

Missouri Independence Plus Initiative
Independence Plus Statewide Task Force
Final Report & Recommendations
September 2007



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The Missouri Partnership for Self-Directed Support Statewide Task Force
(AKA – The Independence Plus Statewide Task Force)**

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The Missouri Planning Council for Developmental Disabilities, and**

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Funding provided by the Center for Medicare and Medicaid Services (CMS). Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official positions of CMS, as well as the Missouri Division of Mental Retardation/Developmental Disabilities, the University of Missouri-Kansas City Institute for Human Development, or the Missouri Planning Council for Developmental Disabilities.



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Independence Plus Statewide Task Force Final Recommendations

Background

In the past ten years self-advocates, families, professionals and state agency staff in the State of Missouri have widely embraced the values, principals and practices associated with individuals and families self-directing their own services and supports.

For example, in 1997, Missouri's State Planning Council on Developmental Disabilities (MPC) engaged a group of self-advocates, family members, state agency staff, and service providers to explore Missouri's service delivery system, and to make recommendations on how it could change to better meet the needs of the state's citizens with developmental disabilities. The group met extensively for a year and produced a report entitled, "Show Me Change: *Building A Participant-Driven System For Missourians With Developmental Disabilities.*" The report concluded:

- **"Resources for supports in Missouri must be allocated and expended from a person-centered rather than a provider centered perspective." ...**
- **"Individuals must be in control of their allocated resources for services and supports and how they are delivered."**

The report recommended that policy makers in the state move forward to plan, test and implement participant-driven approaches in Missouri.

In 2003, a report titled "*DMH Practice Guidelines for Consumer Directed Supports and Services*" was published. The recommendations contained in the report represent another example of DMH's, and DMRDD's commitment to develop a service system that is consistent with putting into practice the expectations associated with CMS approved self-directed program waivers and demonstrations within the Independence Plus framework.

Some Examples:

- *Self Determination Values:* The values of self-determination along with the quality outcomes should be the measure by which the supports and services provided by the DMR/DD are planned and evaluated.
- *Choice:* As in the Olmstead Decision, choice and the money should follow the person. Community capacity needs to be developed to support people in the community.
- *Consumer Input:* Individuals who use supports and services should be provided opportunities to impact the decision making process in the Division regarding allocation of resources/program practices.
- *Consumer Control:* Consumer and family control of resource-policy changes that put control and allocation of resources available for community services and supports in the hands of those who receive the services
- *Fiscal Assistance:* The creation of Microboards/Fiscal Intermediary should assist consumers/families.
- *Person-centered planning:* People who use supports and services should be trained and supported to develop their own person-centered plans.

While progress had been made, it was acknowledged at the outset of the grant that there was work that still needed to be done. Some of the work included the following:

- Person centered planning associated with the waiver programs continues to be primarily conducted for systems needs and under the direction of systems level individuals (i.e. Service coordinators, QMRP's) who have both service coordination and gate keeping functions.
- Efforts should be enjoined that will place the planning process under the direction of the participant, or their designated representative as needed.
- Direct support workers continue to be employees who are primarily directed by the agencies they work for.
- Alternate and creative mechanisms that will expand the available work pool and place workers under the direct control of participants, or their designated representatives, need to be explored and developed.
- Funding and contractual relationships continue to be made directly to providers, who then, in turn, control the disbursements of a person's resources and supports.
- The current self-directed system is cumbersome and difficult to understand and does not include the support broker function.
- Efforts are needed to explore and develop alternatives that place resources, and decisions about who, how and when supports are to be provided directly in the hands of the participant, or their designated representative.
- Use of how "support brokers" and "fiscal intermediaries" can be used to accomplish this needs to be fully explored and implemented.
- Self-advocates and families continue to need training that will equip them to effectively and safely self-direct, control and choose their supports, as well as control the resources paying for their supports.
- The current system requires the individual or family to become the employer of record. Some families interested in self-directing are concerned about legal liabilities if they are the employer of record.
- Consumers prefer utilizing fiscal intermediaries who would address day-to-day administrative responsibilities.

Through the Independence Plus program a lot has been learned about how to address some of the above issues and in some instances changes to address them are already occurring. The remainder of this report is comprised of a set of recommendations for how to continue to make steady progress with implementing quality self-directed supports and services in Missouri.

Overview of Missouri's Independence Plus Program

In the summer of 2003, the Missouri Division of Mental Retardation/Developmental Disabilities (DMRDD) submitted a grant to the Centers for Medicare and Medicaid (CMS) in partnership with the University of Missouri-Kansas City Institute for Human Development (IHD) and the Missouri Planning Council for Developmental Disabilities (MPC). In Part, the impetus for the grant was the growing movement within the State by a variety of stakeholders to find ways to support people with developmental disabilities to self-direct their own services.

The Centers for Medicaid and Medicare Services approved the funding of a three year demonstration project that became known as the Independence Plus Project. The implementation of the project was a collaborative effort between the partners mentioned in the previous paragraph. The overall goal of the project was to plan, develop and implement a life-enhancing, consumer directed system in Missouri that provides choices and control in directing services and supports for people with disabilities and their families.

An integral part of the Independence Plus project was the development and implementation of a pilot initiative. The focus of the pilot was to explore various options and supports that are needed to assist individuals who wish to self-direct their services in Missouri. Closely involved with the development and the evaluation of the Independence Plus Pilot Project was the Independence Plus Statewide Task Force. A brief description of the Task Force and their involvement follows.

The Independence Plus Statewide Task Force

One of the initial activities of the grant was to establish a statewide self-directed task force to assist with the planning, implementation and evaluation of the pilot initiative associated with the project. The Task Force was to be comprised of people with disabilities, family members, disability stakeholder groups, state agency representatives, and other professionals working in the field. The original Self-directed Task Force, known as the “Independence Plus Task Force,” consisted of 22 members, thirteen of which were self-advocates or family members.

The Task Force met frequently during the first year to review the various components associated with self-directing services, and offered guidance in the development of the pilot initiative. Specifically, the Task Force reviewed and gave direction on person centered planning, individual budgets, financial management services, support brokerage, call-in systems, and quality assurance/incident management and emergency back up systems.

