



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.



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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 *Imagine!S* 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