.

Role of the Care Coordinator — RFI respondents generally described the role of the care coordinator as hands-on, knowledgeable and extremely important in ensuring clinical supports are accessed appropriately. The care coordinators were described by some respondents as a Medicaid Service Coordinator with enhanced or expanded skills. The advocacy role of the care coordinator, and establishment of an entity whose primary responsibility is to be knowledgeable of all aspects of the individual's life, were both noted as key elements.

RFI respondents recommended the care coordinator have social work and person-centered planning experience and an established relationship with the individual who receives services. The coordinators should be part of the core planning team and be able to identify and access the most effective clinical members of the planning team. It was noted that it will take experienced care coordinators to develop plans that will cross provider systems, and coordinators may need to work closely with a team of experts in a variety of fields who can together develop a comprehensive care plan.

This "new species" of care coordinators will need to be multi-disciplined and very competent at interpreting data and other information to make smart decisions about the use of clinical supports.

Role of the Individual, Family and Advocate — Respondents noted that individuals should be able to choose who sits on their care coordination team, and that the team should respect decisions made by the individual. It was suggested that individuals should be able to choose their doctors and other clinicians from practitioners in their communities whenever possible and that individuals should be given choices and told about clinical supports available to them. Respondents said that the clinical team should be based on the services desired by the individual, and that every individual needs an efficient, caring advocate to make sure their wishes and needs are being met.

Role of the Circle of Support or Care Coordination Team — It was noted that a good person-centered planning process should reveal what clinicians would be needed for an individual, and that the person-centered planning team is most able to effectively assess the need for supports. It was suggested (by a trained clinician) that the plan of support for the individual should come more from the person, not clinicians, and another respondent recommended (as noted before) that the team should only include people approved by the individual. Viewed from this perspective, it is a matter of the individual and their circle of support being given the option of incorporating those with specialized clinical knowledge in the planning process, as opposed to having a clinician at the center of it.

Several respondents suggested that clinicians and content experts relevant to the individual's diagnosis should be a required part of the care coordination team, with flexibility to include other clinicians as needed. It was recommended by some that a primary care physician should be at the center of system, and a social worker, nurse, and clinical psychologist were commonly suggested as team members. Respondents sharing these views consistently noted that the inclusion of individuals and families in the process is important.

Role of the Provider or DISCO — Many respondents described their ideal system in terms of responsibilities of the DISCO, including that DISCOs should be required to have a specific minimum scope

of available services within their network (including clinical services) and that DISCOs bear the primary responsibility for the success of the system of clinical supports provided on a person-centered basis.

It was noted that providers should employ or have relationships with a range of professionals to make the necessary clinical experts available to support an individual's plan and ensure the individual and their circle of support have easy access to them. This could entail hiring a team of clinicians or contracting with them. It was suggested there are advantages to using in-house clinicians, including their ability to build relationships with individuals, and the training and support they provide direct care staff to implement individualized plans. Suggestions for collaborative models included to network with local providers in conjunction with in-house clinicians, and a private provider-Managed Care Organization partnership whereby the healthcare provider could work with the DISCO (as the provider of primarily community supports) to provide needed clinical support. It was noted that providers and DISCOs should offer training on developmental disabilities so clinicians are familiar with the needs of this particular population.

Role of OPWDD — OPWDD’s role was seen as primarily one of oversight. It was recommended that OPWDD ensure that appropriate training is developed and implemented for staff and that the training of experts from outside the developmental disability system is adequate. It was suggested that OPWDD mandate a minimum list of participants for a comprehensive clinical team within care planning teams and provide oversight to make sure clinical providers are performing satisfactorily.

Other Considerations — Other considerations suggested by RFI respondents included that the cost of travel and time can be prohibitive, especially in rural areas, so realistic geographic service areas must be drawn; there is already difficulty reaching qualified clinical providers in certain parts of the State. It was noted that both flexibility and adequate funding are essential. The home health model incorporates both health care and services programming and was noted as having elements to support a coordinated care system, including clinical team members. It was recommended that the clinical team should be comprised of people from more than one agency and that balance on the care coordination team is needed. It was noted by several respondents that the term “plan of care” connotes a medical model and should instead be called a “plan of support.”

(CC-2b) - Are you aware of best practice models that could be duplicated? If yes, please describe.²

| Number of Responses | % of Total RFI Responses | Yes Responses | % of Yes Responses | No Responses | % of No Responses |
|---------------------|--------------------------|---------------|--------------------|--------------|-------------------|
| 191 | 76.10% | 83 | 43.46% | 108 | 56.54% |

Respondents suggested a wide array of best practices, with special emphasis on the following best practice models:

² This question is a follow up to the previous question, (CC-2) - What would you envision as the most effective system to ensure that there is a comprehensive clinical team of experts available to develop a plan of care in line with an individual’s expressed interests and needs?