During the pilot implementation phase, the Task Force continued to review resource materials, and pilot participant training materials. Training materials were refined based on comments received from Task Force members. Members also offered recommendations on how to recruit pilot participants, and support brokers. In addition, the Task Force offered guidance on including things in the pilot that had not been initially planned for, such as the inclusion of a “call-in” system.

The final responsibility of the Task Force was to review evaluation results and develop a set of recommendations on how the use of quality self-directed services could be expanded in Missouri. As part of the process for developing their recommendations, the Task Force reviewed a great deal of resource material and the content of the following evaluation reports.

- **Independence Plus Pilot Process Evaluation Report – October 2005**
- **Independence Plus Pilot Summit Outcome Report – May 2006**
- **Independence Plus Pilot Participant Survey Report – September 2006**

The following set of recommendations represent’s the collective culmination of the work of the Task Force during the three years they met, but in particular their work in the last six months.

Task Force Recommendations

1. Overall Recommendation – Create a Self-Directed Support Work Group

The Task Force recommends that a self-directed support work group be formed and empowered to work with the Missouri Division of MR/DD in their efforts to sustain and expand self-directed service and support options.

The Task Force strongly encourages that the Work Group be an integral part of the decision making process concerning self-directed supports. As decisions are considered and made about how self-directed supports and services should be implemented in Missouri, the work group should have enough time and staff support to consider information in a timely manner that allows for real input into the process.

Structure and Support of Work Group — The Task Force identified the Missouri Planning Council as the primary advisory group to the Division of MR/DD. Rather than creating another separate advisory group to the Division, the Task Force recommends that the “Work Group” be associated with the Missouri Planning Council.

As such, the activities of the work group would, in part, be supported and coordinated through the Missouri Planning Council. Support could include both financial and staff time. Work group recommendations would be forwarded through the Planning Council to the Division Director for consideration and action. Work group charge and membership appointments should come from the Director of the Division of MR/DD, in consultation with the Missouri Planning Council.

It is recommended that the Division of MR/DD assign a senior staff member to support the activities of the Work Group. It is also recommended, along with the Missouri Planning Council, that the Division financially support the activities of the work group.

Make-up of Work Group — The Task Force recommends that the Work Group consist of up to 10 members. At least 50% of the work group membership should be individuals/families that are, or have self-directed their services. Other suggestions for members included: support broker, service coordinator, waiver provider, agency representatives, DHSS, DMS, SB40, Regional Center Director, and Public Administrator.

While there may be some rationale for representatives from state and non-profit agencies to be members of the work group, it was also suggested that there were other ways to receive their input such as inviting them to participate in specific meetings.

The Task Force felt that representation was secondary to finding people who are committed to expanding self-directed supports in Missouri, and who understand the issues around people with disabilities directing their own support.

Work Group Meetings — The Task Force recommends that the Work Group meet quarterly, and every other month if needed. Travel costs of Work Group members who are individuals with a disability, or a family member, should be reimbursed.

2. Overall Recommendation – Develop and Implement A Sustainability and Expansion Strategy for Self-directed Supports and Services in Missouri

The Task Force recommends that the Missouri Division of MRDD, the Missouri Planning Council and the proposed Self-Directed Support Work Group, along with the support from the UMKC Institute for Human Development, develop and implement a strategy that would move Self-Directed Supports in Missouri from a program option to a way of doing business for individuals and families that desire and choose to self-direct their own services.

To accomplish this, it will require enhanced understanding and capacity on a number of fronts. It will also require concerted effort and leadership from self-advocates and their families, as well as the Division of MRDD, others working in the field and policy makers.

The Task Force is very interested in building on the knowledge that has been gained over the past five years, and sustaining the momentum that currently exists. In order to accomplish this, the Task Force has several recommendations.

Self-Determination – First, the Division of MRDD, the Missouri Planning Council, self-advocacy and parent groups, and other interested parties formally accept the nationally acknowledge guiding principles of self-determination as guiding principles underlying the development and implementation of self-directed services in Missouri.

Name Change – Second, the Division of MRDD change the name of the current self-direction efforts from the “Fiscal Intermediary” program to the “Missouri’s Self-Directed Support Program.” It is felt that in order for self-direction to move to the next level in the State, the nomenclature associated with the self-direction efforts should be more inclusive than the current name that reflects a support mechanism associated with the self-direction of services. While ultimately it is the hope of the Task Force that the self-direction of supports moves from a programmatic consideration to the way that business is conducted in the State, it is recognized that this can only be accomplished over time and that a defined “Programmatic” identity is needed at this time.

Present Independence Plus Findings – Third, the Task Force recommends that at some point soon, findings from the Independence Plus Program, along with the recommendations from this Task Force, be presented to Missouri’s Mental Health Commission for their consideration. The Task Force also recommends that other audiences of policy makers be identified for similar presentations.

Strategy Development – Fourth, the Task Force proposes that the Self-Directed Support Strategy for Missouri address the following:

a. The continued development of materials and processes that will lead to an increased understanding about what self-directing services means, how it can work and the difference it can make in peoples lives. Possible audiences to be targeted could include:

- People with disabilities and families
- Policy makers
- SB40’s and Providers
- Other State Agencies
- The general public

b. The continued development of materials and processes that will lead to increased understanding and commitment at all levels within the Division of MRDD that self-direction of services is not an ancillary option for some individuals or families, but is a primary option available for all individuals or families that desire to self-direct their services. This will mean the development of an infrastructure within the Division of MRDD that supports individuals with disabilities and their families to self-direct their services.

c. The continued development of Missouri's service delivery capacity to support individuals and families who desire to self-direct their services. Areas of capacity building under consideration include:

- Participant Directed Person Centered Planning
- Individual Budgets
- Supports For Self-Direction
 - Support Brokerage
 - Fiscal Management Support
 - Call-In System
 - Designated Personal Advocate
- Quality Assurance

(Detailed recommendations for the items identified above are contained below in Overall Recommendation #3)

3. Overall Recommendation – Continue the enhancement of the various programmatic aspects associated with individuals self-directing their services in a safe and quality manner.

