

REGULATORY REVIEW AND EVALUATION ACT:

EVALUATION REPORTS — JANUARY 1, 2016

Subtitle 22 DEVELOPMENTAL DISABILITIES

SUBMITTED BY:

**Department of Health and Mental Hygiene
Office of Regulation and Policy Coordination
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**Regulatory Review and Evaluation Act
Evaluation Report Form
2012 – 2020**

Chapter Codification:

Chapter Name:

Authority:

Date Originally Adopted or Last Amended:

Purpose:

A. Review Criteria. (State Government Article, §10-132(1)(i), Annotated Code of Maryland; COMAR 01.01.3002.20E)

- (1) Do the regulations continue to be necessary for the public interest? Yes No
- (2) Do the regulations continue to be supported by statutory authority and judicial opinion? Yes No
- (3) Are the regulations obsolete or otherwise appropriate for amendment or repeal? Yes No
- (4) Are the regulations effective in accomplishing their intended purpose? Yes No

B. Outreach and Research. (State Government Article, §10-135(a)(2)(i)–(viii), Annotated Code of Maryland)

- (1) List any stakeholders invited to review the regulations and provide a summary of their participation in and input into the review process.

- (2) List any other affected agencies that were invited to review the regulations and provide a summary of their participation in and input into the review process.

- (3) Describe the process used to solicit public comment, including:
- (a) any notice published in the Maryland Register;
 - (b) any notice published in newspapers of general circulation;
 - (c) any notice posted on the unit's website or on a Statewide website created for units to post notices of regulation review;
 - (d) any mailing by the adopting authority; and
 - (e) any public hearing held.

Town Hall Meetings were held to seek community input.

- (4) Provide summaries of:
- (a) all comments received from stakeholders, affected units, or the public; and
 - (b) the adopting authority's responses to those comments.

See attached.

- (5) Describe any interunit conflict reviewed and the resolution or proposed resolution of that conflict.

N/A

- (6) Provide a summary of any relevant scientific data gathered.

N/A

- (7) Provide a summary of any relevant information gathered related to the regulations of other states or the federal government.

N/A

- (8) Provide a summary of any other relevant information gathered.

The DDA is undergoing dramatic changes in all aspects of the service delivery system. The changes are a result of changing rules dictated by CMS in regards to Community Rules. The DDA has revised its current approved waiver and plans to amend it again in order to move towards required changes over the next several years. The resulting changes will require regulation amendments. The DDA plans to repeal in their entirety all of Subtitle 22 and propose and adopt new regulations as these important changes roll out.

C. Under COMAR 01.01.2003.20E(3), does the agency have any existing policy statements, guidelines, or standards being applied or enforced which should be promulgated as regulations, in accordance with the Administrative Procedure Act? Yes No

Has the agency promulgated all regulations required by recent legislation? Yes No

Provide explanations of the above responses, as needed:

N/A

D. Actions Needed. (State Government Article, §10-135(a)(2)(ix) – (xi), Annotated Code of Maryland)
(check all that apply)

no action

amendment

repeal

XX repeal and adopt new regulations

reorganization

Summary:

By the end of FY2017, the DDA will propose repealing current regulations 1-20 and adopting all new regulations that will include all aspects of the current transition process. Numerous reviews of DDA's operating procedures substantiate this need. A few examples are below.

Developmental Disabilities Administration (DDA) contracted with Support Development Associates (SDA), who provided assistance with identifying a clear pathway towards the development of meaningful outcomes for people who receive support. SDA provided a review and recommendations of the process and subsequent documentation procedures used to establish a person centered service plan. Information received from this review will impact revisions to 10.22.05, The Individual Plan.

10.22.09 Resource Coordination Program Service Plan

An audit revealed that DDA did not have procedures to verify that individuals received services from

10.22.09 Resource Coordination Program Service Plan

(continued)

providers as stipulated in the related individual service plans and that documentation for the individuals' Medicaid eligibility reassessments was obtained. As a result of this finding, DDA transitioned to a Targeted Case Management model (under the Maryland State Plan) for resource coordination services on July 1, 2013. To support this transition, DDA will need to implement regulatory changes and enhance its IT system to improve the monitoring of resource coordination activity.

In 2014 CMS approved DDA's waiver application which merged two waivers in order to provide participants greater opportunity to self-direct certain services and simplify administration. Current regulations were drafted based on provider-driven services, vs. participant directed services. DDA's commitment to self-directed services will require amendments to all regulations to include this service component.

Also in 2014, pursuant to a contract between the Developmental Disabilities Administration and the National Association of State Directors of Developmental Disabilities Services (NASDDDS), NASDDDS conducted a systematic review of the approved waiver, correspondence with CMS regarding the operation of the waiver (historical documents), regulations and certain other underlying documents. In addition, NASDDDS facilitated 15 listening sessions across the State. These included:

- 4 In-person Regional Sessions with Self-Advocates
- 4 In-person Regional Sessions with Families
- 4 In-person Regional Sessions with Providers
- 1 Facilitated Phone Call with a Wide Audience (aimed at self-advocates and families)
- 1 Session with the Developmental Disabilities Coalition
- 1 Session with People on the Go (Self-advocacy organization)

NASDDDS's review of DDA's implementation of services resulted in recommendations to revise regulations. Their report is attached.

Person performing review: Amy Daugherty (410-767-8688)

Title: Policy Analyst

ATTACHMENT A

SUMMARY OF SELECTED ISSUES RAISED AND RECOMMENDATIONS MADE DURING DDA LISTENING SESSIONS AND OTHER PUBLIC FORMS CONDUCTED/Written FEEDBACK RECEIVED IN THE FALL OF 2014 REGARDING THE DDA SYSTEM AND PROVISION OF SELF-DIRECTED SERVICES

10/22/14 LISTENING SESSION #1 IN BOWIE MARYLAND

General Issues and Recommendations That Could Apply to the Self-directed Service Option

- *Issue:* Not enough information about anything, especially in writing. Families need information in their hands to make the best decisions. Serious communication gap especially after transition has occurred. Once into resource coordination, it's a once a year thing...people running through their paces and not getting enough information; push the paper through and get the process done. Meetings are more about paper than talking with individuals and their families.
- *Issue:* Disconnect between SS and DDA; families find themselves mediating between the two to settle the services.
- *Issue:* Clarifying roles and responsibilities. Who does what and what are each person's responsibilities?
- *Issue:* Hard use/navigate the DDA website to get help.
- *Issue:* In self-directed, move money after March unless health or safety issue, which means money goes unspent unless it's moved and what's the reason for this?
- *Issue:* Parent was told son going to day center could not participate in self-direction. Parent wanted to know if this policy changed. Parent said there is uncertainty about what services are available for self-direction; is it all or nothing? Has this been changed by the change in the waiver?
- *Issue:* Metro access for people in this area who are self-directed, you have to pay the money out first and some people can't afford that.
- *Issue:* Messaging is fragmented between regions, there is no consistency.
- *Issue:* Clarify policies and regulations so that all can understand them. At this point no one can.

- *Issue:* Simplify, simplify, simplify – 50 page manuals do not help.
- *Issue:* Service change process does not have the man power to expedite the process and the person suffers. Any mistakes on the form can lead to negative impacts for the person.
- *Issue:* Too administrative focused and not people focused. This really takes away from the person being supported.
- *Issue:* Things are overly complicated; communication needs improvement; people sent running in circles.
- *Recommendation:* Self-directed services need to have regional meetings of individuals who are self-directing to come together and share ideas. Now people have to do this on their own, which is difficult. Annual or quarterly meetings and DDA does not have to reinvent the wheel. Southern region did this previously and it was stopped.
- *Recommendation:* Glossary of Terms needed. DDA needs to use a common language.

Issues and Recommendations Specific to the Self-directed Service Option

- *Issue:* Wants clear explanation of self-directed and non-self-directed services.
- *Issue:* People can't currently be in two waivers at the same time, but now you would be allowed to self-direct some services and use a traditional provider for other services if desired?
- *Issue:* Resource coordinators are not letting families know about the self-directed options; feel that provider agencies are "holding back" this information and support brokers are needed to navigate the system of DDA.
- *Issue:* Resource coordinators are supposed to provide information for informed decisions and they do not and they make it seem too difficult to self-direct.
- *Issue:* Looking for guidance on how to support those that want to self-direct and those that need more supports. Should be able to cater to both sets of needs.
- *Issue:* System needs to support appeals for people that are self-directing as well as receiving traditional services as no one has a clear idea why services are being denied.
- *Issue:* There is confusion between the IP and the PCP. These should be one in the same, but there not as the IP in PCS2 is a check box of sorts and is not person centered at all

and does not provide a comprehensive picture of someone to better support their needs.

- *Issue:* There is not a structure for self-direction, and this can be a dangerous and slippery slope.
- *Issue:* Support Brokers do not have a training program and any subsequent on-going training. In the new directions agreement there are a lot of shared responsibilities without the right training to support it for both parties.
- *Issue:* What are the distinctions between resource coordinators and support brokers?

LISTENING SESSION #2, HAGERSTOWN, MD - OCTOBER 23, 2014

General Issues and Recommendations That Could Apply to the Self-directed Service Option

- *Issue:* Having a person go through agency trainings to provide support does not always make sense and limits the amount of people who can provide assistance/respite.
- *Issue:* Support services are being forced into institutional models.
- *Issue:* Service coordination doesn't have competencies- they do not provide help and supports.
- *Issue:* Three months to get a service funding plan completed and delays.
- *Issue:* Families would like a choice as to whether or not they need a Service Coordinator or if they would like that money put into direct supports.
- *Issue:* Interaction with Service Coordination is not genuine. Paper pushing only.
- *Issue:* Fractures between Medicaid and DDA (No cross system coordination).
- *Issue:* System writes rules without understanding the impact on people and their families.
- *Issue:* Differences between Medicaid and DDA regarding what nursing duties are permitted.
- *Issue:* Resource Coordinators act as mediators to solve problems. "We focus on fixing problems and the individual is not directing the process."
- *Issue:* New RC's do not quite know their role-setting a tone to providers it is not a team.

- *Issue:* DDA does not even have a consistent name for the RC service.
- *Issue:* Intent of RC has changed. Emphasis is mostly on paperwork.
- *Issue:* RC is not a waiver service anymore, so the lag times are huge for families. This really holds up the process.
- *Issue:* Lack of flexibility to move from service to service – too fragmented.
- *Issue:* System does not support individualized services and the outcomes it wants to see for people.
- *Issue:* Options are service oriented and rigid; you lose the natural support focus.
- *Issue:* Regional differences a problem – varies from region to region.
- *Issue:* Eligibility issues between regions. People change regions just to get eligibility.
- *Issue:* Very little confidence that DDA is working on regulations.
- *Issue:* Resources are very different between regions.
- *Issue:* Constant staff turnover – there is no explanation, they are just gone.

Issues and Recommendations Specific to the Self-directed Service Option

- *Issue:* Self-direction should be for everyone – support all to make decisions.
- *Issue:* IP does not connect to funding. Peoples needs change, but funding is so hard to change without extensive documentation.
- *Issue:* Got no support with self-direction, got budget and it was a handoff – had to stop the process.

LISTENING SESSION #3, COLUMBIA, MD - OCTOBER 27, 2014

General Comments and Recommendations That Could Apply to the Self-directed Service Option

- *Issue:* DDA is not clear on goals and has not established structures services/payments) to further community integration.

- *Issue:* Many individuals in the room expressed concern about the complexity of DDA. So many layers that it is hard to get anything done and the focus seems on process not people.
- *Issue:* Role of the RC is unclear – they are not building relationships with individuals and often families worry that they are only doing paperwork. DDA should support quality and stability.
- *Issue:* There needs to be better training of DDA staff – recommendation that DDA staff have experience working with individuals with disabilities.
- *Issue:* Communication is lacking from DDA and is sometimes incorrect.
- *Issue:* DDA needs to build in communication, coordination and accountability.
- *Issue:* There is a gap in resource coordination. The current RC structure does not meet the needs of complex supports, and there is no communication.
- *Issue:* There was an interest in getting clarification on the role of Resource Coordinators.
- *Issue:* The limitation of 82 hours of CSLA/Personal Supports forces individuals with more significant support needs into group homes. This raises questions regarding Olmstead and self-determination.
- *Issue:* There is ambiguity of approval processes and criteria from region to region.
- *Issue:* The state is measuring hours, not outcomes for individuals.
- *Issue:* There are issues with the appeal process – no consistent way to know what is needed to justify the supports.

Comments and Recommendations Specific to the Self-directed Service Option

- *Issue:* Within self-direction, there are some important items that are not covered: (1) snow/ice removal (2) Lawn care, (3) Other essential chores and (4) Transportation a challenge, too.
- *Issue:* Persons need to have the opportunity to choose who they hire, including if they want to hire family. There needs to be a greater emphasis on families.
- *Issue:* For individuals in self direction, there needs to be adequate support for minimum wage and benefits.

- *Issue:* The person-centered planning process needs improvement.
- *Issue:* DDA should help families network with one another (this was a widely held concept at the meeting). This is especially important for families who are engaging in self-direction so that they can learn from one another.
- *Issue:* In self-direction, individuals are not able to get behavior supports.
- *Issue:* Fundamental problem regarding choice. Not emphasized, no choice of resource coordinators- less choice in the system than ever.
- *Issue:* The housing constraints are a real problem for individuals (more pronounced for individuals in self-directed services).
- *Issue:* While there is emphasis on movement to integration, there is such heavy regulation that it defeats the principles of self-determination.
- *Issue:* There is not fluidity to further self-determination. Individuals need a modification for each change. For individuals self-directing, the broker is often not in the loop of communication.
- *Issue:* For self-direction, approval for overtime is a challenge.
- *Issue:* Common law employers do not get funding for needed infrastructure, such as a scanner. Need clear and consistent communication and written policies.