Interdisciplinary Team Model — Respondents suggesting use of the interdisciplinary team model noted that it is effective in coordinating all services for each individual based on need and interest, and also is inclusive of the families of the individual. In addition, it was described as successful in ensuring that all providers are aware of the individual's needs and any changes to the service plan. In this model, as described by respondents, goals are reviewed and discussed by a comprehensive clinical team which supports the individual and family through the process of decision making. It was noted that establishing a plan of care must include a team of individuals who are well versed in all aspects of an individual's life and care needs; this requires the distinction between case management for service coordination and care management for medical care coordination.

Person-Centered Approaches — Several respondents noted that person-centered planning is appropriate for planning all services, including clinical supports, and suggested the use of OPWDD's Consolidated Supports and Services, Essential Lifestyle Planning and other nationally known person-centered planning models.

Medical Home Model — The medical home model was described as being able to facilitate access to services, offer and promote continuity of care and family support, and improve medical, educational, developmental and functional outcomes. An RFI respondent noted that the point of the model is to create linkages and enhance care coordination by integrating medical and behavioral health care to better meet the needs of people with multiple disabilities. The model aims to improve health care quality and clinical outcomes as well as the patient care experience, while also reducing per capita costs through more cost-effective care. The model as described by respondents pulls together health care, social services, educational, day and rehabilitative services to support maximum functioning for a person with developmental disabilities. It takes a holistic view of programming, incorporating preventive medical services and evidence-based treatment into the individual's program. A respondent noted that this model provides a "whole-person" approach to services, including all clinical and non-clinical services and supports.

The Patient-Centered Medical Home (PCMH) model as described by a respondent emphasizes team-based care coordination across multiple health care services and settings. The model also supports shared decision-making by placing the patient at the center of the care team.

Program of All Inclusive Care for the Elderly (PACE) — The PACE model uses an interdisciplinary team to develop a comprehensive plan of care for older adults based on their expressed interests and needs, and several respondents suggested a modified version of PACE could provide a best practice model. It was noted that the PACE model is highly regulated and requires significant clinical monitoring that may not apply to many individuals with developmental disabilities, and that the model would need to be adjusted to reduce its reliance on a center-based approach.

PACE's strength as described by respondents is that it is intended for individuals with chronic medical conditions and enables providers to devise supports for aging individuals. The PACE model also allows for more local decision-making around risk.

Virtual Integration — Virtual integration refers to a networking strategy based on cooperation within and across organizational boundaries, where organizations work cooperatively but maintain a distinct identity. This organizational strategy was suggested as a best practice by a handful of RFI respondents, one of whom pointed to a study prepared under contract between the U.S. Department of Health and Human Services (HHS), Office of Disability, Aging and Long-Term Care Policy (DALTCP) and the City University of New York (“Coordination of Care for Persons with Disabilities Enrolled in Medicaid Managed Care: A Conceptual Framework to Guide the Development of Measures”) which examined how organizations were able to link together to invest in technology and training, and ultimately to improve the cost structure and quality of care of these organizations. In the organizations studied, virtual integration provided those whom they supported increased choices and encouraged members to use informal networks and contacts to open doors in the community and cultivate a commitment to action by community members.

(CC-3) - The sharing of information across providers who support individuals is critical to ensure quality, integrated care plans and consistent proactive treatment strategies to help individuals maintain and/or achieve desired health, functional and personal outcomes. What strategies and Information Technology (IT) solutions would you recommend to ensure effective information sharing?

| Number of Responses | % of Total RFI Responses | Yes Responses | % of Yes Responses | No Responses | % of No Responses |
|---------------------|--------------------------|---------------|--------------------|--------------|-------------------|
| 160 | 63.75% | n/a | n/a | n/a | n/a |

One Integrated System — The most frequently voiced suggestion was for there to be one integrated system created either by linking together existing systems through a compatible framework or implementing the use of one information technology solution to be adopted by all members of the OPWDD system. Respondents depicted a system capable of allowing full integration between providers, DISCOs and OPWDD, and also other service systems outside the developmental disability system. Software that is interoperable, or can be used together by diverse systems, was noted as imperative. It was suggested the system be linked to Regional Health Information Organizations.³

The dual wish of respondents was that all agencies that receive OPWDD funding should use the same system, while at the same time not wasting the time and resources already invested by providers in developing their own systems. It was suggested that the new system interface with a variety of IT systems already purchased and used by providers, and was noted that that the current system is very diverse. Standardized forms used by all providers with performance metrics were suggested as key features.

It was suggested that OPWDD should insist upon the use of one secure, online software package. It was requested that OPWDD educate the DISCO and provider network regarding expectations and requirements relating to information sharing and provide technical parameters to spell out the requirements of the platform that is adopted to provider agency IT departments.