The Independence Plus Pilot Project looked at various aspects identified by CMS that are associated with people successfully directing their own services and supports. The Task Force was charged with defining how these components would be implemented in the Pilot, as well as at the completion of the Pilot, review what had been experienced and make specific recommendations concerning each component. The following represents the Task Force's specific recommendations for each component.

a. Participant Directed Person Centered Planning

CMS identified the following as aspects associated with Person Centered Planning:

- Person centered planning is a process, directed by the participant, with assistance as needed from a representative. It is intended to identify the strengths, capacities, preferences, needs and desired measurable outcomes of the participant.
- The process may include other individuals freely chosen by the participant who are able to serve as important contributors to the process.
- The person centered planning process enables and assists the participant to identify and access a personalized mix of paid and non-paid services and supports that assist him/her to achieve personally defined measurable outcomes in the most inclusive community settings.
- The identified personally-defined measurable outcomes and the training; supports, therapies, treatments and/or other services become part of the person-centered plan.

Based on the above considerations the Statewide Task Force reviewed participant-directed person centered planning practices in the state of Missouri, and best practice around the Nation. After this initial review, the Task Force developed a statement summarizing their perspective and recommendations concerning “participant-directed person centered planning” (See - Attachment “A”). The Task Force recommendations guided the development of the participant directed person centered planning component associated with the Independence Plus Pilot. Recommendations included a description of qualifications for independent person centered planning facilitators, recruitment strategies, training requirements, to name but a few.

While most of the pilot participants did not avail themselves of the additional person-centered planning support offered through the grant, they did feel they had more involvement, control and flexibility over the planning process associated with self-directing their support. Pilot participants reported that they had more control in scheduling planning meetings, and were more able to be creative, make changes and choose who facilitated their meetings (For more detail, see Attachment “B”- Pilot Participant Survey Summary).

The recently approved Medicaid Waiver renewal application expanded the Community Service Specialist definition to include participant directed person centered planning support as a service. With the change to Missouri’s MRDD Waivers, and the information received from pilot participants through the various information gathering and evaluation processes associated with the project, the Task Force proposes the following recommendations.

Recommendation: Find ways to enhance the availability of the community specialist service category to support individuals and families to be able to select an independent person centered planning facilitator. The group agrees with the idea of the “community specialist” service category as a means for those who are self-directing there own services to have access to an “independent facilitator.” However, the “Qualified Mental Retardation Professional” (QMRP) qualification requirements associated with the “community specialist” service category is somewhat restrictive, and may potentially limit access to otherwise qualified person centered planning facilitators. The Task Force recommends that these requirements be reviewed against some of the qualification requirements for person centered planning facilitators identified in Attachment “A.”

Recommendation: There are currently very few qualified independent person centered planning facilitators throughout the State. The Task Force recommends that steps be taken to increase access to quality independent person centered planning facilitators throughout the State. Consideration should be given to issues of recruitment, training, and coordination.

b. Individual Budgeting

CMS defines an “individual budget” as:

“The total dollar value of the services and supports, as specified in the plan of care, under the control and direction of the program participant. An individual budget is not an expenditure cap on the amount of services an individual may receive under the waiver and is:

- Based on actual service utilization and cost data and derived from reliable sources, preferably the State’s Medicaid Management Information System (MMIS);
- Developed using a consistent methodology to calculate the resources available to each participant;
- Open to public inspection; and
- Reviewed according to a specified method and frequency.”

With the above definition in mind, and information the Task Force received specific to Missouri’s situation through the pilot, the following observations and recommendations are shared concerning “individual budgets” and self-direction in Missouri.

Pilot participants were limited to self-directing services that were part of the Missouri Division of MR/DD’s comprehensive and community based Waivers. What this meant was that while many Pilot participants were able to develop and control the majority of the services and supports specified in their plan of care through one “individual budget,” others still had to deal with budgets from other funding streams that they were not able to self-direct. In other words, they did not have an “individual budget” that allowed them to allocate and self-direct all of their resources according to one Plan of Care. The issue of how to “blend funding” was not addressed through the Project.

The primary service that was identified for self-direction in the pilot was “Personal Assistance Services.” While the definition of this service category is very broad and allowed participants a great deal of latitude and flexibility with self-directing their support, other service categories that may have been identified in a person’s plan of care were not included as part of the Pilot. The decision to limit the services for self-direction in the Pilot to Personal Assistance Services, also meant that individuals who were receiving “residential support” as part of their plan of care, were not eligible to participate in the Pilot.

As part of the Pilot, participants were told that they would be able to monitor their budgets and adjust how the resources within their budget could be expended. While some expressed that they were able to access their budgets, other participants experienced great difficulty, and in some cases were not able to access their budget without some form of outside intervention. Without being able to easily access information about the status of an “individual budget,” it is difficult for someone to fully self-direct their services in a planned way.

Concerning flexibility with adjusting how resources within an approved budget could be expended, some pilot participants experienced some challenges. The primary challenge experienced had to do with the authorization of units of services on a monthly basis rather than on an annual basis. Service coordinators seemed to be willing to work with

pilot participants to make adjustments to the service units authorized each month, however, the process involved in making those adjustments was cumbersome at best.

Having individual budgets that incorporate resources from all funding sources was expressed by pilot participants as a need. One individual stated—*seamless service with blended funding*—was needed. Another comment reflected the ongoing challenge with not having the ability to blend funds—*No blended funding meant having to keep the agency and the FI (Fiscal Intermediary), dual paperwork, dual pay sheets*. Having a true individual budget would allow those wanting to self-direct their services to access and manage the resources available to them through a single mechanism. While “blended funding” was a systems change item the grant had identified it would work on, the tight fiscal concerns experienced in the State over the past several years overshadowed efforts that were begun to address this issue.

Based on information reviewed and obtained from those participating in the pilot, the following recommendations concerning individual budgets are proposed:

Recommendation: With the successful self-direction of “personal assistance services” (PAS) by Pilot participants, as well as the many other individuals associated with the Division’s Fiscal Intermediary program, it is time to explore how individuals with disabilities and their families can self-direct the full array of their support needs. This would include looking at those individuals who are currently receiving “residential services.”

Recommendation: That individuals and families be able to see the status of their individual budget minimally on a monthly basis. Preferred, would be for them to have access to the budget information online so that they could access it anytime. It was noted that some fiscal intermediaries are able to provide this type of access. Also, access to someone to explain the budget was also expressed as something that would be helpful.