LISTENING SESSION #4, EASTON, MD - OCTOBER 28, 2015

General Issues and Recommendations That Could Apply to the Self-directed Service Option

- *Issue:* DDA needs consistent, clear, correct and easy to understand information.
- *Issue:* Families find it difficult to navigate the different systems, and RCs are not helping them understand.
- *Issue:* DDA staff need training to have consistent understanding of own policies, and RCs need to train with them so all have the same information.
- *Issue:* There are so many programs with overlapping paper requirements that it is a huge burden on families.

- *Issue:* Transportation is a huge problem, especially on the eastern shore. This is both the cost of transportation and the inability to have aides accompanying individuals on rides.
- *Issue:* Families need help understanding all of the services that they may be able to access.
- *Issue:* Resource Coordinators need to be stronger.
- *Issue:* Families are advocating for better skill development to do person-centered plans and behavior support plans.
- *Issue:* DDA has not been helpful to support people with complex needs (example provided of individual *Issue:* with Prader Willi). The supports are not provided, RCs are not skilled with the requests.
- *Issue:* RC functions are rigid, new staff not skilled; lost staff; No time to be creative and get to know people. Not knowledgeable.
- *Issue:* RC retention issues – job is too complex and administratively focused. Unlike the past. The whole process contradicts getting people everyday lives.
- *Issue:* Resource Coordination has challenges. Do not understand the DORS role and how the services can/should be sequenced. Providers fulfilling more of the RC role.
- *Issue:* Need more flexible approach to services and supports.
- *Issue:* Nee to make sure staff has the necessary training.
- *Recommendation:* Recommend streamlining these whenever possible (DORS, Medicaid, DDA etc).

Issues and Recommendations Specific to the Self-directed Service Option

- *Issue:* Support brokers need training.
- *Issue:* There is a lack of flexibility in financing that is hindering person-centered approach to service.

Recommendations Related to the Self-Directed Service Option

- *Recommendation 1:* The DDA support broker training must be revised and should include a more detailed level of instruction with particular emphasis on how to do budget modifications, plan modifications along with how to create a person centered plan. It should be noted that POG is aware that DDA wishes service coordinators to take over the writing of the plan and budget. However, we feel that all members of the team should at least have a working knowledge of how this is done in order to better support the person receiving the services.
- *Recommendation 2:* With regard to parents who are acting as support brokers for their children, DDA should create a separate workshop series for them. This is not to exclude parents from the overall support broker trainings, however, the current support broker trainings often get overwhelmed with questions from parents about specific issues. This is why a separate training series should be offered with the guidance of the DDA self-directed advocate.
- *Recommendation 3:* DDA should make clear to new persons on the waiver who wish to self-direct that they do not have to have a provider agency in order to access most supports and services. Much of the language that has been suggested for the waiver is often times provider focused and this could leave one with the mistaken impression that they have to use a community based provider in order to self-direct their services.

10/29/14 CONFERENCE CALL WITH AMY DAUGHERTY MODERATING AND MARY SOWERS AND JEANINE ZLOCKIE FACILITATING

General Issues and Recommendations That Could Apply to the Self-directed Service Option

- A family respondent raised an issue about getting information and assistance with navigating the many different types of paperwork, and the person named insurance paperwork, that she has to deal with and the need for a person like a resource coordinator, to assist her in those areas. *Recommendation- the support broker should be providing this information and assistance, particularly related to self-directed services.*
- A provider respondent commented how frustrating the application process is for Community Pathways and New Directions waivers. "There's no unity, or straight direction. Even requesting information from higher up, there's no one answer. And that can be completely overwhelming not only for the families but those who are helping them apply. Feels like (this) needs to be streamlined. And when you're requesting documentation, ensuring that it's not (come back when you just) more documentation and (you just want) documentation. If the families don't turn it in with one week turnaround, then they're shut out of the waiver and that has not just repercussions on the services, but their entire life and their health insurance."

- A family respondent commented that “For many years, I’ve been trying to be part of the (New Direction) waiver and they didn’t allow me to, I don’t know for what reasons. They always force me to go with a provider. They told me that when she graduated then I will have that option. No one in the school educated to me what are the options of how good the (New Direction) waiver would be or how bad it will be. They just encouraged me to be part of the (New Directions) waiver. There is no instructions and only (just) encouragement.”

Issues and Recommendations Specific to the Self-directed Service Option

- A family respondent commented that her daughter was in the New Directions Waiver and is now in the Community Pathways Waiver program. She just wanted to say how valuable she found the New Directions Waiver services [self-directed service option] to be for her daughter. “She’s greatly benefited from being able to self-direct her in life rather than being places where she had to follow the plan of what everyone else was doing. I’m hoping that as it [New Directions Waiver and self-directed service option] merges with the Community Pathways waiver and that nothing will change with it unless it makes it even better.”

DD COUNCIL COMMUNITY PATHWAY WAIVER FEEDBACK- OCTOBER 28, 2014

General Comments and Recommendations That Could Apply to the Self-directed Service Option

- *Issue:* Each region of the state has different practices. There needs to be consistency among regions, with written guidelines accessible to everyone.
- *Issue:* Billing and payment systems are outdated and do not allow agility and flexibility in serving individuals in a person-centered manner.
- *Issue:* Resource Coordinators are a first point of contact for information about and consideration of different services and supports. They play a key role in implementing the Employment First policy, yet too often they are either not knowledgeable about employment for people with a range of needs or don’t consider it a viable option.
 - Expectations and competencies around this issue must be raised.
- *Recommendation:* Review the roles and responsibilities of different entities involved in a person’s life through DDA: [Resource coordinators, support brokers, providers, DDA regional office]
 - Is each entity’s role clearly defined and differentiated?
 - Is there duplication and are there gaps?

- Is the amount of time allocated and reimbursement adequate to allow the role to be performed in a way that has meaningful impact on the individuals served?
- Ultimately, after ensuring health and safety who focuses on helping the individual have the life they want, not just through supports provided through DDA.
- *Recommendation:* Personal Supports should not be artificially capped at 82 hours. This serves to steer people with greater support needs to more traditional service models.

Comments and Recommendations Specific to the Self-directed Service Option

- *Issue:* There are goods and services that are not specifically disallowed in the waiver, however, providers report that DDA denies these even when there is a demonstrated need. Examples include: tutoring and books for school, camp, out of pocket medical expenses, and rent and utilities under appropriate circumstances. These services should be allowed and approved when needed.
- *Issue:* The waiver allows for participants self-directing services to utilize a family member, who does not reside on the property, to provide respite services under certain circumstances. The same provisions should be allowed for people not self-directing services. People unable to self-direct services have no access to this option.
- *Issue:* Is there a reasonable purpose for requiring sub-accounts within a line item? If not, alter this policy so accountability is accomplished by approving an amount for each line item with a notation of what a line-item includes without specifically allocating amounts to each sub-item. Fiscal reporting would include details on actual expenditures within each line if needed.
- *Issue:* There is a need for more highly qualified support brokers. A six hour training is not adequate to ensure necessary competencies in person-centered planning, choice, self-direction, rights, etc. Strengthen training and assessment.
- *Issue:* Resource Coordination:
 - There is a lack of adequate information, understanding and awareness of self-directed services. It has been reported that some RCs have conveyed that they don't know much if anything about self-directed services;
 - Individuals/families are sometimes steered away from self-directed services because it takes more time; and
 - When people self-directing their services need more services or their planning becomes more complex, some RCs are steering them to traditional services rather than figuring out how to make self-direction work.

- *Issue:* There is a need for more highly qualified support brokers. A six hour training is not adequate to ensure necessary competencies in person-centered planning, choice, self-direction, rights, etc. Strengthen training and assessment.
- *Issue:* Self-directed services used to be among the quickest services to initiate but now take much longer (by some accounts what used to take about six weeks now takes many months). Reasons cited include not enough staff at DDA regional offices and more burdensome rules. Some people initially involved in SD services are switching to traditional services either because the approval process is significantly delayed or too cumbersome.
- *Recommendation:* Include “Individual Directed Goods and Services” for all waiver participants, not just those that self-direct. Those are the services that continue to allow for flexibility and the meeting of unique needs. This denies needed goods and services to people who cannot self-direct. When this was previously recommended, DDA noted it was a CMS requirement to limit “goods and services to individuals with self-directed budgets.” Confirmation is needed.
- *Recommendation:* Staff benefits should be covered in self-directed services like they are in traditional service models. This can be a significant barrier to making self-directed services work. It is unclear as to whether it is a DDA policy to disallow these costs because there has been inconsistent approval across regions.
- *Recommendation:* Allow coverage of an inexpensive fax/scanner/printer when individuals/families need it to transmit forms cost-effectively and efficiently to the fiscal intermediary agency, resource coordination, and/or support broker (e.g., budget modification, personnel paperwork). Without this, funds are used for staff salary and travel to pick up the forms. This is more costly and diverts staff hours to administrative functions.
- *Recommendation:* Streamline the annual service funding plan update. Now required to re-review and re-submit; not required of traditional service types. With the process in place for an annual IP and budget modifications and plan modifications as needed, would a year-end reconciliation or an update instead of an approval process be more efficient and timely yet still ensure accountability?
- *Recommendation:* Conduct a thorough analysis to identify and eliminate unnecessary administrative burden on the individual/family, support broker, and resource coordinator. Convert as many processes as possible to online functions. Administrative burden affects the amount of time focused on addressing needs and wishes in the individual’s person centered plan.
- *Recommendation:* Consistently communicate policy and programmatic changes that impact self-directed services to individuals/families, resource coordinators and support

brokers. Include rationale so support brokers can assist individuals/families to understand and comply. Some support brokers report that they do not consistently receive information from DDA like the formal memos traditional providers receive.

- *Recommendation:* Eliminate the requirement that DDA approve modifications to plans and budgets when the change does not impact the original purpose or intended outcome already approved by DDA. *For example,* DDA approval is required to move funds among categories within the same budget line-item (even when the approved line-item total is not being exceeded). *For example,* shifting funds designated for mileage reimbursement to paying for a taxi or paratransit and shifting funds designated for vendors to pay for staff to provide the same service. Waiting for DDA approval can result in a needed support being unnecessarily delayed or not provided, particularly near the end of the fiscal year when approvals are not/cannot be processed quickly.
- *Recommendation:* Eliminate/reduce regional discrepancies; particularly Central Regional Office compared to the other regions. It has been reported that Central Regional Office typically takes months longer to process requests and what it will approve differs. Some perceptions are that CMRO uses its own interpretations.

MDLC FEEDBACK/RECOMMENDATIONS – 10/27/14

General Comments and Recommendations That Could Apply to the Self-directed Service Option

- *Recommendation:* Improved Public Information/Communication
People including applicants, waiver participants, families, professionals and others, need more information about the Medicaid waiver and support services including eligibility, access to the waiver, services and rights. DDA's communications with the public should be understandable to the average reader.
- *Recommendation:* As DDA develops the Community of Practice model, it should provide information about how this model will operate with the Medicaid Waiver.
- *Recommendation:* People who do not speak English need more communication assistance and support.
 - DDA is refusing to provide interpreters to people with hearing impairments whose providers do not have signing staff. People with hearing impairments need signing staff, and until such staff are available, DDA should provide interpreters.
 - Staff should meet peoples' needs to maintain and/or learn and gain communication skills, whether through signing, devices or other means.

Comments and Recommendations Specific to the Self-directed Service Option

- *Issue/Recommendation:* Self-directed services have been extremely difficult to obtain and saddled by extraordinarily dense rules. The rules are especially unclear about the mutual responsibilities of support brokers and resource coordinators. DDA should improve its staff support of self-direction and develop rules that will foster rather than inhibit self-direction.
- *Recommendation:* People need more support from resource coordinators in planning their waiver services.
 - DDA should ensure person-centered planning occurs as required by the new federal rule.
 - To ensure individual needs and desires are reflected in the individual plans, resource coordinators should be required to be trained in and use best practices in person centered planning including tools such as MAPS, PATH, etc.
 - Some resource coordinators are poorly informed about self-directed services and are unable to help people learn their options to self-direct.
 - DDA doesn't provide information about provider agencies, including OHCQ surveys and other relevant public information about quality.

MARYLAND ARC OCTOBER 2014 FEEDBACK AND RECOMMENDATIONS

General Comments and Recommendations That Could Apply to the Self-directed Service Option

- *Issue:* The process for obtaining exceptions to this rule is long, arduous, and overwhelming for people with disabilities and their families. It is recommended DDA abbreviate and streamline the process.
- *Issue:* The new Home and Community-Based Services (HCBS) Federal rule states that States must plan to allow people to have the option to live alone and to choose their roommates.
- *Recommendation:* DDA should provide the staff support people need to live in their preferred living setting in the most integrated setting per their individual needs and preference. The level or severity of their disability should not preclude them from enjoying equal access to integrated and independent housing situations with the supports they need.
- *Recommendation:* DDA should not limit Personal Supports services to 82 hours/week, and develop reasonable criteria for assessing need based on individual support needs.

- The 82 hour limit is arbitrary, greatly limits self-directed services and does not correspond with individual needs or the enabling statute.

Feedback Received from Ms. Beatrice K. Johnson, Executive Support Broker, BKJ Support Brokerage Firm, on 10/27/14 via Email to Amy Daugherty at DDA

- Attended the Bowie, MD Listening Session and “was saddened to see so many families going through the same problems. These families need to be introduced to the self-directed service option.”
- Wanted to have the opportunity to say how great the self-directed service option is but the mood was very tense.
- “My suggestion would be to offer training to the Resource Coordinators and Service Coordinators about New Directions/Self-directed Service so that they can assist the family in making a more informed decision about which service [option] to use.”
- “Some of the RC/SC that I have worked with in the beginning didn’t know about self-directed services. But since working with me and we navigated the system together, they are becoming more comfortable. The RC/SC are on the front line and they need as much information as possible.”
- “I truly believe that if 60 percent of the individuals who came out to the Public Feedback Session last night were to choose self-directed services, their problems would diminish.”
- “I speak from experience. I was a Program Director for a local provider agency and I was tired of telling families that we didn’t have funding for them to receive some of the services entitled to them. I had enough, I resigned and became an independent Support Broker and started working in the New Direction Waiver. The families didn’t know that these services were available and if they did, they were misled to believe that it was very difficult, horrible, time consuming, and non-beneficial. It was my honor to change the perspective in my area because the service is so desperately needed.”
- “Self-directed services might not be for everyone, but I know first-hand that it is for at least 75 percent of the population we serve.”