³ Regional Health Information Organizations (RHIO) allow sharing of health data between service delivery systems. Most references to RHIOs were from RFI respondents from the Buffalo and Rochester areas.

Other suggestions for an integrated system include integrating OPWDD secure applications within a broader IT system and partnering with medical practices and other entities to enable information sharing between provider and practice. It was suggested that one dedicated contact be provided for each individual and their family member to facilitate the process.

Electronic Health Records (EHR) — Electronic records were described as having many advantages compared to traditional systems, including that they lower costs and maximize accuracy while preventing duplication of effort. Use of a single master form and electronic signature capability were described as ideal. It was noted that EHR can track integrated care plans, medical records, quality outcome measures and financial information. It was suggested auto-fill forms be used when possible to reduce the amount of redundant paperwork.

Web-based, Online System — A system that is web-based was described by respondents as having significant advantages, most broadly that such a system allows for information sharing as needed across service providers so long as people are granted access to the system. It was recommended that the system be secure and that records should be available online to the person receiving services. It was noted that the online system should be usable on all current technology platforms and should only require a browser and Internet access from users in order for them to connect to the system. As a caveat, one respondent noted that many families do not have access to the Internet.

Hosting the system off-site using the Internet (“in the cloud”) was described by RFI respondents as having advantages over traditional in-house IT management. As one respondent put it, with the advent of cloud computing technology, the requirement for individual files to be hosted at a physical location particular to a provider has been lifted, and barriers that have previously limited information sharing are slowly being dissolved.

It was recommended that social media features be integrated and personalized preferences be available for users. User portals which allow different stakeholders (including individuals and families) to access information via the web were suggested.

Confidentiality and Roles — User roles and confidentiality were both noted several times in regards to the functioning of the electronic system and online access. RFI respondents voiced a need to balance both confidentiality and access. It was noted that information does not need to be given to professionals who do not need it, and that providers should only be able to see information related to the services they provide. Respondents requested the capability to see all information or only specified documents, and noted that only people with appropriate access privileges should be able to access information regarding different individuals.

It was noted that access can be restricted to user roles, but that these roles must adhere to HIPAA rules and confidentiality. It was suggested that individuals with disabilities should be able to regulate privacy settings and control access to their information. It was also noted that managing multiple levels of access becomes more challenging and costly when there are more providers using the system.

CHOICES — Some RFI respondents referred to the CHOICES system in implementation by OPWDD. One suggestion was that CHOICES be transitioned to meet federal standards for electronic health records, including meaningful use and interoperability. It was suggested that CHOICES should integrate with existing commercial electronic records software and hospital electronic medical record systems.

System Development Process — Respondents offered advice for the development of the IT system, including use of a “standards board” made up of representatives from DISCOs, providers, and vendors to advise on the development of a common information sharing platform. It was suggested that the system must be developed by people who will use it, and that development and implementation should take place in incremental, iterative phases.

In-Person Visit — While many respondents focused on the use of technology to allow meetings to take place from a distance, others reiterated the benefits of personal contact and face-to-face visits while describing the current process whereby a Medicaid Service Coordinator collects and communicates information. The importance of relationship-building was stressed.

A Diverse Toolkit — Respondents noted a number of the tools they are using or would like to see used more to facilitate information sharing. These included web-based video meetings known as webinars to reduce travel to videoconference sites, and using websites, email groups, instructional videos and iPads to share information. Others said they would prefer to stay with traditional methods of communication including personal letters and phone calls, and cautioned against the overuse of technology. As one respondent put it, “we find that in some instances our efforts are still primitive in nature. A notebook in a knapsack on the back of a person’s wheelchair so the day program teacher can write a note about a specific occurrence during the day remains as an effective way to communicate.”

Funding — A handful of respondents noted that there should be funding for IT conversion and development in the 1115 Waiver, and that OPWDD should include the cost of maintaining the IT system in individual capitated rates. It was suggested that OPWDD make IT more of a priority to facilitate transition and implementation.

(CC-3b) - Do you know of or currently use IT systems that are effective?⁴

| Number of Responses | % of Total RFI Responses | Yes Responses | % of Yes Responses | No Responses | % of No Responses |
|---------------------|--------------------------|---------------|--------------------|--------------|-------------------|
| 180 | 71.71% | 86 | 47.78% | 94 | 52.22% |

General responses to this question included references to numerous successful proprietary IT systems developed by provider agencies. Respondents noted several challenges with IT systems, including

⁴ This question is a follow up to the previous question, (CC-3) - The sharing of information across providers who support individuals is critical to ensure quality, integrated care plans and consistent proactive treatment strategies to help individuals maintain and/or achieve desired health, functional and personal outcomes. What strategies and Information Technology (IT) solutions would you recommend to ensure effective information sharing?