Recommendation: That individuals and families who are self-directing their supports have an individual budget that allows them to manage their budget on an annual basis rather than on the current month to month basis.

Recommendation: That concerted efforts be undertaken to find ways to address systemic issues that continue to challenge individuals and families who are self-directing their services from having an “individualized budget” as defined by CMS.

c. **Supports for Self-Direction**

It is understood that individuals with disabilities or families self-directing their own services will need to have access to supports that will assist them with self-directing. The two primary support services include “support brokerage” and “financial management.” The following represents the Task Force’s recommendations concerning these two primary self-directed support services, as well as recommendations concerning other support considerations, a “call-in” service, and the use of “designated advocates.”

i. - Support Brokerage

CMS describes “Support Brokers” as follows:

- The supports broker serves as a personal agent who works on behalf of the participant and is under the direction of the participant.
- The broker serves as a link between the participant and the program, assisting the participant with whatever is needed to identify potential personal requirements, resources to meet those requirements, and the services and supports to sustain the participant as he/she directs his/her own services and supports.

One of the first items the Task Force worked on was to define the role, characteristics and qualifications of a support broker, and identify ways to recruit and train support brokers. Based on this work, materials were developed that assisted with the recruitment and training of the support brokers associated with the pilot, as well as pilot participant resource materials that described the role of support brokers, and how to hire and supervise them.

In early fall of 2005, the Task Force directed staff to conduct a process evaluation of the Independence Plus Pilot Program, particularly as it related to support brokerage services. Based in part on the findings from that evaluation, the Task Force developed a Support Brokerage Information Bulletin that was shared with the Director of the Division of MRDD. The bulletin contained what the Task Force had determined to be important elements associated with “support brokerage” as a service. Through a communication sent with the Bulletin, the Task Force expressed its support for adding Support Brokerage as a new Waiver service, and requested that the information contained in the “Information Bulletin” be considered by the Division as it proceeded with looking at including “support brokerage” as a Waiver service within the existing MR/DD Waivers.

With the above CMS definition in mind, and information the Task Force received specific to Missouri’s situation through the pilot, the following observations and recommendations are shared concerning “support brokerage” and self-direction in Missouri.

Recommendations: That the Division of MRDD continue to consider the information and recommendations contained in the “Support Brokerage” Information Bulletin #1, published in November, 2005, as it implements the new “Support Broker” Waiver service (See Attachment “C”).

Recommendation: That concerted efforts be undertaken to build the number of quality and/or qualified Support Brokers throughout the State.

Concerted efforts to include:

Sub-Recommendation: Conduct (6) six competency based support broker training events in the next six months in the areas of the State expressing the greatest interest and/or experiencing the highest need. Associated with this recommendation were the following considerations:

- That experienced support brokers be used in the training, and possibly be used as mentors.
- That an individual or family member who has used a support broker be part of the training.
- That funding be secured from MPC for support broker training.
- That prospective support brokers be charged a nominal registration fee to participate in the training.
- That ongoing feedback mechanisms be maintained to obtain information that would enhance support broker training.

Sub-Recommendation: That online technology be used to provide accessible, affordable and uniform support broker training statewide. The College of Direct Support was suggested as the means for accomplishing this. It would involve the development of a competency based Support Broker training module. It was also suggested that those who had successfully completed the module receive some form of certification, or certificate verifying this.

Recommendation: That MRDD Service Coordinators throughout the State receive competency based training on self-directed services, particularly as it pertains to Support Brokers.

Recommendation: That a process be developed quickly that would assist those self-directing their services to be able to access support broker and community specialist services.

Recommendation: That resource materials and an orientation process be developed for interested individuals and families to become familiar with what support brokers do, and how to access and manage support brokerage services.

ii. - Financial Management Support

Financial Management Services as defined by CMS includes:

- Assisting the participant to understand billing & documentation responsibilities;
- Performing payroll responsibilities—Key employer-related tasks include: withholding and filing Federal, state and local income and unemployment taxes; purchasing workers compensation or other forms of insurance; verifying citizenship and alien status; collecting and processing worker timesheets; calculating and processing benefits; and issuing payroll checks;
- Purchasing approved goods and services on behalf of the participant;
- Tracking and monitoring individual budget expenditures; and
- Identifying expenditures that are over or under the budget.

The Independence Plus pilot explored the use of the Division of MRDD’s current fiscal intermediary (FI) process, as well as an independent fiscal intermediary to provide pilot participants with financial management supports. After some initial enrollment challenges, participants generally expressed satisfaction with the financial management support received through either of the fiscal intermediary’s approaches that were used in the pilot.

While Task Force members did not express any major concerns with the Division of MRDD's current FI approach, there was discussion around hidden costs, access to individual budget information, and limitations associated with managing multiple funding sources through the existing FI program. The discussion concluded with the sense that further exploration of other ways the State could provide financial management support to those self-directing their services was warranted.

The Agency with Choice model was used by several of the pilot participants. It was observed that this model had been able, to some extent, to allow for the use of multiple funding sources by participants, but it required them to manage supports with different rate structures, with distinct restrictions, and unique documentation requirements.

The Task Force discussed the inability of those self-directing their own services to access affordable workman's compensation through the current FI approach if needed. It was acknowledged that Division staff had been actively pursuing ways to add workman's compensation as part of the current FI Program. Task Force members observed that if this issue could not be resolved, it would seriously limit those who could participate in self-directing their own services.

Based on these discussion and the experiences conveyed by pilot participants, the following recommendation are offered for consideration:

Recommendation: That the Division of MRDD, while it continues to use the current FI approach, actively explore other financial management approaches being used throughout the country that support people to self-direct their own services. The exploration should involve looking at the full range of FI options, including centralized, independent and agency with choice.

Recommendation: That the Division of MRDD find a way to address the workman's compensation issue either through the current centralized FI approach, or through whatever other financial management mechanism it would select to use.

iii. - Call-In System

As part of the pilot, a worker call-in service to document and verify a workers time, as well as the type of service that was provided, was explored. Use of the call-in service relieved pilot participants from having to process timesheets to get their workers paid. The use of this service by pilot participants was voluntary and limited.