Feedback Received from Mr. and Mrs. Young, Parents, on 10/27/14 via Email to Amy Daugherty at DDA

- Parents of 24 year old daughter funded in Anne Arundel County. Daughter lived in a residential home operated by the ARC for 2 ½ years and recently moved to use self-

directed services and into a home purchased by parents and staff chosen by the daughter.

- Thanked the State of Maryland for the funding.
- “While the funding was in place for the day and residential program, I definitely did not feel supported by DDA. I assumed once the ‘letter to begin’ had gone out, that I am now in partnership with DDA. This is NOT the case.
- “The original budget was cut twice. The second cut (\$1,500) was for services paid to the ARC not being delivered. I would have appreciated someone talking with me before that money was taken out. I had \$3,000 remaining in the budget not allocated, with it stated in the IP that money would be there for any shortages as this was our first year. That money too was swept away and we are not having to do a RFSC to put the money back on for 45 days of nursing (a figure I could not get from DDA, other agencies, nursing association, etc).”
- “Seems like needless paperwork continues on.....”
- “I have taken two Broker classes. Neither class spoke about the budget AND when I wrote the budget using my manual, I got denied on many items in the budget with staff telling me ‘that has changed.’ DDA must inform people in advance of changes.”
- “When I called my representative at DDA with questions while writing the budget, there was never an answer EXCEPT ‘Ask your Service Coordinator.’” Service Coordinators have said over and over, ‘THEY ARE NOT TRAINED AND DO NOT HAVE THE TIME TO HELP WITH THIS. Believe them?’”
- “The second Broker class I took there was a very clear feeling of ‘us against you’ (DDA against Broker) and it was extremely uncomfortable and troublesome. However, I did feel DDA staff did NOT understand the program, the rules, the materials, the budget, Broker problems, etc. A Power Point presentation was read verbatim and questions left unanswered. Please assume Brokers can read and have questions from being on the front lines. We need answers and help with how DDA views the budget.”
- “DDA staff need to be trained on the self-directed [service option].”
- “[Regarding] facilitating individualized services and supports- I honestly cannot see where DDA does this except financially. The next step is to have qualified people work with families. I have a B.S. in education, a minor in special education, advanced classes in special education, worked for the Department of Education at UT Texas when PL. 94-142 was passed and have taken numerous continuing education classes. I still need help with finding services and supports.”

- “They also raised issues about the development of accessible housing and promoting employment that were not related to self-directed services

Feedback from Carol Custer, Support Broker, on October 31, 2014 via Email to Amy Daugherty at DDA

Ms Custer has been a Support Broker for over four years and now support 18 clients, most of whom have one or more family members as staff. She represents clients in three of the four regions of the state but most of her clients are in the western region.

Her concerns included:

- “Disparity between regions in rules, procedures, budgets.”
- “Mistreatment of families and lack of embracing/welcoming them on the Team and as staff.”
- “Need for habilitative services in the waiver, especially sensory integration.”
- “Lack of effective behavioral supports.”
- “Lack of understanding by DDA staff regarding the needs of individuals with specific diagnoses and the trauma individuals and families are put through to make DDA understand what they need.”
- “Family staff members provide invaluable support to participants and it would be a disservice to the participants if this was curtailed in ANY way.”
- “Rules/policies are not the same from region to region! This is a state-wide program, there should be more consistency.”
- “DDA needs to recognize habilitation needs and include them in a self-directed option.”
- I would like to see DDA consider letting behavioral supports be self-directed.”
- “Originally, DDA was paying for therapies (e.g., OT, PT). When they learned they could not do this because these services were not written into the waiver correctly, that part of people’s individual service plans was not allowed anymore. However, the funding that was associated with those services was not removed! People were just told to spend the money another way while other people, especially people new to the program in the last two years, were not able to get funding for the supports they needed that were allowable under the waiver. Perhaps it is time for DDA to consider reviewing all budgets to see [how] they are being implemented and possibly redistributing some funds.”

- “DDA employees should be knowledgeable about special needs diagnoses and the needs of individuals with these diagnoses and the strain this puts on families. I attended an appeal meeting where an individual was not diagnosed with autism until he was beyond the age of 21. DDA would not give him the DD category because the parents could not produce the diagnosis prior to age 21....even though the young man had been misdiagnosed for many years. In going back through his assessment reports we could piece together all the characteristics of autism that were labeled as something else. One member of the DDA team was a special education teacher and she knew that this was a developmental disability prior to age 21, but she could not get the rest of them to see that the lack of a paper diagnoses pf that didn’t make it less true. DDA was stuck on its procedures and not listening to the evidence in these old papers about the proper diagnosis and they asked the family to produce something that did not and could not ever exist. The young man never did get the DD diagnosis and is struggling to get supports from other agencies/organizations that are not set up to meet his needs. His parents are in their seventies and very worried about what will happen to their son after they are gone.”

1/28/15 Conference Call with Gail Godwin, Executive Director of Shared Support Maryland

- Confirmed many of the issues raised in feedback related to clarifying roles and responsibilities for entities and individuals involved in regulating, providing and using the self-directed option (state agencies, resource coordinators, service coordinators, support brokers, FMS entities, DDA staff, advocates, individuals who provide self-directed services and those that use them and those that monitor effectiveness of services and supports (resource coordinators, service coordinators, support brokers and FMS) provided; outreach and access to self-directed services, communication and education about self-directed services; variation in access to and use of self-directed services and provision of supports by region, needed for improved education and training for DDA staff, resource coordinators, service coordinators, support brokers, waiver participants, families, and self-directed service providers; administrative burdens, complexity and delays in developing and implementing individual service plans and budgets, needing more professional support brokers, disconnect between DDA and Medicaid and program and fiscal integrity issues.

February 20, 2015

To: Nancy Hatch, MD Developmental Disabilities Administration

FR: Sue Flanagan, MPH, Ph.D.

Re: Review and Analysis of Public Sector Feedback Related to the Self-directed Service Option and Recommendations for Improvement (Deliverable #5)

The purpose of this memorandum (Deliverable #5) is to summarize the review and analysis of public sector comments received by the Developmental Disabilities Administration (DDA) related to the self-directed service option provided under the Medicaid §1915(c) Community Pathways Waiver and provide recommendations for improving the delivery of these service and related CMS required supports.

I. APPROACH USE TO CONDUCT THE REVIEW AND ANALYSIS OF PUBLIC SECTOR FEEDBACK

The approach used to conduct the review and analysis of public sector feedback regarding the self-directed service option included a number of steps. First, the DDA's Medicaid §1915(c) Community Pathways Waiver renewal was reviewed, and findings and recommendations for improvement were documented (see Deliverable #2). In addition, various DDA documents and materials related to the §1915(c) Community Pathways Waiver renewal and the self-directed service option were reviewed. Attachment C of this memorandum includes a summary of the findings and recommendations related to Appendix C of the §1915(c) Community Pathways Waiver renewal.

Then public sector comments collected from a number of different forums and posted on the DDA website and received through interviews and emails were reviewed and analyzed. Sources of public sector feedback included:

- 10/22/14 Listen Session #1 in Bowie, MD
- 10/23/14 Listening Session #2 in Hagerstown, MD
- 10/27/14 Listening Session #3 in Columbia, MD
- 10/28/14 Listening Session #4 in Easton, MD
- 10/27/14 People on the Go Feedback
- 10/29/14 Conference call with A. Daugherty , DDA Moderating and Mary Sowers and Jeanine Zlockie Facilitating
- 10/28/14 DD Council Community Pathways Waiver Feedback
- 10/27/14 MDLC Feedback and Recommendations
- October 2014 Maryland ARC Feedback and Recommendations
- 10/27/14 Feedback from Ms Beatrice K. Johnson, Executive Support Broker , BKJ Support Brokerage Firm via Email to A. Daugherty, DDA
- 10/27/14 Feedback from Mr. & Mrs. Young, Parents
- 10/31/14 Feedback from Carol Custer, Support Broker
- 12/22/14 Interview with Edward Willard, Director of Advocacy Supports, DDA
- 1/28/15 Conference Call with Gail Godwin, Executive Director, Shared Support Maryland.

The feedback was organized based on issues and recommendations that were specific to the self-directed service option and those that were general in nature, but could apply to the self-directed service option. A summary of the public sector feedback from the Listening Sessions and emails received, reviewed and analyzed can be found in Attachment A of this memorandum. A summary of the 12/22/14 interview with Edward Willard, Director of Advocacy Supports is included in Attachment B.

Feedback received could not be categorized in all cases by the type of person providing it (e.g., family member, support broker, self-advocate, other) and was not collected using research methods that allow for drawing inferences that are statistically significant and generalizable. However, a number of themes emerged from the analysis that are considered important for enhancing the provision of self-directed services under the Medicaid §1915(c) Community Pathways Waiver. These are discussed in the following sections of this memorandum.

II. KEY ISSUES AND FINDINGS RELATED TO THE SELF-DIRECTED SERVICE OPTION BASED ON THE ANALYSIS OF THE PUBLIC SECTOR FEEDBACK

A number of key issues and findings related to the self-directed service option emerged based on the analysis of public sector feedback received. The following summarizes the key issues and finding and provides recommendations for improvement.

1. Public Sector Comments in Support of the Self-directed Service Option

a. Statement of Issue and Findings

There is clearly a following and support for the self-directed service option, even in its current implementation. A family respondent commented that her daughter was in the New Directions Waiver. She wanted to say how valuable she found the self-directed service option.

“She’s greatly benefited from being able to self-direct her life rather than being places where she had to follow the plan of what everyone else was doing. I’m hoping that as it [New Directions Waiver and self-directed service option] merges with the Community Pathways waiver and that nothing will change unless it makes it even better.”

Another respondent reported, “I wanted to have the opportunity to say how great the self-directed service option is but the mood was very tense [in the listening session she attended].”

A respondent who was a service provide and now is a support broker reported, “I truly believe that if 60 percent of the individuals who came out to the Public Feedback [Listening] Session last night were to choose self-directed services, their problems would diminish.” She went on to say:

“I speak from experience. I was a Program Director for a local provider agency and I was tired of telling families that we didn’t have funding for them to receive some of the services entitled to them. I had enough and I resigned and became an independent Support Broker and started working in the New Direction Waiver. [I found] families didn’t know that these services were available and if they did, they were misled to believe that it was very difficult,

horrible, time consuming, and non-beneficial. It was my honor to change the perspective in my area because the service is so desperately needed.”

The respondent ended her comments by stating “Self-directed services might not be for everyone, but I know first-hand that it is for at least 75 percent of the population we serve.” Another commented, “Self-direction should be for everyone and support all to make decisions.”

A number of “successes” were reported related to the provision of self-directed services. These included:

- “Individuals have a choice in hiring staff – more personal.”
- “Under the New Direction’s Waiver individuals had the freedom to determine their support worker’s wages, as long as they were in compliance with MD Department of Labor Wage and Hour Laws.”
- “Support workers are more dedicated and committed and help individuals meet their goals.”
- [Individuals and families are] more confident in the support workers they hire directly and have more comfortable interactions.”
- “Being able to use the services of a Financial Management Service (FMS) organization is very good.”
- “Having control over the individual budget for services is very good.”
- “Service delivery more seamless and flexible.”
- “Information about upcoming rule changes has improved.”
- “DDA has improved its policy for persons who have children under guardianship.”
- “DDA receives a lot of “free” natural supports from families.”

b. Recommendations

The following recommendations are presented for DDA consideration based on the public sector comments received and analyzed.

1. DDA should identify those individuals and families who are users and supporters of the self-directed service option and document and analyze why this is so, what they think might improve the delivery of self-directed services from their perspective and what are the key supports that they think should be provided to make individuals and families comfortable in using self-directed services.
2. Consider recruiting and training some of the users/supporters of the self-directed service option as “peer mentors” and develop a role for them in the outreach and introduction to the self-directed service option function and during enrollment of individuals and families in the option to dispel myths and inaccuracies about the service option and to address questions and concerns individuals and families may have about using self-directed services.
3. Consider developing participant/representative testimonials that describe the individual’s experience using self-directed services and the benefits they have received from them. An

example of a participant testimonial from the Arkansas *IndependentChoices* Program is provided in Attachment A.

2. Accessing Self-directed Services

A number of issues related accessing self-directed services were raised in the public sector comments.

a. Statement of Issue and Findings

In effective outreach and introduction to and information about the self-directed option resulting in a lack of access to self-directed services was raised in the public sector comments and in a number of ways. This lack of access and information could be a major driver in low enrollment in the self-directed service option.

One respondent reported,

“Resource Coordinators are the first point of for information about services and supports, however, they often lack adequate information, understanding and awareness of self-directed services.”

In addition, the respondent reported,

“Some Resource Coordinators conveyed they don’t know much if anything about self-directed services.”

A number of respondents reported that individuals and families sometimes are not informed of or steered away from the self-directed service option because it takes more time [for the Resource Coordinator]. One respondent reported,

“Resource coordinators are not letting families know about the self-directed service option; [I] feel that provider agencies are “holding back” this information and support brokers are needed to navigate the DDA system.”