significant financial costs associated with the IT product, required maintenance, and training of staff. Respondents also mentioned RHIOs several times, noting that RHIOs should be built upon since they offer opportunities for open sharing of health information within a protected information environment. It was suggested that RHIOs will play a critical role in integrating information. Below is a table indicating some of the systems noted by RFI respondents, their comments, and information on how many people suggested each system:

Some IT Systems Noted by RFI respondents

| IT System (Count*) | RFI Respondents Comments |
|--------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| CareTracker (3) | provides full electronic documentation of service planning , coordination of client outcome |
| CHOICES (9) | produces ISPs, level of care, MSC Coordination Notes, and DDP forms |
| PrecisionCare (9) | currently used by 80+ OPWDD provider agencies |
| | can link to both a doctor's office and to other agencies providing OPWDD services |
| | requires customization and careful implementation |
| | effective internal agency tool for service coordination |
| | the software must incorporate an Electronic Medical Records component to be truly integrated |
| | it is cost prohibitive |
| Therap (15) | allows information to be shared quickly over a wide number of users across a broad area |
| | available everywhere there is a computer or a device able to connect to the internet |
| | generates ISPs, Habilitation Plans, Monthly Data formats, communication logs, internal email, scanning capability, nursing and medical tracking, behavioral plans and data, incident management, staff training tracking |
| | does not cover all content areas |

*Count refers to the number of RFI Respondents who referred to the system in their comment.

It was recommended that several systems be examined to determine the best choice, and that trained individuals should be available to assist those who need assistance accessing information from the IT system. It was also suggested that social media be incorporated in “a social network-like application where the DISCO, service provider and person receiving services could interact and share information and have unique privacy and account settings.”

Numerous respondents referred to the use of Electronic Health Records or EHR (also called Electronic Medical Records or EMR.) The benefit of EHR in communicating information is that different community and medical providers can access and enter information via a database they are linked to. Also, respondents reported costs savings from the use of EHR as a replacement for time consuming paper systems. Respondents noted certain IT systems required an EHR to be most functional.

(CC-4) - Effective Care Management calls for sharing pertinent information between involved providers of supports and services. As we transition to more flexible and natural models of support, do you foresee obstacles or challenges to information sharing as the result of confidentiality standards and HIPAA Privacy requirements that are currently in place?

| Number of Responses | % of Total RFI Responses | Yes Responses | % of Yes Responses | No Responses | % of No Responses |
|---------------------|--------------------------|---------------|--------------------|--------------|-------------------|
| 159 | 63.35% | n/a | n/a | n/a | n/a |

Speaking broadly, respondents expressed what might be termed “cautious optimism” with regard to this question. Of those who gave an affirmative or negative response to the question, 90% thought there were either no obstacles or that the obstacles they identified could be remedied with varying degrees of effort (such as providing training, revising forms or upgrading IT systems.)

Direct responses to this question fell in one of three broad categories. Two categories describe obstacles which are either viewed as resolvable or more permanent, and one describes responses which identified no obstacles.

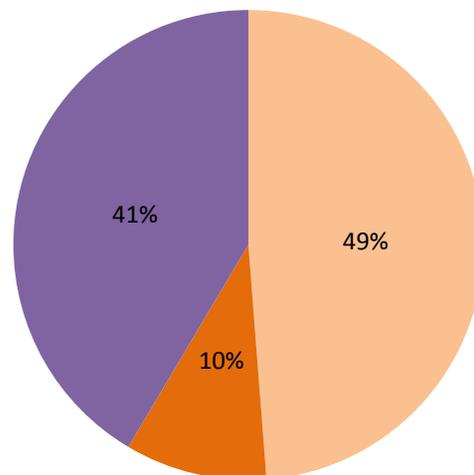
Category 1: Yes, obstacles were identified but with solutions. These issues are resolvable with varying degrees of effort.

Information Technology — A major focus for RFI respondents was the way in which information is communicated appropriately through systems while maintaining confidentiality in accordance with required protocols. It was noted that a protocol would need to be developed and adopted that would permit easy, but protected, access to private information within appropriate security parameters. It was suggested that a secure enterprise IT system be used because it provides the necessary infrastructure to allow sharing of information while adhering to HIPAA rules and guidelines through the use of user roles, groups and permissions. It was noted that the complexity of the data exchange environment poses challenges, and that there is an expense to administer access through roles and permissions.

It was noted that not all natural supports may have the software or permissions required to access information from an IT system, and that providers will need to upgrade their capabilities to secure systems outside of their own in-house networks. An obstacle noted was the lack of a universal platform that all

RFI Respondents' Perception of Obstacles to Information Sharing with Increased Use of Natural Supports and Flexibility Related to Confidentiality and HIPAA Privacy Requirements

- Yes: obstacles were identified but with solutions. These issues are resolvable with varying degrees of effort
- Yes: there are serious challenges. It is not clear if these obstacles could be resolved, even with great effort
- No: there are not apparent obstacles.