The Task Force briefly discussed that because of the limited use of the call-in system there was limited information about how it worked. It was noted that while some initial concerns related to the implementation of the call-in system had been expressed by the Division staff, most of those concerns seemed to be the consequence of experiencing something new and different. It was also shared that those participating in the call-in system generally seemed to have had a positive experience.

Based on the limited information available, the Task Force recommends the following:

Recommendation: That Division of MRDD actively continue to explore the use of a Call-in System for individuals and families who are self-directing their own supports.

Recommendation: That if the Division decides to use a call-in system, that it be a mandatory system for all those who choose to direct their own services.

Recommendation: That whatever call-in system might be used, that it include a way for those self-directing their own services to access information about the status of their individual budget.

iv. - Designated Personal Advocate

As part of its initial work, The Task Force discussed the use of “designated personal advocate” that could assist an individual to self-direct their own services. The Task Force identified some characteristics and criteria associated with the role of a “designated personal advocate.” Attachment “D” summarizes the initial work of the Task Force in this regards.

None of the individuals participating in the pilot used a designated advocate. The Task Force reconsidered the information contained in Attachment “D” and identified a number of concerns. Based on the concerns discussed, the Task Force offers the following recommendation:

Recommendation: That the role of a “designated personal advocate” seems to be a needed support component for some individuals who choose to direct their own services. The Task Force recommends that further exploration and definition of this role in relation to supporting an individual to self-direct their own services occurs. Individuals with disabilities, family members and other policy makers need to review the information in Attachment “D”, and develop a more comprehensive response to ways the role of a designated personal advocate could work.

d. Quality Assurance (Participant Protections)

CMS identifies the following two participant protections associated with self-direction and quality assurance.

Emergency Back-up System:

- A statewide emergency back-up system is a formal arrangement the state uses to respond to emergency situations. This system includes assuring emergency back-up and/or emergency response capability in the event those providers of services and supports essential to the individual’s health and welfare are not available. This system may include: 1) accessing traditionally-delivered services, other waiver or state plan services; 2) implementing a worker registry; 3) designating emergency funding to purchase additional necessary services; 4) linking participants directly to the state national disaster or public emergency system; and 5) coordinating with the states’ incident management system.

Incident Management System:

- Is a formal plan, developed and implemented by the state, to define, identify, investigate, and resolve incidents, events or occurrences which jeopardize the health and welfare of participants.
- States must develop a definition of what constitutes an incident, identify who is responsible to review the incident, and describe how the information is shared among/between responsible parties and agencies.

In response to the above requirements, staff from the Division of MRDD in conjunction with the Task Force, developed a Statewide Quality Management Plan For Individuals Who Self-Their Direct Services. (Attachment “E”) The plan was used for the individuals participating in the Independence Plus Pilot.

At the conclusion of the Pilot, the Task Force reviewed the Statewide Quality Management Plan, and discussed pilot participants experience with their emergency back-up system. In general, participant back-up systems seemed to have worked.

Recommendation: That the Division of MRDD Statewide Quality Assurance Team review the attached “Statewide Quality Management Plan for Individuals Who Self Direct Services” to expand it beyond health and safety compliance concerns, and include quality of life outcomes for people self-directing services as they define them. Some other specific elements identified for further consideration by this group include:

- Stronger emphasis on back-up plan, should be at least three tiers deep, should be specific.
- Back-up plan be broader than – staff not showing up. Incorporate power outages, natural disasters, illnesses.
- Revisit the idea of community pools of back-up support staff.
- Contract with agency of choice to provide back-up staff.
- Have an on-line listing of back-up staff.

Summary

Missouri has been actively engaged over the past five plus years with exploring and implementing self-directed approaches. Much knowledge and experience has been gained with the implementation of the Independence Plus Project and the Division of MRDD’s *Fiscal Intermediary* program. The Task Force is excited about how the self-directing of services has positively affected people’s lives, what has been learned, and the systemic progress that has been made in the State. The Task Force is very interested in building on the knowledge that has been gained and sustaining the momentum that currently exists. The Task Force feels that the recommendations presented in this report, if implemented in a timely manner, will result in continued progress being made with the implementation of quality self-directed supports and services in Missouri.

ATTACHMENTS

Attachment “A”

Independence Plus

Summary of person centered planning discussions and recommendations
June 2, 2004

Attachment “B”

Pilot Participant Survey Summary:
September, 2006

Attachment “C”

Missouri Independence Plus Initiative
“Support Brokerage”
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Attachment “D”

Designated Personal Advocate

Attachment “E”

Missouri Independence Plus Initiative
Statewide Quality Management Plan
For Individuals Who Self Direct Services

Attachment “F”

Original Independence Plus Task Force Members

Attachment "A"

Independence Plus

Summary of person centered planning discussions and recommendations

June 2, 2004

Introduction

When done well the person's plan is the foundation, which defines desired changes and clarifies the actions and outcomes that will move the person's agenda forward. The focus person has the ultimate control over both the planning process and the purpose and outcomes of the work generated. Since every paid service has a "plan of action," a clear distinction must be maintained between the person's plan and how this becomes "translated" into authorized/paid services or supports.. The work and outcomes which are the result of the person's plan transcend any given service plan. The person's plan must remain the "real plan." Key features of a good plan include:

- Active participation from the planners whom the focus person has asked to support their change work
- Focusing on the ongoing work, rather than the "meetings" per se
- The plan is not a document; various summaries should reflect what is learned, commitments to action and accomplishments.
- Seeking clarity over time of the person's hopes and dreams for the future v Ongoing attention to the *focus* person's interests, gifts and talents
- Planners do not allow current available supports or services to constrain the person's real vision of a desirable future
- Those who participate are doing so at the person's request
- The plan is dynamic and flexible, reflecting the changes in circumstance as well as change resulting from the group learning process
- The plan outlines clearly the actions to be taken
- The person's plan encompasses all parts of a person's life that her/she expresses a desire for change in.
- Planners attend to supports and services needed to assure success; an assortment of support possibilities are explored and the *focus* person determines those which make sense

Qualities of facilitators

A good facilitator makes the planning and work go smoother. A practiced facilitator understands and reflects the values and assumptions of person centered work. They are able to "use" these values as they facilitate the planning process. They also are skilled in using the tools and strategies which are part of the person centered planning process. They are able to facilitate the group learning process, keep the planners focused on the individual and their vision, and assist planners in translating ideas into action. They demonstrate good communication and interpersonal skills. They demonstrate an ability to encourage all to participate, keep the work moving, assist planners by summarizing and clarifying and use group graphics to capture discussion, direction and action steps. Finally, they understand the planning process. They make the work occur in an efficient and effective manner by assuring that work is accomplished, that gatherings occur and begin and end on time; that summaries are developed and disseminated to all group members. A skilled facilitator seems to do this work in a way that seems effortless.