Another commented:

“[I found] families didn’t know that these services were available and if they did, they were misled to believe that they were very difficult, horrible, time consuming, and non-beneficial [to use]. Another respondent reported “....I feel that provider agencies are ‘holding back’ this information [about self-directed service option].”

In addition, a respondent reported that when people self-directing their services need more services or their planning becomes more complex, some Resource Coordinators are steering them to traditional services rather than figuring out how to make self-direction work.

One respondent reported there is a fundamental problem regarding choice under self-direction.

“[It is] not emphasized...there is less choice in the [service delivery] system than ever.” Another respondent reported that messaging about the

self-directed service option is fragmented and inconsistent across regions.
“Self-direction should be for everyone and support all to make [their] decisions.”

One respondent reported that access to self-directed services is difficult and raised an issue about the level of regulation and lack of clarity related to the roles and responsibilities of the resource coordinator and the support broker.

“Self-directed services have been extremely difficult to obtain and saddled by extraordinarily dense rules. The rules are especially unclear about the mutual responsibilities of support brokers and resource coordinators. DDA should improve its staff support of self-direction and develop rules that will foster rather than inhibit self-direction.”

Another respondent commented:

“DDA should make clear to new persons on the waiver who wish to self-direct that they do not have to have a provider agency in order to access most supports and services. Much of the language that has been suggested for the waiver is often times provider focused and this could leave one with the mistaken impression that they have to use a community based provider in order to self-direct their services.”

One respondent recommended:

“DDA should make clear to new persons on the waiver who wish to self direct that do not have to use a provide agency in order to access supports and services. Much of the language that has been suggested for the waiver is often provider focused and this could leave one with the mistaken impression that they have to use a community-based provider in order to self-directed their services.”

One respondent commented:

“ Self-directed services have been extremely difficult to obtain and are Saddled with extraordinarily dense rules. The rules are especially unclear About the mutual responsibilities of support brokers and resource coordinators.”

A respondent reported that the DDA needs clear, correct, consistent and easy to understand information about its service delivery system including the self-directed service option. “Families need help understanding all of the services they may be able to access.”

A number of respondents reported a need for increased infrastructure in order to effectively use self-directed services. One respondent reported:

“[DDA should] allow coverage of an inexpensive fax/scanner/printer when individuals/families need to transmit forms cost-effectively and efficiently to the FMS, Resource Coordinator and/or support broker. Without this, funds are used for staff salary and travel to pick up the forms. This is more costly and diverts staff hours to administrative functions.”

Another respondent reported: “Common law employers do not get funding for needed infrastructure [to use self-directed services], such as a scanner.”

b. State Promising Practice Example

It should be noted that the Tennessee Bureau of TennCare has implemented an approach that has improved enrollment in their self-directed service program for older people and individuals with physical disabilities (“Choices” Program). They requires care coordinators (case manager) to reintroduce the self-directed service option to waiver participants who are not enrolled in the self-directed service option each time they do waiver participants’ periodic reassessment/individual service plan updates using a standard protocol and materials. They found this very effective in improving waiver participant enrollment in the self-directed service option.

In addition, TennCare staff mentioned that the State’s Medicaid ID/DD Self-Determination Waiver Program does not require case managers to reintroduce the self-directed service option to waiver participants who are not enrolled in the self-directed service option during the reassessment/individual service plan update. As a result, the state program staff found that some case managers who are supportive of the self-directed service option do reintroduce it on their own and have significant number of individuals in their case load enrolled in the self-directed service option. Other case managers who are not supportive of the self-directed service option do not reintroduce the self-directed service option on their own and have very few waiver participants in their case load enrolled in the self-directed service option.

c. Recommendations

The following recommendations regarding outreach and information about the self-directed service option are presented for DDA consideration based on the public sector comments received.

1. Develop and implement a clear approach to branding the self-directed service option.
 - a. The name of the self-directed service option should clearly translate to self-directed services.
 - b. An introductory *Self-directed Service Option Brochure* and a *Self-directed Services Option Question and Answer Fact Sheet* should be developed for the self-directed service option and be used consistently by individuals and entities performing the self-directed service option outreach and information function consistently in all regions of the state. An example brochure from the New Mexico *Mi Via* Program is provided in Attachment C.

- i. These documents should be reviewed at least annually, and as needed to make sure the information provided is current and accurate.
 - c. A letter should be issued from someone in authority that is known and respected by the ID/DD community (e.g., DDA Executive Director Bernie Simons) introducing them to the self-directed service option. Groups should include, but not be limited to members and families of the intellectual and developmental disabilities community including those individuals currently using Medicaid State Plan and Community Pathways Waiver services and those on any wait lists.
 - d. A “No Wrong Door” approach should be developed and implemented for the self-directed service option outreach and introduction function that is the same in each region of the state. DDA may need two approaches, one for the ID/DD community not yet receiving Medicaid-funded services (i.e., through the State’s No Wrong Door System) and the other for individuals already receiving Medicaid-funded State Plan and Community Pathways Waiver services (i.e., through DDA’s Support Coordinators).
- 2. The individuals and entities responsible for conducting outreach and introducing individuals to the self-directed option should be identified, have appropriate qualifications and competencies to perform the function, be trained using a standard curriculum developed by DDA, and perform in compliance with standard DDA operations policies and procedures and be monitored using a systematic approach regardless of where they perform the function in the State.
 - a. DDA needs to clarify who the individuals and entities responsible for the self-directed outreach and introduction function will for (1) an individual who is new to the DDA system versus (2) individuals currently being served by the DDA system including the Medicaid Community-First §1915(k) SPA, §1915(i) SPA and §1915(c)Community Pathways Waiver but are not using the self-directed service option and make sure that all individuals responsible for performing the outreach and introduction function are held to the same qualifications, competencies, training, implementation policies and procedures and monitoring requirements regarding of where they perform the function in the State.
 - b. The individual/entity responsible for conducting person-centered planning and individual budgeting (e.g., Coordinator of Community Services)¹required to reintroduce waiver participants not using self-directed service to the option using a standard approach every time waiver participants are reassessed for services and their individual service plans are revised/updated.
 - c. The performance of individuals and entities performing outreach and introduction on self-directed services (either initially or when reassessments/individual service plan updates are done) should be monitored in a consistent manner across the state using a

¹ The term “Coordinator of Community Services” is the term proposed to replace the terms “Service Coordinator” and “Resource Coordinator” at DDA.

standard curriculum developed by DDA that includes a discrete number of performance standards and consequences for poor performance.

3. The qualifications/competencies, training, operational policies and procedures and performance monitoring policies, procedures and internal controls for the outreach and initial education function should be developed and implemented in the same way for all individuals and entities responsible for performing the outreach and introduction function, regardless of where they perform the function in the state.
4. DDA should consider providing some funding for individuals and families to purchase select infrastructure items (fax machine) that assist individuals and families in effectively performing and administrative duties related to using self-directed services.

3. Communication and Information About Using the Self-directed Service Option

A number of issues related to communication and information about using self-directed services were raised in the public sector comments.

a. Statement of Issue and Findings

Lack of clear, accurate and current information and communications about using the self-directed service option was raised in the public sector comments. A respondent commented:

“Things are overly complicated; communication needs improvement, people [are] sent running in circles.”

A number of respondents reported that communication and information about the self-directed service option was insufficient to meet individuals’ and families’ needs to effectively use the service option and that it varied significantly by region.

One respondent reported,

“[There is] not enough information about anything, especially in writing. [There is] a serious communication gap, especially after a transition [to the community] has occurred. Once [a person receives] resource coordination, it [communication and information] is a once a year thing.... people [are] running through their paces and not getting enough information; push the paper through and get the process done.”

Another respondent reported that it is hard to navigate the DDA website to get help.² A respondent reported “Messaging is fragmented between regions. There needs to be a clear explanation of self-directed versus non self-directed services.” It should be noted that any inaccurate and old information presented on a website can cause more harm than good.

Another respondent commented:

² DDA is currently revising its website.

“DDA should help families network with one another. This is especially important for families who are engaging in self Direction so they can learn from each other.”

One respondent mentioned that DDA needs to:

“[DDA needs to] consistently communicate policy and programmatic changes that impact self-directed services to individuals and families, resource coordinator and support brokers. They should include the rationale for the changes so that [resource coordinators and] support brokers can assist individuals and Families to understand and comply. Support Brokers report they do not consistently receive information from DDA like the formal memos that providers receive.”

Another respondent reported:

“DDA needs to improve public information and communication. People need more information about the Medicaid waiver and support services, including eligibility, access to the waiver, services and rights. DDAs communications with the public should be understandable to the average reader.”

One respondent reported that a glossary of terms is needed. “DDA needs to use a common language.” Another commented, “DDA needs to build in communication, coordination and accountability.”

Finally, a respondent commented that communication is lacking from DDA and is sometimes incorrect and another respondent commented, “DDA needs consistent, clear, correct and easy to understand information.”

b. Recommendations

The following recommendations regarding information and communication about the self-directed service option are presented for DDA consideration based on the public sector comments received.

1. DDA should develop a flow chart on what information and communications about the self-directed service option be available and how it will be distributed (e.g., by whom) occur with the goal of standardizing the approach in each region of the state to ensure accuracy, currency and consistency.
2. DDA should develop a glossary of terms for its service delivery system including the self-directed service option. Then everyone should consistently use these terms.
3. Develop bulletins that describe updates on policy and programmatic changes and rationale for regional DD office staff, coordinators of community services and support brokers, and individuals/families, not just for service providers.

- a. Bulletins prepared for individuals and families should be written in language that is culturally competent and understandable to the average reader.
4. Develop and issue a monthly or quarterly *Self-directed Services Options Newsletter* that provides programmatic updates, addresses current issues and provides “tips” and promising practices on using self-directed services. An example newsletter from the New Mexico *Mi Via* Program is provided in Attachment D.
5. DDA should develop a set of standard informational documents about the self-directed service option that are used consistently in all regions of the state.
 - a. These documents should be reviewed at least annually, and as needed to make sure the information presented is accurate and current and do not contradict each other.
6. A *Participant-Representative-Employer Enrollment Packet* and a *Support Worker Employment and Individual-directed Goods and Services Vendor Engagement Packet* should be developed that includes all the key forms and agreements with corresponding instructions. Participant/representative-employers should be provided with assistance by the Vendor F/EA FMS entity and support broker, as appropriate, in completing the required forms and agreements and submitting other required information to the Vendor F/EA FMS entity for collection and processing in a manner that is seamless and reduces administrative burden for the participant/representative-employer and increases accuracy and timeliness of the information received.
7. The DDA website should be revised to make it more user friendly and informative.
 - a. DDA should poll the ID/DD community on the challenges they have experienced in using the current website and what they think is important to include on the website.
 - b. The website should be reviewed at least quarterly to make sure all information presented is accurate and current.
8. DDA, through its Advocacy Support function, should develop ways for individuals and families using self-directed services to network so they can learn from each other and be peer mentors for individuals and families who are new to using self-directed services.
- 5. Role, Responsibilities and Performance of the Resource Coordinator, Service Coordinator and Supports Broker**

A number of issues related to the role, responsibilities and performance of the Resource Coordinator, Service Coordinator and Support Broker were raised in the public sector comments.

a. Statement of Issue and Findings

Issues related to the lack of clarity about the role and responsibilities of the resource coordinator, service coordinator and support broker related to the self-directed service option, their knowledge of the self-directed service option and their performance were raised in the public sector comments. Comments related to roles and responsibilities that apply to all three included:

- “Who does what and what are each person’s responsibilities?”
- “What are the distinctions between resource coordinators and support brokers?”

Comments Received Related to Resource Coordinators

A number of comments were received about the role, responsibilities of the Resource Coordinator. These included, but were not limited to:

- “DDA does not have a consistent name it uses for the Resource Coordination Service [across the state].”
- “Role of Resource Coordinator is unclear- they are not building relationships with individuals and often families worry that they are only doing paperwork.”
- “New Resource Coordinators do not quite know their role-setting a tone to providers it is not a team.”
- “The intent of Resource Coordination has changed. Emphasis is mostly on paperwork.”

A number of comments were received regarding Resource Coordinator performance. These included, but were not limited to:

- “There is a gap in Resource Coordination. The current Resource Coordination structure does not meet the needs of complex supports and there is no communication.”
- “Resource coordination is not a waiver service anymore so the time lags are huge for families. This really holds up the process.”
- “Resource Coordinators need to be stronger. The function is rigid, new staff not skilled, lost staff [staff turnover]. No time to be creative and get to know people.”
- Related to Resource Coordinator retention, “Job is too complex and administratively focused, unlike in the past. The whole process contradicts getting people everyday lives.”
- “Resource Coordination has challenges. Do not understand the DORS role and how the services can/should be sequenced. Providers fulfilling more of the Resource Coordination role.”

- “Families find it difficult to navigate the different systems and Resource Coordinators are not helping them understand.”

A number of comments were received regarding Resource Coordinator knowledge of self-directed services. These included but were not limited to:

- “Resource Coordinators are supposed to provide information for informed decisions [making] and they do not and they make it seem too difficult to self-direct.”
- “Resource Coordinators are not knowledgeable.”
- “Resource Coordinators are the first point of for information about services and supports, however, they often lack adequate information, understanding and awareness of self-directed services.”
- “Some Resource Coordinators conveyed they don’t know much if anything about self-directed services.”
- “Some of the Resource Coordinators and Service Coordinators that I have worked with in the beginning didn’t know about self-directed services. But since working with me and we navigated the system together, they are becoming more comfortable. The Resource Coordinators/Service Coordinators are on the front line and they need as much information as possible.”

Comments Received Related to Service Coordinators

A number of comments were received regarding the service coordination function. They included, but are not limited to:

- “Interaction with Service Coordination not genuine. Paper pushing only.”
- “[It took] three months to get a service funding plan completed.”
- “Service coordination [function] does not have competencies- they do not provide help and supports.”