Note: the above chart factors out responses which provided information but did not provide a direct affirmative or negative response to the question.

agencies can afford to maintain. A secure messaging center with greater capabilities was requested.

Training and Education — Many respondents noted that natural supports, including families and friends, are likely not knowledgeable of HIPAA, confidentiality requirements and best practices in maintaining confidential information. Training on confidentiality and HIPAA was suggested by a number of respondents for natural supports to ensure consistent safeguarding of information. It was also suggested that the risks and benefits of sharing information should be spelled out so that individuals and families can better understand the reasons for sharing information. It was noted that the complexity of information sharing arrangements can make it difficult for individuals and their families to understand the nature and implications of these arrangements so that consent can be truly informed.

Consent Issues — Respondents suggested that consent waivers be streamlined and use a single consent form. It was noted that sharing information outside of the network can be more challenging and require additional releases, and that regulations should be clarified so that releases are not required between entities outlined in the care plan.

Category 2: Yes, there are serious challenges. It is not clear if these obstacles could be resolved, even with great effort.

Responses which fell in this category point to challenges which may be difficult to resolve or control. One major concern was that the increased flexibility for natural models of support could open up easier access to an individual's file, increasing the likelihood of a confidentiality breach. It was also suggested that natural supports may not share the same culture of confidentiality or be bound by the same laws as provider agencies.

Another point noted was that the sharing of information via Internet assumes that caretakers or neighbors will have computer equipment and Internet access, which they may not. It was suggested that setting permission levels (to regulate access to information in the IT system) may be a challenge to operate flexibly and make changes as services or supports change. Other respondents noted that HIPAA violations are a current problem and that some agencies don't enforce the laws, although this does not refer specifically to natural supports and flexibility.

Category 3: No, there are not apparent obstacles.

A number of respondents suggested that no additional obstacles stem from the transition to more flexible and natural models of support. It was noted that individuals should retain privacy protections and control who shares their information, and IT solutions must meet confidentiality standards and HIPAA Privacy requirements that are currently in place. Respondents qualified their opinion with the following additional comments:

There are no apparent obstacles...

- as long as all are trained on confidentiality and HIPAA rules.
- as long as there is a system in place to ensure that parents/guardians/individuals are asked to sign consents prior to the sharing of pertinent information.

- as long as there are standards that are clear for everyone to follow and there are consequences in place if the protocol is not followed.

(CC-5) - Supporting a person to establish and maintain natural supports through relationships with their family members and their home community is key to ensuring that they are fully integrated and included in the community of their choosing. What strategies would you suggest to ensure that these relationships are fostered through an effective care coordination process?

| Number of Responses | % of Total RFI Responses | Yes Responses | % of Yes Responses | No Responses | % of No Responses |
|---------------------|--------------------------|---------------|--------------------|--------------|-------------------|
| 182 | 72.51% | n/a | n/a | n/a | n/a |

Respondents suggested a broad array of strategies to foster relationships and build community connections:

Involve the Individual, Family and Advocates in Person-Centered Planning (PCP) — Respondents noted that the most effective way to foster relationships between the individual, natural supports and community is to involve stakeholders from these arenas in the planning process, which was described by some as “life planning” and not “care planning.” This is consistent with the mentality of person-centered planning. The primary method of conducting meetings related to PCP identified by respondents was the circle of support, which respondents suggested every individual should have. They also suggested that natural supports should be part of the circle of support.

In fostering relationships, it was suggested that family involvement be encouraged or required and include an attempt to solicit the participation of community members in supporting the individual. It was noted that family members and other natural supports must be identified and actively engaged. A recommendation was that family members be encouraged to participate in the planning process with their family member. It was suggested that individuals be encouraged to identify friends they would like to attend their meetings. Respondents noted there should be an overt acknowledgement that those team members both inside and outside the service system are critical to the person's success.

Many RFI respondents suggested that the PCP process has to include people who are familiar with the person receiving services and integrate natural supports into the person's plan. It was noted that relationships are the true foundation of PCP and that the values of self-direction promotes and reinforces relationships. It was suggested PCP be used for all individuals to maximize the use of natural supports, and that nationally recognized PCP tools such as relationship maps can facilitate the process.

Specific comments about family involvement suggested that the care planning process engage the entire family to allow for comprehensive coordination of support for the family system as a whole. It was suggested that involvement and empowerment of family members should extend to adult siblings, and also that some families will choose not to be involved unless they are required to be.

Lastly, measurements which evaluate the extent to which the planning process results in maximizing natural supports were noted as essential in keeping the focus person-centered.

Provider Organizational Culture — An important way to promote relationships with natural supports is to make them a focus of every individual support plan. It was suggested that for the organizational culture of the provider organizations to be truly person-centered, community membership should be the ultimate goal. It was recommended that OPWDD needs to work at creating a statewide community-inclusive approach to access the widest variety of community supports. It was suggested that the new approach constitutes a major paradigm shift which stakeholders will have to embrace for change to occur.