Finally, a skilled facilitator possesses a strong sense of community inclusion and, because they see the value in each individual, believe that everyone has contributions to make and that communities are stronger when each member has that opportunity.

Facilitator training

Recruitment of facilitators

Various avenues will be used to recruit person-centered facilitators. These sources might include:

- Support organizations, such as Independent Living Centers and community agencies
- Direct support professional of Missouri
- Self-advocates & family members
- Faith based organizations
- Social work students
- The business community
- Regional centers

Efforts will be made to recruit a wide range of people, who have a broad range of experiences and backgrounds, but generally share a common interest in supporting grassroots community change through a commitment to supporting changes that individuals desire.

Content

- "History" of development of person centered planning
- Values and assumptions
- A review of the overall process
- Demonstration of planning tools/ maps
- Practice of tools and maps
- Overview of various planning approaches
- Problem solving strategies
- Facilitation skills
- Basics of group graphics
- Summary-importance of ongoing learning; resources

Process

- Will involve a combination of classroom learning, practice under the guidance of a mentor and follow-up
- Learning will be competency based
- Will involve development and support of local or regional facilitator networks
- Will include mechanisms for initial as well as ongoing evaluation of facilitators .

The format for training will begin with a two day training which introduces the trainees to the history, assumptions, tools and strategies of person centered planning. Some practice using various tools would also occur. In addition, each trainee will be "linked" with a mentor, some one who has experience in person centered planning, and is available to work with the trainee on an ongoing basis to support him or her in learning

The format for training will begin with a two day training which introduces the trainees to the history, assumptions, tools and strategies of person centered planning. Some practice using various tools would also occur. In addition, each trainee will be "linked" with a mentor, some one who has experience in person centered planning, and is available to work with the trainee on an ongoing basis to support him or her in learning how to facilitate plans. After one to two planning gatherings, facilitators will meet together to review progress, discuss problems or issues and look at ways to improve particular skills. Each trainee will develop an individual learning plan, which will identify specific target skills and a strategy for attaining proficiency. Facilitators, with support from their mentors, will continue to plan with planning teams and meet together on a regular basis to review progress and share experience.

Evaluation

Several evaluation measures will be used throughout the learning process to review acquisition of competency and provide feedback to trainees and to the trainers. These will include a self-evaluation, which will be completed by trainees, an evaluation completed by mentors, and an evaluation, which will be completed by the focus person along with members of their planning team.

**"You can't do person centered planning in a system
centered way."
--- Beth Mount**

Attachment “B”

Pilot Participant Survey Summary:

Due to the limited number of participants in the pilot project the number of survey responses is not large and caution should be exercised in making too many generalizations from the data. Nonetheless, the opportunities provided by the pilot project to allow individuals with disabilities, and their families to choose and manage their own direct support staff, budgets, and even lives, has had an impact. The survey respondents indicated that the pilot has enabled participants to become more involved, and to exercise more control over different aspects of their lives. Some these are as follows:

More Involvement, Control and Flexibility in the Planning Process:

- The percent of individuals saying that they were *completely* involved in the planning process increased from 42.3% pre survey, to 73.1% being *completely* involved in the planning process.
- Control of individuals and families in scheduling planning meetings went from 75% pre survey to 95% post survey.
- The percent of respondents who felt the ability to be creative, to think differently in the planning process *a lot* or *completely* went from 40% pre survey to 96% post survey.
- The percent of individuals indicating that the ability to address changes through the planning process *a lot* or *completely* went from 60.0% pre survey to 100% post survey.
- Respondents felt they were more able to choose who facilitated the planning meetings. Pre survey 48% answered yes—this increased to 88.5% on the post survey.

Increased Decision Making Power:

- Pilot participants and their families are more involved in choosing the people paid to support them. Pre-pilot, individuals and families were *a little* to *a lot* involved (mean of 2.50) in making these choices. Through the pilot project, individuals indicated they have been able to become *a lot* or *completely* involved (mean of 3.62) in making this choice.
- Participants feel more empowered to choose the amount of personal care assistance in their budgets. Pre-project, participants and families felt they only *somewhat* had the ability to decide on PCA amounts (mean of 2.08). Post-project, pilot participants feel like they *completely* have this ability (mean of 2.50).
- Participants feel more empowered to decide how and when to change their budgets. Pre survey pilot participant responses were *not at all* (mean of 1.61). Post survey participants state they *somewhat* have this ability (mean of 2.28).
- The percentage of participants and their families who feel they have more real decision making power increased from 78.3% pre survey to 88% post survey. It was also felt that the unpaid people on the planning team had more power to make decisions. (Increase from 52.0% pre to 83.0% post survey).
- On the pre-survey, respondents felt they were only *a little* (mean of 2.00) involved in developing their budgets. The post survey shows an improvement, individuals are now involved in budget development *a little* to *a lot* (mean of 2.73).

Enhanced Relationships With Direct Support Staff:

- On the pre survey, 84.6% of the survey participants indicated that their direct support staff listened and understood them *a little* or *a lot*. This increased to 100% saying their direct support listed and understood *a lot* to *completely* on the post survey.
- The percentage of survey respondents who felt that direct support staff knowledge of the pilot participant's likes and dislikes increased from 84.6 % *a little* or *a lot* on the pre survey, to 100% indicating staff had knowledge of their likes and dislikes *a lot* to *completely* on the post survey.
- Perception of respondent's concerning direct support staff's respect for the person they were supporting went from 81% *a little* or *completely* on the pre survey, to 100% indicating that they respected as a person *a lot* to *completely* on the post survey.
- The percent of respondents who felt that direct support staff understood they worked for the pilot participant or their family went from 64% *a lot* or *completely* on the pre survey, to 100% on the post survey.