Comments Received Related to Support Brokers

A number of comments were received regarding the support broker function. They included, but were not limited to:

- “Support brokers do not have a training program and any subsequent on-going training in the New Directions [Waiver program] agreement there are a lot of shared responsibilities without the right training to support it for both parties.”
- “Support Brokers need training.”

- “There is a need for more highly qualified support brokers. A six hour training is not adequate to ensure necessary competencies in person-centered planning, choice, self-direction, rights, etc. “
- “The DDA support broker training must be revised and should include a more detailed level of instruction with particular emphasis on how to do budget modifications, plan modifications along with how to create a person-centered plan.”
- “With regard to parents who are acting as support brokers for their children, DDA should create a separate workshop series for them. This is not to exclude parents from the overall support broker trainings, however, the current support broker trainings often get overwhelmed with questions from parents about specific issues. This is why a separate training series should be offered with the guidance of the DDA self-directed advocate.”
- “For individuals self-directing, [the support] broker often is not in the loop of communication.”

Finally, a family respondent raised an issue about getting information and assistance with navigating the many different types of paperwork she has to deal with and the need for a person such as a resource coordinator or support broker to assist her in this area.

b. State Promising Practice Example

Another important issue related to support broker services not addressed in the public sector comments is the size of support broker caseload. In 2004, Charles Moseley at the National Association of Directors of Developmental Disability Services (NASDDDS), reported that regardless of the configuration of support broker responsibilities, a consistent theme among both the Robert Wood Johnson Foundation-funded Self-Determination and Cash and Counseling Demonstration projects was that the effectiveness of support brokers was influenced by caseload size. Caseloads that consisted of a single or only a few individuals did not seem to involve the support broker enough in the process of brokerage to fully develop their skill and competence. On the other hand, caseloads with large numbers of individuals forced the worker to focus on the needs of only those individuals in crisis to the exclusion of those persons who needed consistent, albeit less intensive assistance.

In February 2014, Jeon, et al in a study of support broker services in three cash and counseling model self-directed service program, found striking state case load differences for support broker services. In State A, seventy-four percent of support brokers had a caseload of less than 20 while the majority of support brokers in State B (55%) and State C (86%) had a caseload of more than 20. However, within the total caseload, support brokers in each state served both self-directing and non-self-directing individuals. This trend was especially prominent in State B where nearly a quarter of the clients were not enrolled in the self-directed service option.

Comments on the Level of Support Received from These Entities Related to the Self-directed Service Option

A comment was received about the lack of support provided when using self-directed services. One respondent reported:

“Got no support with self-direction. Got a budget and it was a handoff.
Had to stop the process.”

c. Recommendations

The following recommendations regarding Resource Coordinator, Service Coordinator and Support Broker functions under the self-directed service option are presented for DDA consideration based on the public sector comments received.

Resource Coordinator

1. DDA should consider dropping the term “Resource Coordinator” and “Service Coordinator”. It has been reported that DDA is consider using the term “Coordinator of Community Services” for these functions. Another term to consider is “Support Coordinator.” Most ID/DD programs are using at this time for the case management function.
2. DDA should consider reviewing and updating the tasks required for Resource and Service Coordinators and require that these staff introduce/educate all waiver participants not enrolled in the self-directed service option when the individual’s initial assessment is conducted and initial individual service plan and budgets are prepared and each time a reassessment is conducted and an individual service plan and individual budget is updated.
3. DDA should consider reviewing and updating its policies, procedures and internal controls for the providing Resource Coordination and make sure they are implemented the same in all regions of the state.
4. DDA should consider reviewing and updating Resource Coordinator qualifications and developing and implementing competencies for the function, including those related to the self-directed service option and how they will communicate and interact with support brokers.
5. DDA should consider developing operations policies, procedures and internal controls for the Resource Coordinator function that are implemented consistently in all regions of the State.
6. DDA should review and revise mandatory initial and ongoing training and a curriculum on the self-directed service option for Resource Coordinators and make sure it is implemented consistently in all regions of the state.
7. DDA should consider developing policies, procedures and internal controls for monitoring Resource Coordinator performance including their ability to introduce individuals to and educate them on using the self-directed service option and resultant enrollment. The

monitoring system should include a discrete number of performance standards and consequences for poor performance.

8. DDA should consider developing a standard curriculum and materials for introducing waiver participants to and educating them about the self-directed service option and require that all Resource Coordinators use it both initially for all waiver participants and during the reassessment/individual service plan and individual budget update process for waiver participants who are not using the self-directed service option.

Service Coordinator

1. DDA should consider eliminating the Service Coordinator position and include it under the Coordinator of Community Services function used throughout the State.

Support Broker

1. DDA should develop qualifications and competencies Support Brokers that increase their knowledge and professionalism to perform the function. These should be implemented consistently in all regions of the State.
2. DDA should consider developing and implementing mandatory support broker initial and ongoing training and develop and implement a standard curriculum and training materials that are used consistently in all regions of the State.
3. DDA should develop operations policies, procedures and internal controls for support brokers that are implemented consistently in all regions of the State.
4. DDA should consider not allowing family members to be support brokers for their family members – only for non-related parties.
5. DDA should consider developing a maximum for the number of waiver participants the support broker can serve.
6. DDA should consider developing and implementing policies, procedures, protocol and internal controls for monitoring support broker performance and that include a discrete number of performance standards and consequences for poor performance.

Provision of Supports in Using Self-directed Services by Resource Coordinators and Support Brokers

1. DDA needs to determine and document the role and responsibilities for the Resource Coordination and Support Broker functions (now Coordinator of Community Services) to eliminate gaps in supports for individuals and families and so needed supports are provided consistently and effectively in all regions of the State.

2. DDA needs to develop materials that inform individuals and families using self-directed services of the supports available any by whom they will be delivered. These materials should be standardized in all regions of the State.

6. Knowledge of DDA Staff on DDA Service Delivery System and the Self-directed Service Option and Training

A number of issues related to training for DDA staff on the DDA service delivery system and the self-directed service option were raised in the public sector comments.

a. Statement of Issue and Findings:

DDA staff's inconsistent/lack of knowledge of the DD service delivery system and the self-directed service option and the need for consistent DDA staff training in all regions of the State were raised in the public sector comments. One respondent commented:

“There needs to be better training of DDA staff. DDA staff should have Experience working with individuals with intellectual and developmental Disabilities.”

Another respondent commented:

“DDA staff need training to have consistent understanding of its own policies and Resource Coordinators need to train with them so all have the same information.”

One respondent reported, “DDA staff need to be training on the self-directed [service option].

One respondent mentioned:

“ [During a support broker class] I felt that the DDA staff did not understand the program, the rules, the materials, the budget and problems [countered by the support brokers]. A Power Point presentation was read verbatim and questions were left unanswered.”

Finally a respondent suggested:

“.... Offer training to Resource Coordinators and Service Coordinators about New Directions/self-directed services so that they can assist the family in making a more informed decision about which service option to use.”

b. Recommendations:

1. DDA should develop and implement a curricula and materials for training central office and regional office DDA staff on the self-directed service option. This training should “match” the

information and training provided for Resource Coordinators, Support Brokers, Advocacy Support function and individuals and families.

2. DDA should develop and implement a training curriculum and materials for staff performing the Advocacy Support function on Medicaid, the DD service delivery system and services, and the self-directed service option so they can effectively advocate for and address questions from individuals with ID/DD and their families.
3. Mandatory in-person, initial training should be provided to all central and regional DDA staff and staff performing the Advocacy Support function.
4. Ongoing in-person, training should be provided to all central and regional DDA staff and staff performing the Advocacy Support function at least once a year, and more often as necessary.

7. Orientation and Training for Individuals and Families on the Self-directed Service Option

a. Statement of Issues and Findings:

A number individuals raised issues about the lack of effective training for individuals and families on using self-directed services. The provision of effective training for the end user (individuals and families) is critical to the development of “informed consumers” who use self-directed services effectively.

One respondent commented that DDA needs to clarify individuals and families roles and responsibilities. “[Need to clarify] who does what and what are each person’s responsibilities.” Another respondent reported:

“Families need help understanding all the services that they may be able to access.”

Finally, another respondent commented, “Families are advocating for better skills development to do person-centered plans and behavioral support plans.”

b. Recommendations:

1. DDA should develop and implement a standard training curriculum and materials for end users (individuals and families) on using self-directed services and being the common law employer of support workers.
2. Mandatory in-person, initial training and ongoing should be provided to all individuals and families using self-directed services.

8. Clarifying Waiver Services That Are Self-directed

a. Statement of Issue and Findings:

The Community Pathways Waiver renewal offers 20 waiver services, 14 that offer a participant-directed approach, 13 of which allow for both self-direction and provider

management and one that is only participant-directed (Support Brokerage). Services include:

Community Residential Habilitation Services (not SDS)	Community Learning Services*#
Day Habilitation – Traditional (not SDS)	Community Supported Living Arrangement*#
Live-in Caregiver Rent*	Employment Discovery and Customization*#
Medical Day Care/Adult Day Health (not SDS)	Environmental Accessibility Adaptations*
Community Supported Living Arrangement/ Personal Supports*#	Environmental Assessment (not SDS)
Respite*#	Family and Individual Support Services*#
Supported Employment*#	Shared Living
Support Brokerage+^	Transition Services*
Assisted Technology and Adaptive Equipment*	Transportation*#
Behavioral Supports (not SDS)	Vehicle Modifications*

9. *This service may be participant-directed or provider managed.

10. + This service may be participant-directed only.

11. # This service may be provided by a relative or legal guardian.

12. ^ This service may be provided by a legally responsible individual, relative or legal guardian.

A review of the services provided under the Medicaid §1915(c) Community Pathways Waiver it was found that a number of services seemed to be duplicative and a number were designated as both self-directing and provider managed but in many incidences they were more frequently provider managed.

A respondent commented: [I want a] clear explanation of self-directed and non-self-directed services.” Another respondent reported,

“Within self-direction, there are some important items that are not covered (1) snow/ice removal, (2) lawn care, (other essential chores, and (4) transportation.”

A respondent reported a “lack of flexibility to move from service to service—too fragmented.”

Finally, a respondent commented that “The 82 hour/week limit on Personal Supports is arbitrary, greatly limits self-directed services and does not correspond to individual needs or the enabling statute.”

b. Recommendations:

1. It is recommended that DDA review the definitions of services available under the Community Pathways Waiver and determine any overlapping functions and revise the pertinent definitions so they address discrete functions, as applicable.

2. It is recommended that DDA review the services that are indicated as both self-directed and provider managed and review utilization by each option. Then determine if any of the services reviewed should be solely self-directed or provider managed.

8. Self-Directed Policies and Procedures and Administrative Burden Related To Self-Directed Services

a. Statement of Issues and Findings

A number of respondents commented that policies and procedures for using self-directed services were not clear and resulted in significant administrative burden for individuals and families. Respondent comments included:

- “Simplify, simplify, simply – 50 page manuals do not help.”
- “[Policies and procedures for self-directed services are] too administrative focuses and not people focused. This really takes away from the person being supported.”
- “[DDA] system writes rules without understanding the impact on people and their families.
- “[I have] very little confidence that DDA is working on regulations.”
- “DDA is not clear on goals and has not established structured services/payments to further community integration.”
- “There is ambiguity in approval processes and criteria from region to region.”
- “There is no fluidity to further self-determination. Individuals need a modification for each change.”
- “Need clear and consistent communication and written policies.”
- “There are so many programs with overlapping paper requirements that is a huge burden on families.”
- “Seems like needless paperwork continues on.....”
- “Billing and payment systems are outdated and do not allow for agility and flexibility in serving individuals in a person-centered manner.”

One respondent reported:

“Self-directed services used to be among the quickest services to initiate but now it takes much longer. [Reasons for this include] not enough staff at DDA regional offices and more burdensome rules. Some people initially involved in self-directed services are switching to traditional services either because the approval process is significantly delayed or too cumbersome.”

Another respondent recommended:

“Conducting a thorough analysis to identify and eliminate unnecessary administrative burden on the individual/family, support broker and resource coordinator. Convert as many processes as possible to online functions.”

b. Recommendations

1. DDA should develop a crosswalk of the roles and responsibilities all key players in regulating, providing and using self-directed services with a focus on central and regional office staff to

determine gaps and duplications in policies, procedures and paperwork associated with the provision of self-directed services.

2. DDA should consolidate reporting functions as much as possible and develop effective “packets” with instructions to facilitate accurate and timely reporting and reduce administrative burden.
3. DDA should develop and maintain a Self-directed Services Operations Manual. This manual should include all policies, procedures and internal controls for all required functions and tasks and identify the individual/entity performing them. When developing the manual, the DDA should review the functions and tasks and determine and address any gaps and/or duplication in order to streamline policies and procedures and reduce administrative burden for individuals, families and those administering and monitoring the self-directed service option.