Care Coordinator and Natural Supports Facilitators — Respondents suggested a variety of responsibilities which would be covered by the care coordinator or other staff facilitating the inclusion of natural supports. Respondents suggested that the care coordinator will be central to the process and assist in identifying, locating and accessing natural and community resources as part of their overall responsibilities. The care coordinator envisioned by RFI respondents will be familiar with the community, experienced, and able to maintain close ties with all involved. It was noted that individuals and families should have control over who their service coordinator is, and efforts should be made to retain existing relationships between individuals and their current service coordinators. It was recommended that the coordinator should monitor the individuals' progress via follow-up, implementation and revision of their person-centered plan; sufficient time must be allotted for planning, and caseloads should be limited to enable meaningful relationships to be fostered.

Respondents noted that care coordinators should be locally based, very familiar with local resources, and have contacts they can call upon for assistance. It was suggested that the individual should remain in close proximity to their family and home community to build upon the community connections they have made since childhood. It was noted that community members should take part in support whenever possible. Respondents suggested that the care coordinator should assure that persons who are natural supports are appropriately vetted and trained. It was recommended that the care coordinator be certified as a person-centered planning facilitator and knowledgeable about regulations that may limit community integration.

Other recommendations and innovations regarding facilitators of natural supports include:

- Delegate a team member to be responsible for the oversight of community inclusion.
- Have a facilitator dedicated to ensuring relationships are established and maintained.
- Family support coaches can point the way to opportunities.
- Establish an Innovation Developer position that can identify natural supports, network with the community and show people how to use natural supports.
- There needs to be an advocate who knows the individual and is in regular contact with the individual and family members. To ensure there is no conflict of interest, the advocate should be separate from the DISCO.

Training, Education and Outreach — Respondents suggested a variety of training opportunities to foster community acceptance and the building of relationships. It was noted that education of community

members about people with disabilities is essential to this end. Information and trainings about the developmental disabilities system, person-centered planning, community resources, direct support, legal safeguards and advocacy were suggested for virtually all stakeholders, including individuals, families, advocates, other natural supports, business leaders, community members, and the extended care team. Community educational forums were also suggested.

Respondents suggested creating a community resource database, possibly based off of the Career Service Centers used by universities, to create a library of available community services, coordinate access to these resources, and provide centralized access to the information. Family education sessions were suggested, as were community outreach and education activities that would facilitate better preparation of families and communities for an expanded role in supporting individuals. It was noted that a Community of Practice could share information, identify and develop solutions to service delivery concerns, map community knowledge and resources to identify and respond to gaps and deliver training.

Support for Family and Natural Supports — A number of respondents referred to supports that should be provided to family members and natural supports to provide them with the resources and confidence they need to fulfill their roles. Respect and direct but informal communication between the coordinators and family were noted as key factors in establishing and fostering good relationships.

The use of family support services and care coordination for the entire family unit were recommended to enable families to keep their loved ones at home and maintain close family bonds. These services include respite and quality weekend programming with activities in an individual's home community, day habilitation programs, and crisis intervention strategies. It was noted that this support may be necessary for parents to maintain employment and prevent an out-of-home placement for their loved one.

Another suggestion was to allow family members to be compensated when appropriate and allow for paid relationships without the formality of habilitation service provision. Community recognition was recommended to reward the efforts of families and natural supports.

Finding and Recruiting Family Members and Natural Supports — Respondents suggested developing and maintaining family communication and outreach programs that define family and community as important parts of the system chosen for use as an IT solution. . It was suggested that attempts should be made to contact family members and natural supports, and that the natural supports that are available have to be sought out. A few agencies described using Internet tools to find family, including a process to help an individual create a DVD to reach out to family members with an invitation to be involved in his or her life and support. It was suggested that staff experienced in family dynamics can facilitate meaningful and effective supports with less paid services.

Community Engagement, Employment/Volunteerism and Generic Services — Respondents suggested individuals pursue a variety of strategies to connect and contribute to their communities, and also access community services available to the general public. One suggestion was to explore the needs of the local community and support individuals to choose areas where they can contribute. This can be achieved through a review of experiences, documenting opportunities offered, and matching likes with community resources.

It was suggested that meaningful employment is a major source of community involvement and that employers are an important natural support network. One hindrance noted in this area is the inability of members of a community to see value in a person with disabilities for employment.

To access general services, it was suggested that OPWDD provide funding for community programs and services so people can access activities and supports in places such as YMCAs, recreation leagues, and camps. Furthermore, it was suggested that individuals should be asked if they want to go to a house of worship or join clubs and should be helped to make those connections.