Attachment “C”

Missouri Independence Plus Initiative

**“Support Brokerage”
Information Bulletin**

November, 2005



**Developed By -
The Missouri Partnership for Self-Directed Support Statewide Task Force**

**In Partnership With -
The Missouri Department of Mental Health-Division of MR/DD,
The Missouri Planning Council for Developmental Disabilities, and
The UMKC Institute for Human Development, Missouri’s University Center for Excellence**

**Kay Green, Interim Principal Investigator
Vim Horn, Co-Principal Investigator
Susan Pritchard-Green, Co-Principal Investigator**

Funding provided by the Center for Medicare and Medicaid Services (CMS)
Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions.
Points of view or opinions do not, therefore, necessarily represent official positions of CMS.



UMKC Institute for Human Development • A University Center for Excellence in Developmental Disabilities, Education,
Research and Service (UCEDD) • 2220 Holmes Road • Kansas City, MO 64108 • (816) 235-1770

Introduction

Across the state of Missouri, we have heard many times that individuals and families want control and choice over the services and supports they receive. One of the significant barriers self-advocates and families experience when wanting to direct their own supports and services is the time commitment it takes to hire, train, manage, and sometimes fire their supports. Traditionally, the person “coordinating” supports and services either works for the agency funding the services, or the agency providing the services. These individuals generally provide assistance to multiple individuals and are, for the most part, directed by the agency they work for and not by the person on whose behalf they are working.

The question is often raised by self-advocates and families, “who do you work for? Me or the provider?” The hope is that these individuals work for the person and/or family, but this can sometimes be challenging due to conflicting interests. One approach to remove this conflict is to have independent "support brokers" who do not fund or provide direct support services to the individual self-directing their services. The support broker serves as a personal agent who works on behalf of the participant (or family) and is under the direction of the participant (or family). The broker assists the participant with whatever is needed to identify potential personal requirements, resources to meet those requirements, and the services and supports to sustain the participant as he/she directs his/her own services and supports. Most importantly, the support broker works for the person/family and is chosen by the person/family.

Support Broker Qualities and Qualifications

The person or family that is self-directing their services and supports should be able to choose who they think would best secure supports that meet the needs identified through their person-centered planning process. This could be a family member, a friend, or someone who has training and/or experience in securing supports.

It is not necessary for someone to have any formal training or education to be a *Support Broker*, although it certainly can be helpful. What is essential is that they are caring and sensitive, and are committed to the rights of individuals with disabilities and their families as they apply the principles of self-determination.

Listed below are the values upon which support brokerage should be based.

Each person with a disability has a fundamental right to:

- Live a life of dignity
- Be fully self-determined
- Be fully included in community life
- Access the supports needed to be fully included
- Choose and be supported by a network of family members and friends

A skilled support broker will have applied knowledge (experience) of the service system(s), resources, community, and person centered planning process. They are not only knowledgeable but they apply the principles of self-determination in the work they do. In addition, the person knows and is active in his/her community. They demonstrate good communication and interpersonal skills, as well as creativity in designing and implementing supports and services. They are action oriented and able to negotiate well with a variety of partners, they are consensus builders. They are able to work independently, problem solve, are self-motivated and have good management skills.

Individuals and families who use a support broker identified the following characteristics as helpful qualities:¹⁾

- Caring
- Enthusiastic
- Organized
- Follows through
- Creative
- Honest
- Not controlling
- Communicates well

Support brokers who were interviewed identified the following as basic entry level skills for a support broker:¹⁾

- Organizational and business skills
- Some experience working with people with developmental disabilities
- Knowledge of resources in the community
- Familiarity with families' needs
- Self-motivation
- People and customer service skills
- Creativity
- Be able to role-release
- Address support issues outside their expertise

Support Broker Training

Whoever is selected as a support broker should either have received, or should be provided with, basic competency based training on what is involved in being a support broker. The current training for brokers consists of six modules with follow-up as requested from project staff. The modules are as follows:

1. Self-determination
2. Consumer directed services
3. The role and function of the support broker
4. Navigating the service system
5. Managing support personnel
6. Accessing community resources and making connections

Support Broker Roles and Responsibilities

A support broker is someone who is selected by an individual with a disability, a family member, or a designated personal advocate, to assist them with self-directing the services and supports identified in the person centered plan. A support broker works for, and under the direction of the person who has hired him/her.

Support brokers should adhere to the basic principles of self-determination while providing or arranging for requested services. The support broker must provide supports in ways that are flexible, responsive, and controlled by the individual. The support broker must be able to provide quality information and technical supports since they may be called upon to assist in various aspects of someone's plan. Accountability of the support broker is defined in terms of meeting the individuals support needs.

The type of support typically requested includes, but is not limited to:

- Recruiting, interviewing, hiring and training personal assistants under the participant's direction and according to their specifications
- Establishing work schedules for supports based upon the person's support plan

- Assisting with the development and implementation of a back-up/emergency plan and quality assurance mechanisms
- Supporting an individual with managing their individual budget as requested. May include looking at ways to use the allocated budget creatively and effectively, and negotiating rates and contracts for the services.
- Working with a fiscal intermediary to hire and pay personal assistants as directed by the person/family
- Assisting the person with building circles of friends and developing other important relationships
- Seeking other supports or resources outlined by the person’s plan (e.g., adaptive equipment, home modifications, etc.)
- Assisting the person/family in evaluating various options/resources that are available, and supporting them to access selected resources

Independent Support Brokerage and Service Coordination

As service systems increasingly embrace the principles and practices of self-determination and individual funding, new functions and roles are being developed like that of an independent support broker. New roles, such as this, raise questions about how they relate to existing roles, such as service coordination. The following briefly describes the interrelationship between independent support brokerage and traditional service coordination.

The role of the service coordinator continues to be important in the defining, authorizing and monitoring of supports for the Division of Mental Retardation/Developmental Disabilities, while the independent support broker assists individuals and families with being able to self-direct their support. It is important to understand that each role is vital to the support of the individual and their family. It is also important to understand that service coordinators also assist individuals and families with self-directing their support, however, not necessarily at the level of intensity that is needed by many.