9. Challenges Related to Developing and Implementing Person-centered Service Plans and Budgets

a. Statement of Issues and Findings

A number of respondents raised issues related to developing and implementing person-centered service plans and budgets. Respondent comments regarding individual budgets included:

- “[In] self-directed, can’t move money after March unless health or safety issue, which means money goes unspent unless it is moved. What is the reason for this?”
- “Three months to get a service funding plan completed and delays.”
- Is there a reasonable purpose for requiring sub-accounts within a line item? If not, alter this policy so accountability is accomplished by approving an amount for each line item with a notation of what a line-item includes without specifically allocating amounts to each sub-item.
- “Waiting for DDA approval can result in a needed support being unnecessarily delayed or not approved, particularly near the end of the fiscal year when approvals are not/cannot be processed quickly.”
- “The original budget was cut twice.I would have appreciate someone talking with me before that money was taken out. “

Comments related to person-centered individual service planning included:

- “[The] Individual service plan does not connect to funding, People’s needs change but funding is so hard to change without extensive documentation.”
- “Person-centered planning needs improvement.”
- “Streamline the annual service funding plan update; now required to re-review and re-submit; not required of traditional services. With the process in place for an annual individual service plan and budget and modifications as needed, would a year-end reconciliation or an update instead of an approval process be more efficient and timely yet still ensure accountability?”
- “Waiting for DDA approval can result in a needed support being unnecessarily delayed or not approved, particularly near the end of the fiscal year when approvals are not/cannot be processed quickly.”

b. Recommendations

1. DDA should review its policies, procedures and internal controls for developing, updating and monitoring person-centered service plans and individual budgets to determine logic, soundness and level of administrative burden on individuals and families.
2. Revise policies, procedures and internal controls for developing, updating and monitoring person-centered service plans and individual budgets based on review described in #1 above and clearly document them for use by DDA central office and regional office staff and the public sector including individuals and families.
3. Develop a curriculum and materials for training DDA central and regional office staff, Coordinators of Community Services, support broker and individuals and families on developing, updating and monitoring person-centered individual service plans and individual budgets.
4. Conduct initial and ongoing training on developing, updating and monitoring person-centered individual service plans and individual budget for DDA central and regional office staff, Coordinators of Community Services, support broker and individuals and families.

10. Addressing Regional Differences in Implementing the Self-directed Service Option

a. Statement of Issues and Findings

A number of individuals raised issues about regional issues related to accessing and using the self-directed service option. One respondent commented, “[There are] eligibility issues between regions. People change regions just to get eligibility.”

Another respondent reported, “Resources are very different between regions.” Yet another commented, “Messaging is fragmented between regions, there is no consistency.” One respondent reported, “Regional differences is a problem – variation from region to region” while another commented, “[There is] disparity between in regions, rules, procedures and budgets.”

Finally, a respondent recommended,

“Eliminate/reduce regional discrepancies, particularly Central Regional Office compared to other regions. It has been reported that Central Regional Office typically takes months longer to process requests and what it will approves differs. Some perceptions are that CMRO uses its on interpretations.”

b. Recommendations

1. DDA should consider developing a cross walk of the roles and responsibilities, qualifications and training requirements of all individuals/entities involved in a person's life through the DDA system (e.g., resource/service coordinators, support brokers DDA central and regional office staff, providers, support workers) and identify gaps and overlapping activities.
2. DDA should make sure that all elements of the self-directed service option, including information and materials, and operational policies, procedures and internal controls for outreach, education, enrollment, provision and monitoring of services, program staff and Coordinators of Community Services and support broker competencies and Coordinators of Community Services and support broker staff and individual/family training and performance monitoring are standardized and consistently implemented in all regions of the state.

I hope this information is helpful. Please let me know if you have any questions or comments regarding this information (202) 337-0180 or sflanagan@westchesterconsulting.com.

March 26, 2015

To: Nancy Hatch, DDA
Edward Willard, DDA

Fr: Sue Flanagan, MPH. Ph.D.

Re: Summary of Issues Raised at 3/25/15 Self-Advocates Webinar/Listening Session for Users of Self-directed Services (Deliverable #12).

On Wednesday, March 25, 2015, with great assistance from Tami Goldsmith and Ken Capone from *People on the Go*, Edward Willard, Director of Advocacy Support at DDA and I facilitated a webinar/listening session with self-advocates and their parents on their experience using self-directed services. Participants in the webinar included:

Tami Goldsmith (TG) – *People on the Go*
Ken Capone (KC) – Self Advocate, *People on the Go*
Edward Willard (EW) - Director of Self-Advocacy Support, DDA
Sue Flanagan, (SF) – Westchester Consulting Group
Laurie Bittinger (LB) – Self-Advocate
Melanie Smith (MS) – Self- Advocate
Maria Ahmad (MA) – Self-Advocate
David Perry (DP) – Self-Advocate
Lisa Bittinger (LB2) – Laurie Bittinger’s Mother
Marcie Perry (MP) – David Perry’s Mother
Tony Fitch (TF) - Ben Fitch’s Father/Guardian (new to using SDS)
Babette Smith (BS), Melanie Smith’s Mother
Terri Pumputis (TP), Parent of Justin Sauter and Direct Support Worker

Edward Willard (EW) opened the webinar/listening session, introduced me and welcomed all to the session. Then I took people through a brief power point presentation that described the goals of the session, provided a brief overview of self-directed services and the DDA self-directed service option and included the questions to be discussed during the session (See Attachment A). The following summarizes and the key issues raised during the webinar/listening session and provides some recommendations.

I. What has worked for you related to using self-directed services?

Edward Willard also asked the group, “Do self-directed services help people get into the community? Participants had a variety of experiences using self-directed services.”

1. Findings

Participants reported a number of ways in which using self-directed services has worked for them (See Section #2 below). Some reported being able to hire, schedule work and fire direct support staff and

being able to have family as paid direct support worker as being important. One Self-Advocate reported being able to hire an independent support broker was important, while another reported the flexibility of when she gets to work due to medical episodes being important. Finally, one parent of a Self-Advocate reported that self-directed services allowed him to attend college at this own pace, while another parent mentioned the importance of being able to change the individual budget as the year goes on as needs change as important.

2. Comments

The following are the comments received from participants related to this question.

- TP - "As the parent, being able to be a paid direct support staff person."
- KC- "Hiring and firing [my direct support staff]."
- BS - "For her [MS] to be able to develop [the direct support staff's] the schedule to her [needs and wants] rather than having a schedule that does not work for her."
- LB - "I have been able to stay at home after seizures and can stay home and sleep and then go to her job."
- LB - "I make more choices for myself. I can live the way I want to live."
- LB - "I love this program."
- KC - "[Being able to set] the budget is needed."
- MP - "We can change the budget as the year goes on as his needs change."
- MP- "David has had the opportunity to go to college at his pace. He would not have had this opportunity in a day program."
- KC - "I am able to hire an independent support broker."

II. What have been the biggest challenges you have experienced using self-directed services?

Participants raised a number of issues regarding the current DDA service delivery system and using self-directed services. In general, they reported that it should not be so much work to use self-directed services. The area that received the most comments in general and of a negative nature where those that addressed communication and receipt of information about self-directed services. Findings and participants' comments are provided below by sub-question.

A. Accessing self-directed services?

1. Findings

Overall, participants did not report any significant barriers accessing self-directed services. However, one participant reported that some resource coordinators discourage people from using self-directed services because they do not know much about the service delivery option.

2. Comments

The following are the comments received from participants related to this question.

- TP - "[Justin] did not have to wait long to receive self-directed services and he has great support staff and support broker."

- KC – Stated he was not sure what the question meant and I described the question further to the group.
- KC –“I think more people would use self-directed services if resource coordinators knew more. Some resource coordinators discourage people from using the option because they don’t know much about it.”
- MP – “No, David did not have a long wait [to get to use self-directed services] and has been using them for about two years.”

B. Communicating with and receiving information about the self-directed service option?

1. Findings

Participants had a significant number of comments, and negative ones, related to the communication and receipt of information related to receiving self-directed services (see below). Some participants reported being pleased with their communication and receipt of information about self-directed services from their support brokers and resource coordinators. However, others, particularly a participant new to self-directed services, reported having an extremely difficult time getting the information he needed to manage his son’s self-directed services including from formal resources (i.e., resource coordinator, DDA website and materials). Satisfaction with the level of communication and receipt of information appeared to vary by region, knowledge of the resource coordinator and support broker and whether a person was new to using self-directed services or a “veteran.” In addition, it appeared that participants thought it was essential to receive and be certified as a support broker in order to receive the information necessary to successfully use self-directed services.

2. Comments

The following are the comments received from participants related to this question.

- TP – “When changes are made to the self-directed service option, how do we get updates?”
 - EW and SF commented that DDA is working on their process for communicating with families including revising its website.
- MP – “Without a good support broker you are kind of at a loss as far as hearing about any changes.”
- TF – agreed with MP comment above. “When you are just beginningI have had a very hard time and I am very aggravated about, learning the basic ‘ropes’ of the program. Where can I find the rules and regulations? How do I find out information on due dates? I have now given up being a support broker and have retained one. A good one is essential. I cannot emphasize how difficult it has been to get underway and to understand what needs to be done next. You [people on the phone] are light years ahead of me. I have had a great deal of trouble in the last two months since the submission of a cost neutral service change request in January authorizing him [son Ben] to go into the self-directed service program.”
- KC – “This [TF comment above] is typical due to all the controversy at DDA over the past couple of years.”
- LB2 – The easiest way for a person to learn about the self-directed service option and learn the ropes is to go to the support broker training. LB’s sister and I have taken all of the training to keep our support broker certificate current because that is where you find out information and

hearing experiences of other clients parents and their family members. Need to attend those to get the full picture.”

- TF – “I took the support broker training last summer [2014] and found it useful. But it did not prepare me know where to find all the information, such as regulations, who I can hire and who I cannot hire, where are the authorized rates of compensation and for contractual services and budgetary forms.”
- LB2 – Do you (TF) have the disc or the hard copy of the [DDA Self-directed Services] Manual? It has hundreds of pages where that information can be found.”
- TF – “I never knew about this.”
- EW – Reported that DDA no longer has the disc or hard copy of the Manual anymore.
- TG – Asked “Is there a place where people should go to get the information or should they talk to their Resource Coordinator?”
- EW – “Should talk to your Resource Coordinator.”
- TF – “The problem with that is I live in Montgomery County and it ceased providing resource coordination services directly. Now they contract it [the service] out. When I tracked down the new resource coordinator from the contractor, I learned in 18 seconds that she had never heard of a self-directed program. Although she is a very nice person, she is of no use what so ever. The whole process has been extremely difficult and frustrating for a person who is not stupid.”
- TP – “Isn’t there a place on the DDA website that has all the information [on the program]?”
- EW – “We are working on the website.”
- KC – “I think more people would use self-directed services if resource coordinators knew more. Some resource coordinators discourage people from using the option because they don’t know much about it.”
- TF – “I couldn’t agree more [with KC comment above]. In fact I have been searching the website with assistance from the chief executive of Ben’s day program and neither of us could find much on the website at this time.”
- LB- “My resource coordinator told me about the New Directions Waiver and self-directed services and helped me a lot.”

C. Developing, implementing and updating your IP? Does you IP meet your need for services?

1. Findings

Overall, participants appeared to be satisfied with their individual plans (IPs) and the process used to develop, implement and update them.

2. Comments

The following are the comments received from participants related to this question.

- BS – “We have had great success developing, implementing and updating Melanie’s individual plan (IP) and helping her think outside of the box to get what she needs in the plan to get her to reach her full potential in the next year. We have good success with that and we have a great service coordinator.”

- LB- “My team meets every 45 days and talk about everything including what needs to be changes and asked about.”
- KC – “I help develop my plan so yes, it meets my needs.”

D. Developing, implementing and updating your individual budget?

1. Findings

Overall, participants appeared to be satisfied with their individual budgets (IPs) and the process used to develop, implement and update them.

2. Comments

The following are the comments received from participants related to this question.

- KC – “[Being able to set] the budget is needed.”
- MP – “We can change the budget as the year goes on as his needs change.”
- MP – “With the help of the support broker it is a piece of cake. I am learning from the support broker so I can do a lot of it on my own. So I am saving money and able to apply it somewhere else.”
- TP- “I agree with MP, with the help of a support broker we have not had any problem developing and implementing the budget.”
- KC- “I help with developing the budget too. My support broker and I do the budget together.”
- LB – “I work with my communication device before I make decisions. I make more choices for myself while working on the budget.”
- TP – Regarding the process and approval time for the budget – “The budget we currently have, we added services we need with the service coordinator and support broker. That [budget] has been turned into the DDA Central Region but we have not received a yeah or nay yet. I believe we met in January.”
- BS – “We have found that when we get the budget into the Resource Coordinator it seems to go fast [through the approval process].”

E. Receiving supports to facilitate your use of self-directed services?

1. Findings

Overall, participants seems to be satisfied with their FMS and their Information and Assistance (I&A) Services (e.g., support brokerage and resource coordination services. This is very different from the Listening Session Nancy Hatch and I conducted earlier this month in Landsdowne, Maryland. One participant reported having trouble with a support broker hired through a corporation and that the corporation subsequently was not financially viable. Finally, at least one participant reported that it would be good if resource coordinators had more knowledge and that more people probably would use self-directed services if resource coordinators had more knowledge about self-directed services.

2. Comments

The following are the comments received from participants related to this question.

- MP – “Recently we had a challenge with the support broker. We hired a corporation to provide support broker services. The corporation was falling apart. We got rid of them and I took over until we could get another support broker. Now I am doing some of the tasks (invoicing) and the new support broker is doing the paperwork with DDA and acting as out outside eye [on collecting program information and updates].
- KC- “FMS is great. Would be good if my service coordinator knew more.”
- KC –“I think more people would use self-directed services if resource coordinators knew more. Some resource coordinators discourage people from using the option because they don’t know much about it.”
- TP- “FMS, service coordinator and support broker are excellent. We have not experienced any problems.”
- DP – Signed that things are okay for him.
- LB2 – “The Western Region is excellent. The resource coordinator is on top of everything. Have had good experience with local resource/service coordinators. The two she has had introduced them to New Directions and using self-directed services.”

F. Using self-directed services?

1. Hiring staff?

a. Findings

Overall, participants reported hiring direct support staff is a challenge. One participant reported that in some cases direct support staff candidates “glorify” their abilities. Once hired and after a few week, some find the job more challenging that they thought and either quit or have to be let go.

b. Comments

The following are the comments received from participants related to this question.

- MP – Finding the right people with the right knowledge and experience can be challenging. Some direct support staff candidates “glorify” their abilities. Once hired and after a week or two, some find the job more challenging that they thought and either quit or have to be let go.”
- MP – “It was nice to have the support broker sitting in on interviews.”
- BS- “I think this is one of the reasons why it is great that we can hire family who have a history [with the person receiving services] and not starting from scratch.”