Other Considerations — A major concern for respondents in terms of accessing community locations were issues related to transportation infrastructure. It was noted this creates difficulties in developing relationships as individuals cannot be involved in the community because they cannot get to where things are taking place. The use of technology for communication and to build individual independence through the use of assistive technology were both suggested.

A point of concern over the use of natural supports was that OPWDD must address who will take risk and responsibility, and there is a need to assure families that the process will be effective. Satisfaction surveys and frequent communication between the individual and care coordinator were suggested. It was noted by respondents who question the reliability of natural supports that backup systems are needed.

It was suggested that care coordination in its focus on "care" is inconsistent with natural supports and community integration, and that the service delivery environment should not become unnecessarily "medicalized." It was also noted that for individuals who do not have family members or natural supports to build these relationships, a provider of supports that is community-based, with ties and commitments to the local community, will be the best way to insure maximum integration and inclusion.

(CC-6) - Please describe how you would foster relationships and coordinate best practice interactions with providers from other systems to ensure the most appropriate evidence based, coordinated treatment approaches which reduce the likelihood of stays in high cost and at times inappropriate settings? (e.g., if you are a provider of services to persons with developmental disabilities, how would you foster relationships and coordinate best practice interactions with providers such as behavioral health programs, inpatient hospital medical and psychiatric settings, dental care settings and substance abuse treatment programs?)

| Number of Responses | % of Total RFI Responses | Yes Responses | % of Yes Responses | No Responses | % of No Responses |
|---------------------|--------------------------|---------------|--------------------|--------------|-------------------|
| 158 | 62.95% | n/a | n/a | n/a | n/a |

Respondents generally noted that being proactive is the best way to build relationships between providers and reduce the likelihood of stays in high-cost or inappropriate settings. Respondents

suggested building relationships with other providers by forming partnerships and developing a core team of practitioners in a network to ensure coordinated treatment approaches. Early intervention and preventative strategies were regarded as essential to reduce stays in inappropriate settings. It was suggested that OPWDD establish an Internet presence for the sharing of best practices to provide the widest venue for dissemination.

As one respondent noted, "An ounce of prevention is worth a pound of cure," and the escalation of situations can sometimes be prevented if the signs are not missed or ignored. Suggestions included looking at what a person needs to be stable outside of more intensive settings and ensuring that supports are in place for their successful return to their original setting. Other suggestions included the designation of liaisons for each of the specialty areas mentioned (behavioral health programs, inpatient hospital medical and psychiatric settings, dental care settings and substance abuse treatment programs) and incentivizing the development of medical homes which were noted as being able to help integrate medical with behavioral and developmental models through the use of evidence-based practices.



Behavioral Supports — A number of suggestions were received related to behavioral supports. Some general comments were that there is a need for easy access to short-term intensive behavior programs. It was noted that OPWDD or the DISCOs must employ highly qualified professionals with appropriate licenses to develop and monitor behavior plans.

Preventing behavioral situations from developing was the priority for many, and one agency articulated their belief that providing an individual with as home-like and caring a setting as possible minimizes behavioral issues, in contrast to a semi-institutional setting where individuals with developmental disabilities tend to become stressed. It was recommended that behavior specialists give ideas and guidance to staff and help maintain a focus on small, but critical, proactive steps to take to help mitigate behavioral concerns before they start.

It was noted that Intensive Behavioral Supports was well received by families who need more formal services in a home setting so that a situation does not reach a crisis and result in an inappropriate placement. Another agency noted that it trains parents in basic concepts of Applied Behavior Analysis and coaches parents in how to conduct a functional behavior assessment so that parents can improve appropriate behaviors and decrease problem behaviors. The training decreases the likelihood that

individuals get placed in inappropriate settings. Partnerships with rapidly emerging Behavioral Health Organizations were also suggested.

Other Specialized Supports — Comments received related to inpatient hospitals included that providers should employ board certified physicians and that managing costs can most readily be achieved by partnering with a single hospital system. It was suggested that providers partner with Medicaid Managed Care organizations that focus on mental health. It was also noted that there are dental facilities dedicated to serving people with developmental disabilities, and it was recommended that good oral care should be a life outcome and that better training should be provided to people providing oral hygiene care.

Care Coordination — Respondents noted that the care coordination team must include individuals knowledgeable and experienced in the health insurance industry who are familiar with brokering relationships with a wide range of providers from other systems and negotiating effective rates and intervention strategies. It was further suggested that understanding local capacity ensures that support services and medical supports are available that match the person's needs and preferences. It was suggested that the care coordinator would be responsible to facilitate and organize relationships and accountability between service providers and to negotiate whose responsibility the shared solution becomes; to this end, they must understand the responsibility of each system.