- TP- "I totally agree with BS [above]."
- KC – "Finding good people [direct support staff] is always a challenge but I am glad to be able to hire and fire my direct support staff."
- LB – "You can't have care without love. Love is why it is great to be able to hire relatives. I ask my staff to have a drug test."

2. Managing staff?

a. Findings

b. Comments

The following are the comments received from participants related to this question.

- MP – "at this stage in David's program, it seems like the staff is managing him; they act like independent contractor and I have to remind her that she works for David. This really is a job that she has to do (i.e., regardless of her personal appointments).
- KC – "I like being able to set their [direct support staff] work schedule to meet my needs."
- MP- Experienced having a direct support staff not completing their timesheet properly. "I corrected it myself and went to our support broker [and informed them]. If it is incorrect by a few hours it's a big deal. [The direct support staff] reported hours he/she was absent. [The direct support staff] found out about the correction when they received their paycheck. There was no push back from the direct support staff."

3. Firing staff?

a. Findings

In general, participants' agreed that firing direct support staff is stressful and that they welcome receiving support regarding this employer tasks. However, it was reported that in some cases, support brokers, rather than the waiver participant or family member employer is firing waiver participants' direct support workers. This puts the support broker at risk of being a joint employer and at risk of any potential liability that may arise from performing that employer function.

b. Comments

The following are the comments received from participants related to this question.

- MP – "...nice to have the support broker and tell him/her to fire the direct support staff. The discussion that takes place between David, myself and the support broker and if the support broker is willing to fire the direct support staff I let her do it."
- SF – "Hiring, managing and firing direct support staff really is not the job of the support broker. It makes the person either a joint employer or sole employer of the direct support worker and could introduce liability for the support broker that he/she may not want to take on if she is made aware of it. The employer (waiver participant or family member) can receive training and assistance from the support broker on how to be an effective employer (hiring techniques,

management techniques and problem solving, and good firing practices and practice roll playing), but he/she is not the employer of the direct support staff.”

- BS – “I am concerned about what you mentioned that support brokers should not be firing staff. I am a support broker for others (not my child) and the list of tasks for support brokers on the DDA website includes firing staff if the person is not up to the task.”
- SF – “Technically, if the support broker is allowed to fire direct support staff, it makes that person at least a joint employer of the direct support staff and I don’t know if a support broker would want the potential liability that goes along with being a joint employer. We will need to bring this issue back to DDA for discussion. If there is a problem the Department of Labor could come back and say it’s not just an issue for the waiver participant or family member, it is also an issue for the support broker because he/she did the firing.”
- EW – If someone needs support, while firing a direct support staff, is that okay for the support broker to provide?
- SF – Yes, as described above. “Might want another person in the house when firing a direct support staff.”

G. Other Issues Raised by Participant

1. Findings

Participants raised a number of final issues related to self-directed services. Issues included tuition not being an allowable expense, and why school systems are not being informed of the self-directed service option.

2. Comments

The following are the additional comments received from participants.

- LB2 – One of the most unique things about self-directed services is that family members can be involved.”
- MP- “Yes, I agree with LB2 above. I have a question about job coaching and comparing that to education. If they are assisting you in getting an education to get a job, why is there such an argument about it?” Why don’t they help you with the tuition as an allowable cost?”
- EW – “Not a Medicaid waiver expense that is allowable.”
- TP- “When my son graduated from high school, the self-directed service option was not common knowledge in the schools. They talked about what Center was available and if the person was high functioning, what job opportunities might be available. Self-directed services wasn’t provided as a choice until a couple of years ago. Why isn’t Medicaid/DDA getting more information about this option to the schools? A lot of these Centers do not want to deal with people who have behavior problems.”

III. Recommendations

DDA should consider the following recommendations based on the comments received from Self-Advocates and their families during this webinar/listening session.

A. Have the Appropriate Person Be the Common Law Employer

The common law employer of direct support workers should be able and willing to perform the employer tasks including participating in an unemployment claims hearing. If a waiver participant is not able or willing to be the common law employer of his/her direct support staff, then his or her representative, including a family member, should assume the role of the common law employer. In both cases, the participant or his representative should receive adequate orientation, training and supports to be able to perform the tasks successfully. It should be noted that supports provided by the support broker to the participant/representative-employer should not include performing employer tasks (i.e., hiring, managing or firing direct support workers directly) that would result in the Department of Labor making the determination that the support broker is either the sole employer or joint employer of the participants' direct support workers.

B. Standardized Initial Orientation and Training on Ongoing Training and Materials for Participant/Family Employers

As mentioned earlier, family members feel they must become a support broker to obtain the information necessary to use self-directed service and perform as an employer effectively. This should not be the case. Rather, it is recommended that DDA develop and implement materials and orientation and trainings specifically for waiver participants and family members responsible for self-directing services and being the employer of direct support staff. They also should receive regular, periodic updates regarding self-directed service policies and procedures and all information about the self-directed service option should be current and available in hardcopy and online in a centralized location such as the DDA website. Also, it is recommended that DDA develop standardized "packets" of forms, agreements and information for enrolling the individuals in self-directed services and being the common law employer and for hiring direct support staff. Finally, a system for providing remedial training for participant/family employers should be developed and available.

C. Review and Revise Support Broker Role and Responsibilities Under Self-directed Services

Recently the Federal Department of Labor has placed an emphasis on identifying when joint employment exists and potential liability for the joint employer. This emphasis has raised the importance of clarifying support brokers' role and responsibilities related to assisting waiver participants and representative-employers with performing employer-related tasks when using self-directed services. Currently, DDA support broker tasks include the support broker providing direct supports to waiver participants and families related to performing employer tasks (e.g., hiring managing and firing staff directly). These policies, as currently stated, put support brokers at risk of being considered a joint or sole employer of waiver participants' direct support staff and any potential liability that may result in being a joint or sole employer.

It is recommended that DDA review support broker role and responsibilities related to performing employer related tasks. These should be revised to state that the support broker will provide supports directly to the employer and include technical advice, problem solving and role playing with the waiver participant or representative-employer but not directly perform employer tasks with the direct support staff. This will reduce the incidence of a support broker being considered a joint or sole employer of a direct support staff person and related potential liability and clarify the role of the participant or representative as the common law employer.

D. Improve Training, Certification for and Monitoring of Support Broker Performance

Support broker services should be provided by knowledgeable and experienced staff who perform the function as professionals. In addition, when a person resides on western Maryland or on the eastern shore they should expect and receive the same level of knowledgeable support broker services. Support broker training should not be used by families to learn about the self-directed service option. It is recommended that DDA develop and implement a comprehensive, statewide support broker training curriculum and materials that support the provision of high quality support broker services by individuals who provide support broker services to individuals other than their immediate family member. Initial an ongoing training, including programmatic updates should be provided on a regular, periodic basis.

Also, it is recommended that the performance of support brokers be monitored on an annual basis and include incentives for excellent performance and consequences for substandard performance.

E. Improve Training for and Monitoring of Resource Coordinator Performance

One reason given for people not enrolling in self-directed services is that resource coordinators throughout the state do not consistently have the necessary knowledge and experience to provide effective information on self-directed services. Moreover, this lack of knowledge and experience has resulted in resource coordinators discouraging waiver participants and their families from using self-directed services.

It is recommended that DDA develop and implement a comprehensive, statewide resource coordinator training curriculum and materials that support the provision of high quality resource coordination services no matter where a waiver participant resides in the state. Initial an ongoing training, including programmatic updates should be provided on a regular, periodic basis.

Also, it is recommended that the performance of resource coordinators be monitored on an annual basis and include incentives for excellent performance and consequences for substandard performance.

Copy to: Amy Daugherty, DDA



Support Development Associates, LLC

Maryland Developmental Disabilities Administration Technical Assistance for HCBS /Plan Development and Outcomes Feb-June, 2015 Final Report

Introduction

In November 2014, representatives from Maryland Developmental Disabilities Administration (DDA) contacted Support Development Associates (SDA), seeking assistance with identifying a clear pathway towards the development of meaningful outcomes for people who receive support. Upon further discussion, the request broadened to include a review and recommendations of the process and subsequent documentation procedures used to establish a person centered service plan. Specifically, SDA was asked to

Describe what current best practice regarding the development of person centered plans suggests about:

- Effective and efficient processes used to develop the information needed for a plan that meets current federal guidelines
- How to best organize and present the information gathered so that it meets the purpose of the plan

Compare the description of best practice with current practice and

- Identify the benefits and drawbacks of the current person centered assessment (information gathering) completed within the 18 TCM agencies and counties.
- Identify the benefits and drawbacks of the current person centered plan development process used by the 18 agencies.
- Identify challenges to measuring outcomes encountered when the person centered planning monitoring takes place.

Note: the term Resource Coordination and Resource Coordinators were changed to Coordination of Services and Supports during the project implementation. Throughout this report, the terms are used interchangeably. References to RC and /or Coordinator are the individuals who perform this work. Where documents were already published with the Resource Coordination terminology, we maintained that descriptor.

Approach Utilized

Partners from SDA met with DDA staff in early February to identify the concurrent assessments taking place, and identify the existing and current policies, procedures, regulations and other guidance documents related to service plan development within the various programs administered by DDA. Following this initial discussion, DDA Staff forwarded to SDA several sample plans and an excel spreadsheet containing more than 20,000 outcome examples from every region in the state. These documents were reviewed and compared to the following basic expectations of a person centered approach:

- Language demonstrates respect for, and dignity of, the person
- Language is easily understood, not clinical in nature, and not disparaging
- Clear indication of the person's preferences
- Easily identifies those things important TO the person: relationships, status, financial stability, rituals or routines, things to have or do.



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- Sequence matters: Issues which are important FOR the person are addressed, but only after the context of preferences and important TO has been identified: Health, safety and actions required as a valued member of society (follows social/civil rules) are addressed in the context of personal preferences

Document review: Additional policies and procedures, and recent reports, provided by DDA were reviewed by SDA. These included:

1. Annotated Code of Maryland *COMAR* 10.22.05: Department of Mental Health and Hygiene: Developmental Disabilities: Individual Plan requirements.
2. Annotated Code of Maryland *COMAR* 10.22.01 Definitions and 10.22.02 Health General Updates
3. Memo From Frank Kirkland to all Regional Office Directors, Support Brokers and QA Directors, dated: February 6, 2012 RE: Individual Plans
4. Memo From Frank Kirkland to all Providers and Resource Coordination Directors, Dated March 15, 2013 RE: Individual Plans.
5. TO BE Process Flow Chart: Individual Plans Chapter 2.
6. Annual IP Checklist: Regional Office Review
7. Resource Coordination Waiting List Work Group Final Report
8. Resource Coordination Coalition Training Work Group Final Report
9. Resource Coordination Report on Transfers
10. Resource Coordination Report on Service Units
11. Regional Office Report on RFSC Data (Requests for Service Change)

Discussions with DDA staff and NASDDDS Consultants on the findings from a review of Targeted Case Management took place on two occasions. The review, and subsequent recommendations from NASDDDS are consistent with the recommendations included below.

At the request of the Maryland DDA, we replaced the final task of mapping the IP process with meetings with the Resource Coordination Coalition and the Self-Advocates Organization (People on the Go) to discuss and gather their ideas on the IP Process and the Documentation related to the IP. These meetings were held separately on May 15, 2015 (Resource Coordination Coalition) and May 30 (People on the Go).

Observations

Best practice in Plan Development and Outcomes

Current best practice in person centered planning has four distinct yet interrelated areas:

- a. Information gathering/Assessment;
- b. Individual Plan development procedures;
- c. Individual Plan format; and
- d. Outcomes development.

Information gathering



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Assessment used for plan development, now often referred to as discovery, should be tailored to the person, their preferences and identified needs. However, current assessment practices in Maryland take a one size fits all approach: lengthy assessments are used for everyone, with no tailoring or customization to the individual. For example, in the *New Directions: Self Directed Services* program, the assessment used exceeds 28 pages. 13 areas are assessed, the first five of which are safety, health, sexuality and behavioral in nature. In Best Practice areas, assessment begins with individual preferences, what contributes to comfort, satisfaction, and desired lifestyles, and then proceeds into capabilities and skills, areas of need for support with skills that are not yet fully developed, and finally into areas of safety and /or health related concerns. In addition, current Best Practice allows for the person to indicate if they need support in the area or not. If not, the area is not pursued further unless there is an individually compelling reason to gather information for the person's well-being. The challenge with creating standardized forms on paper is the inevitable management practice of assuring all blank spaces on forms are complete, "just in case". Thus, the form drives the function of the process.

Plan Development and Electronic Records

Electronic access to plans and supporting documents in Maryland's DD System (such as assessments and discovery information) is very limited. Coordinator's must enter the information, and then print it and request handwritten additions or corrections from the person and their family members. New or corrected information must then be re-entered. Most Coordination Units have developed their own software or plan development documents, which are stored on local servers or desktop computers, but are not compatible with the PCIS system run by DDA. Therefore, uploading of scanned or pdf documents is necessary. Providers have "read only" access to PCIS, and again must send any changes or additions to the coordinator separately. Much information is sent via scanned and emailed, or faxed documents; encryption and security are an issue, as is the inefficient data entry methods. Very little data is then available to Coordination Units in real time, for quality assurance and aggregate data trending. In the regions and counties we reviewed, the plan is available to the person via printed copy only. One note of additional importance: during the review of the Mississippi ISP files forwarded by DDA, it appears to combine multiple documents into one electronic "file" but refers to all of it as the person's Individual Plan. When reviewing Mississippi's document, it became clear that health histories, recent medical evaluation results, medication reviews, and numerous other health and medical *records* were being included when referencing a person's plan. We believe it is very important to keep a very distinct and separate definition of the person's Record and the person's Service Plan.

Outcome Based Services

Several states have moved toward a method of outcome development anchored in both the person's desired life style and the results a person seeks to gain through access to supports and services. To this end, Maryland has included in its COMAR Chapter 10.22.05 a definition of Outcomes which is in clear support of both best practice and CMS expectations. The definition of an Outcome in relationship to an Individual's Plan is: "... tangible results of goals that reflect the desired quality of life as defined by the individual." In COMAR Title 10, Chapter 10.22.04, outcomes are specifically linked to Values and Fundamental Rights. The policy and rules governing the intended practices of Maryland's DDA clearly describe what is considered best practice in the field. To determine how well actual practice matches this intended practice as laid out in policy, we reviewed a spreadsheet provided by DDA staff, which contained 10,672 outcome statements. (see Appendix A) It was not clear how many people accounted for these outcomes as names were omitted for privacy, however the spreadsheet also included 18,000+ goal statements. The training modules we reviewed indicate the outcome is to represent the desired results the person



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hopes to gain from accessing their unique set of services or supports. Goals are to indicate the specific steps that will be taken to reach those outcomes. Of the Outcomes reviewed, the majority included phrases or words that appear to indicate the outcome was written to benefit the system, or were written to assure something that Professionals, or people other than the person supported, identified as a priority. We typically refer to these as things that are important FOR the person. For example, more than 2,400 outcome statements included the word skills or function(al); more than 300 included the word appropriate and over 500 included either compliance or behavior in the outcome statement. Conversely, issues that address preferences, relationships, status, and having your own control are typically referred to as things that are important TO the person. For example we saw outcome statements, more than 1,500 of which, included references to a job, or earning money. Another 500 made reference to friends or family members. This indicates the outcomes addressing issues of importance TO the person do exist some of the time. The outcome statements addressing issues of importance to the person – that is, based clearly on their preferences- did address either relationships of meaning, jobs, or gaining/holding status. Those outcomes which addressed solely issues of importance FOR the person addressed either functional/clinical needs, or compliance with a service. Many of the outcomes in this category actually provide support for a systemic need, not a personal need. For example, many outcomes identified actions required of the service provider, or the service itself: “xyz agency will provide information on financial resources.” Or “xxx will select a service provider” or “John will continue to receive wrap around and necessary medical services.” And, it appears a state requirement exists, or the interpretation of a state requirement occurs, that if a person receives behavior support services, they MUST have an outcome and a goal which directly tie to the behavior service goals. The language from the behavior plan must match the language in the person’s own plan. This does not seem to be consistent with the CMS requirements that goals and outcomes reflect the person’s preferences. The final area of note were those heavily laden with clinical/medical language. For example: “Increase her independent living skills by assisting with meal planning and preparation” or “D will increase her socialization skills;” and finally “M will reduce non-compliance.”

Plan review and approval

CMS requires states who are using a 1915(c) or a 1915(i) HCBS waiver authorities to provide a description of how the plan will be “...subject to the approval of the Medicaid Agency.” During our discussions, and upon review of the COMAR section 10.22.05, it appears that the DDA approval process meets the CMS requirement. However, DDA may want to reconsider how it currently describes the approval of plans. IN COMAR 10.22.05.05 (B) it simply states that the “approval of the plan will be based on the individual’s current needs.” This leave much room for interpretation across regions, across agencies and across Coordination Units. The families and self-advocates whose plans are subject to this approval feel that the details of their preferences and their own personal outcomes should not be rejected for contents. (See notes from Self Advocates Meeting) The description of procedures and guidelines for expectations of what should and should not be included in plans, and what must or must not be included, needs to be broadly distributed. In particular, the office of Health Care Quality Licensing and Review surveyors carry a significant amount of influence and authority regarding what is and is not recorded in plans. It appears that they have the final say, and if they believe a plan is not in compliance due to a person’s preferences, the plan will be changed. It appears the HCQ prefers to see health and safety issues presented prior to personal preferences, which is in conflict with some of the training and values both DD providers and Coordination Units have received over the years. It was not clear if the HCQ staff had received the same training. Further, in one Region, it is standard procedure that the Provider Coordinators, the Provider CEO, the Coordinators of Services and Supports and the COORDINATOR Supervisor all sign the individual’s plan, indicating they agree to the goals; however the person whose plan it is, nor their family/representative, sign off on agreement to the goals.



Data Based Management Systems

Most discussions of the Individual Service Plan development, management or monitoring included a reference to the PCIS system. PCIS was reported as an outdated system that requires a significant amount of staff time for entry, with little to no return on investment (ROI) for the RC's or providers or the person supported by the system. The lack of ROI is due to variations in accuracy, missing information, and timeliness. Further investigation related to PCIS was outside the scope of this project. The ROI of developing an effective new IT system would likely be easily calculated. Perhaps the most extreme example came from supervisors who have to help their Coordinators of Services and Supports try to verify information from PCIS regarding people who are meaningful in a person's life, which cannot be readily changed by the field staff. In several examples, when the Coordinator asked if the person still stays in touch with someone on the list, they discover the person has died or been long gone. This discussion is embarrassing, emotional and encourages the belief that the Coordinator does not care about the person. The only way to update this information is to update the list of names, then call the state office and request a formal change. It is not clear who is responsible for making these updates in PCIS, nor that there is a specific time frame in place to assure the changes are made in an efficient manner. The Coordinator receives no notice when the changes have been made. On point worth noting: Any IT system is only as good as the process and procedure upon which it is based. With current technology, we have seen some systems that make Case manager's work easier, and improve accuracy and timeliness. However, in each instance, the human system was updated and redesigned prior to updating the technology.

When reviewing the Request for Service Change report submitted by one Regional Office, it was difficult to see how the method used to collect, organize and report the data contributes to the effective management of the system. For example, the percentages identified were calculated by comparing the number of total people (646) with the number of each type of request. However, more than one request is made by some individuals, and not all requests are recorded on the table (when it results in cost neutrality). Therefore, the total number of requests does not equal 100% of all requests. It makes it very difficult to identify the frequency of the type of request, so that decisions about trends and projecting future needs cannot be made.

Recommendations

CMS requires, and the Maryland DDA wants, plans that are developed through a person centered process, and a document that reflects person centered standards. In addition, both CMS and Maryland's DDA system seeks to assure the process facilitated by the Coordination Units results in the identification of outcomes reflective of the preferences and desires of the person. In order to achieve this, the following recommendations are made, based on current findings indicated above.

1. Replace the current IP with a plan document and process that includes these characteristics:
 - a. Prioritize the sequence of information. It introduces the person before the disability or the health and safety risks. The planning format should inform the readers about what others like and admire about the person and what is important to the person before describing issues of health or safety
 - b. Language matters. In addition to using person first language, the use of grammatical first person does not alone make the plan person centered. First person should only be used when quoting



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the person, when the person actively edited the plan, or when those closest to the person feel certain that is exactly what the person is saying with her/his behavior. (We saw an egregious example where a plan said "I must follow my behavior program".) Avoid language that reflects power over rather than power with (e.g. using the verbs let or allow.) The format used by DDA for the New Directions Waiver should be reviewed and updated during any interim period before a new IT system is developed.

- c. It is reflective of an assessment process that was both respectful of the individual and designed to identify personal preferences, abilities and strengths first, followed by needs for support or services.
- d. The depth and breadth of the plan, and the assessment needed to develop the plan, reflects the depth and breadth of the request for support and the services which will be provided.
- e. Insures that whatever planning format adopted separates preferences from strengths so that the difference is clear; the format should be designed to assure identified outcomes reflect preferences of the person whose plan it is.
- f. It should be easily accessible and easily retrievable by all who need to act on the plan.
- g. It addresses risk areas that are real for the person – not potential unknown risk, but real risk, and does so in a way that still supports the desired lifestyle.

We recommend the DDA review the ISP contained within Ohio's *ImagineIS* for an example of a plan format and process which demonstrates all of these characteristics.

2. Develop a discovery process that determines what is important to each person and a structure to record that learning in the person centered plan (the discovery material is part of the record but not the plan). The breadth and depth of discovery should be determined by what is being requested with more comprehensive services resulting in more comprehensive discovery efforts.
3. Distinguish between the record and the service plan: Clearly describe what IS in the plan and you may need to describe what is NOT in the plan – for example, Incident Reporting and summaries may be a necessary part of a *discovery process*, but would not actually be part of the person's annual *plan*. Past medical history- is important information to know, and would be part of the record, but not part of the annual plan. The existing IP Plan review checklist, is more about the process than the plan document. The checklist is an administrative function, and is not part of the person's actual plan. Checklists do not assure work was done, they only assure the checklist was completed.
4. The current IP has Strengths/needs/preferences all in one section. We recommend separating these, as they are not the same, and including them in one section infers they are interchangeable. This may be contributing to the challenge of outcomes written as a description of the system needs.
5. Clarify the roles and responsibilities of those engaged in developing and approving plans.
 - a. Good plans that are implemented are done in partnership. This includes when a person would like to direct the development of their own plan. Systems must determine how to guide and support someone to be successful in this self-direction. When good plans are developed, there is



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- collaboration among all the participants. Functional partnerships require clarity about roles, responsibilities, and authority. It is common to say it is the person's plan, it is less common for the person to have determined the outcomes that are at the core of the plan.
- b. Among those who use services, there is a wide range of capacities and interest in developing plans, leading meetings, and developing outcomes. DDA needs to have support in place so that capacities are supported and interest is encouraged. For some of those who use services this is already occurring. For others it could easily occur with some support.
 - c. For many people, the coordinators and other people CMS refers to as individual representatives, need to use supported decision making (see <http://www.supporteddecisionmaking.org/>) and "substituted judgement". It should be noted that the self-advocates that we spoke with are very interested in directing the parts of the process that result in outcomes but they are not interested in the administrative aspects. Where possible the administrative parts of the planning should be done before the meeting. The expectation that all routine administrative functions will be completed during the planning meeting needs to stop. The focus of the meeting must return to the development of a plan for the next year of the person's life. Administrative functions should be held until after the plan is completed, or completed during a separate visit.
 - d. In order for coordinators to have the time needed to support people on directing their plans the administrative work associated with their role will need to take less time. Some of the recommendations made by other consultants (NASDDDS) address this issue
6. Develop and offer training for those who use services in directing the development of plans, leading the planning, and developing outcomes. Require that coordinators be trained in how to best support individuals in directing these activities and that coordinators and guardians be trained in supported decision making and substituted judgment
 7. Have a process whereby learning is recorded and the person can ask for changes in the plan
 - a. Require that, where the outcome is not related to risk, the person can determine if enough effort has gone into meeting it
 - b. Reports of dissatisfaction with the outcome result in plan review and potential outcome revision.
 8. Address issues of risk (health and safety) in the context of what is important to the person
 - a. Train coordinators in how to support the development of outcomes that reflect what is important to the person as well as what is important for and describe the balance between them
 - b. The plan should describe how to mitigate and/or manage risk while at the same time honoring what is important to the person. When tradeoffs are needed, the person and their closest family should be consulted on deciding which carries the priority.
 9. Develop plan review processes
 - a. Have a consistent process for reviewing individual plans that determine if preferences are adequately reported and assess if the outcomes support the preferences.



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- b. Review outcomes in the aggregate to determine if there are trends of outcomes in regions, or by provider, or by the Coordination Unit, which reflect either what is important to or important for the individual. (see above for categories of each). Use this information to inform the quality improvement efforts related to Individual Plans.
10. Require that outcomes identified by the person and their team, which have not been implemented due to a deficit in local community capacity, be tracked by DDA central office. DDA should then use this information to recognize the need for capacity building, and develop an appropriate response.
11. Establish quality management expertise in each regional office, with formal training and credentials in the development of data utilization which can support management decisions. While this may not seem related to the ISP or Outcomes, it is a crucial step in making use of data to support decisions about the effectiveness of the ISP process, and the actual implementation of meaningful outcomes for people.

Training needs to be developed and required for each recommendation which makes a substantive change in practice. A summary of the areas for training is below. Significant training in most of the areas is already present and being offered by some of the key stakeholders. All of the training listed has been developed, is available, and is being used in other jurisdictions. In each area, any existing training should be adapted and customized to Maryland's specific training needs. It is important that distinctions be made between training that is to deliver new knowledge, and areas where training requires that people develop new skills. These each require different methods and styles of training. While the training does need to be customized to Maryland, it is important that the same training be deployed across all regions of the state, so that consistency begins to return. In particular, the training developed for individual planning, outcomes development, and how to correctly use the plan format must be consistent across the state.

Areas of Training that will be needed:

- The application of the core concepts of important to and important for and the balance between them
- Supporting self-advocates in leading their own planning process – from discovery to implementation
- The application of discovery skills and assessing which skills to use
- Using plain and effective language when writing plans to capture the critical elements
- Developing outcomes that reflect individual preferences
- Supported decision making
- Risk mitigation and management
- Plan review and authorization



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Summary of Outcome Statement Analysis

A Database of over 30,000 entries was provided to SDA, inclusive of 10,672 Outcome Statements and Over 17,000 Goal Statements. The remaining entries indicated how progress would be verified for the goals and /or the outcomes.

A brief analysis of the entries revealed the following categories, based on frequency of language used:

Key Words	Category	Important To/For	# of instances
Independent	Society's Rule	For	1,167
Appropriate		For	334
Social skills		For	203
Positive		For	128
Manners/Etiquette		For	18
Behavior	Compliance	For	477
Compliant/compliance		For	60
Safe		For	415
Shower		For	63
Provide, Provider	Provider Action	For	507
Skills	Function	For	2,468
Medication	Health	For	75
Money	Financial Gain/ Responsibility	To/For	383
Job	Financial/Material Gain	To	1,582
Friends	Relationship	To	167
Family		To	341
Would like	Decision Making	To	703
Wants	Decision Making	To	524
Desire	Decision Making	To	89