It was noted that care coordinators must anticipate the barriers that the individual is otherwise going to be confronted with and prepare for success through education while paying careful attention to choice, the rights of individuals and adequacy of funding. As envisioned by RFI respondents, persons conducting this care coordination function would be highly trained and work within a system of accountability as it relates to expected, measurable outcomes. To this end, data collection methods that encourage transparency in decision-making and continuous reevaluation of care plans were suggested, as was the utilization of an online application to clarify roles and verify that outcomes have been completed.

Individualized Care Coordination Teams that would work in concert with strategic service providers were noted as an agency practice, and a family member suggested that each individual should have an advocate who would coordinate between the agencies and have final say.

Partnerships — A number of methods for outreach, building partnerships and establishing lines of responsibility were suggested by RFI respondents. It was suggested that providers of developmental disability services partner with a healthcare system, and that relationships with outside providers should be recognized as part of a provider network with standard agreements listing expectations. Providers will need to share and discuss their intentions, core values, and present clear expectations of the partnership, and it was noted that each provider should commit to have case-specific discussions with appropriate healthcare entities. Participation in partnerships and task forces was noted as a source of information about best practices and local needs. It was suggested that building upon the No Wrong Door concept is key to cross-system relationships.

Agencies described their outreach by mail or phone to outside providers, follow-up with personal contacts, and attendance of trainings offered by outside providers. Over time, staff deepen and strengthen these relationships in the course of collaborating in service provision. Identification of mutual

benefit, accountability and follow-up were noted as important to successful partnerships, and it was suggested that area providers engage in memorandums of understanding to establish a wide array of services to be offered through established clinics, specialists and community resources.

Other suggestions included associations or regional meetings which cross systems, committees to establish goals, and networking systems and other formal sessions among service providers from various sectors to ensure true coordination of care. Regional meetings and conferences were suggested to ensure communication, cooperation and collaboration.

Reducing High Cost Stays — Respondents suggested a variety of ways to reduce high cost stays in inappropriate settings. It was suggested that with appropriate professional support and monitoring there would be less need for restrictive environments and, when crisis intervention is required, the stay would be shorter. It was noted that in the event someone is moved from a community setting into a more specialized health setting, consistent evaluation is needed to strive for the least restrictive setting. It was also voiced that those involved must be proactive to the specific needs of individuals so that they do not lose functional skills while in the more intensive setting, which may prevent their return to a less intensive (and less costly) setting. Liaisons for people with developmental disabilities within the various other provider systems were suggested to clarify lines of communication and save money by facilitating different partners. It was suggested that more community based systems and sites need to be in place to respond to immediate needs so that expensive or long-term care can be avoided.

Communication — Communication between providers, individuals and families was noted as a primary concern by respondents. It was suggested that regular, open communication and consistent efforts to collaborate on individual-specific and program-wide issues led to the development of relationships, which are fostered by meetings, ongoing communications, and written consultations developed specifically to alert the service provider to the unique needs of persons with developmental disabilities. Open communication is also essential for the sharing of best practices.

Documentation and communication systems were noted by some respondents who stressed the importance of having documentation in one system with universal access so each party knows what the other is doing. One respondent suggested using communication and collaboration software to facilitate remote input of information from nursing staff, house managers and parents during a doctor visit.

Training — Training was noted by many respondents who said it is important to understand the various perspectives of treatment, regulatory standards, staffing and service ability as well as the challenges that the various providers face when working with people who may have multiple diagnoses. Cross training to facilitate understanding between systems was recommended.

It was suggested that educating providers not familiar with individuals with developmental disabilities will foster better supports, and that the DISCO network could provide specialized training to the staff of healthcare and behavioral agencies in regards to working and communicating with someone with developmental disabilities. Team communication and discipline were noted as essential in providing continual oversight of programming and data collection in residences and in community-based settings.

Regulatory and Financial Factors — Respondents noted regulatory obstacles, which can be a barrier to developing new supports when there are multiple systems involved. It was suggested that an individual disability should not exclude a person from accessing other services, and that OPWDD should loosen up on regulatory rigidity to foster innovation and efficiency, as well as collaborate more with other State agencies. Issues include restrictions which preclude individuals to return to the OPWDD system from the mental health system. A single comprehensive regulatory environment was also suggested for New York State.

Financial factors noted by respondents include that incentives must be put in place to make providers want to serve the developmental disability population, and that agencies can have issues getting reimbursed for care from other systems. It was noted that if funding for services is controlled by the individual, inter-agency collaborations will be fiscally rewarding rather than a drain on one agency's budget.

Obstacles — Some obstacles noted by respondents included a lack of sufficient number of providers willing to serve people receiving Medicaid-funded services (e.g. for dental services) and that many specialized treatment practitioners are not familiar with people with developmental disabilities and are not clear on how best to support them in their practices. Another obstacle suggested was the lack of specialized living options with clinical supports to support an individual once the person has been discharged from a setting such as a hospital or skilled nursing facility. It was also suggested that the staff who take individuals to appointments are often poorly equipped to interface with medical professionals.

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