Real change needs to begin with an understanding of the desired outcomes followed by developing the structures to support them. This comes down to partnerships. Partnerships with those supported and those involved in their lives. The table below represents one way to show these partnerships:

<u>Independent Support Brokerage</u>	<u>Traditional Service Coordination</u>	<u>Individual/Employer</u>
Under participants direction: <ul style="list-style-type: none"> • Determine flexibility with the budget • Explore community resources outlined in the individual plan • Recruit, interview, hire and train personal care assistants • Implement back up plan • Communicate with service coordinator 	<ul style="list-style-type: none"> • Monitor health and safety • Complete waiver monitoring and documentation • Getting the plan through utilization review • Quality assurance • Assist with budget • Communicate with support broker 	<ul style="list-style-type: none"> • Keep within budget • Sign invoices to verify services provided • Keep support broker and service coordinator aware of issues that arise • Monitor support broker, personal assistant and back up plan

It is important to remember that this is a journey, not an event. If the support broker is completely independent this will surely impede success. However, a strong working relationship with service coordinators can bridge these voids. If the work is done in partnership, the development of the roles of the service coordinator and the support broker will provide an opportunity for positive change more quickly. It is also an opportunity to create a learning environment from which changes in the system itself can occur. With collaboration, families, self-advocates, support brokers and service providers can develop and implement remarkable life plans. Ongoing, continuous learning is essential to success and can only happen in partnership!

Recommendations for Implementation

We believe that if support brokerage is approved as a Waiver service that individuals and families receiving supports and services from the Division of MR/DD must be made aware of this option and how it will work. Information concerning “support brokerage” needs to be couched in the broader construct of individuals and families self-directing their services and supports. This information would best be provided through clear informational materials reviewed and discussed in a series of informational meetings conducted by each regional center. Our experience during the pilot has shown us that individuals and families need access to this type of information early on, and need the opportunity to ask questions to gain a clear understanding of self-directed services and how support brokerage could work for them. At a minimum these informational meetings should explain such things as:

- What is involved with self-directing services and supports. Including all components and aspects of self-direction.
- That support brokerage is an enhancement service, for those who choose to self-direct their supports, that goes beyond what a service coordinator may be able to provide in carrying out their existing responsibilities. It is important to stress that support brokerage and service coordination are not in competition with each other. Both types of services may be needed.
- That a support broker is independent of the service system, and they are hired and directed by the individual or family. The support broker works for the individual and/or their family.
- How a support broker can assist the person with self-directing their supports, and what is involved with recruiting and hiring a support broker.
- How support brokerage, as a Waiver service, would affect the persons overall support budget, and how it relates to the implementation of their overall plan.

References:

- 1) Independence Plus Pilot - Process Evaluation Report #1, October, 2005
- 2) Missouri Independence Plus Initiative Participant Guide – Support Broker Workbook

Attachment “D”

Designated Personal Advocate

A designated personal advocate is a person over the age of 18 that an individual with a disability, or guardian, or parent if their child is under the age of 18 may designate to assist, or make decisions related to supports and services, as well as obtain and utilize benefits or resources on behalf of the pilot participant.

The following expectations exist about the identification and use of a designated personal advocate include, but are not limited to:

- A designated personal advocate may be used any time the pilot participant or another responsible designee names one, is identified in the person centered plan, who has been approved by the Division of MR/DD or local regional center office in writing, on a form designated by the Division of MRDD.
- Designated personal advocates other than immediate family members or guardian of the pilot participant will be required to submit to a criminal record check, abuse neglect registry (name of other registries ??).
 - If the designated personal advocate is found to have a record of a conviction, the Division of MRDD may determine whether circumstances exist that allow the individual to function as a designated personal advocate without endangering the consumer.

Attachment “E”

Missouri Independence Plus Initiative
Statewide Quality Management Plan
For Individuals Who Self Direct Services



Developed by: Nancy Nickolaus

In Partnership With
The Missouri Department of Mental Health-Division of MR/DD,
The Missouri Planning Council for Developmental Disabilities, and
The Missouri Partnership for Self-Directed Support Statewide Task Force

Kay Green, Interim Principal Investigator
Vim Horn, Co-Principal Investigator
Susan Pritchard-Green, Co-Principal Investigator

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Statewide Quality Management Plan For Individuals Who Self Direct Services

Overview

Quality Management is the constellation of activities undertaken to promote the provision of effective services and supports on behalf of participants and to assure their health and welfare. Missouri's quality management process establishes mechanisms to prevent, discover and remediate problems in order to improve the quality of life for all consumers including those who self direct, to ensure their health and safety and to improve the overall system of service delivery.

Process

Statewide Quality Management Activities

Currently there are several Quality Management activities to ensure people who self direct services are healthy and safe. There are a variety of entities, organizations and stakeholders involved in the quality management process. A description of these stakeholders, their roles, responsibilities and related activities follows.

Service Coordinator Responsibilities:

Activity: Monitoring

Service coordination for DMRDD Waiver participants is provided by service coordinators employed by DMRDD Regional Centers or County SB-40 Boards approved by DMRDD to provide service coordination. During monitoring visits, the service coordinator monitors the effectiveness of personal assistant services and the individual's overall health and welfare. Progress notes document the contact and whether the outcomes related to personal assistant services as stated in the participant's person centered plan are occurring.

It is also the service coordinator's responsibility to review notes written by the personal assistant or family at least quarterly and note any problems, discrepancies, dramatic changes or other occurrences which indicate a need for renewed assessment. The service coordinator's review of the employee's notes includes making further inquiries and taking appropriate action if there is reason to believe the person's health or welfare is potentially at risk.

Service coordinator monitoring includes assessing the effectiveness of services provided by the support broker and the independent person centered plan facilitator, determining whether the participant's back up plan was initiated and if so, whether the plan was successful. If the plan was not successful the service coordinator will work with the participant, support broker, and plan facilitator to determine why the plan failed and develop a new back-up-plan.

The service coordinator is responsible for ensuring the written plan of care meets the DMRDD waiver guidelines even if it is written by the participant, support broker, or independent plan

facilitator. All plans must identify and document potential risks and strategies for risk management associated with self directing including participant back up plans.

Back Up Plan

A back up plan is developed as part of the person centered planning process. It is individualized and reflects the individual's needs and resources of the participant. The back up plan will be based on:

- Information about the types of situations that could arise that would put the person at risk including personal assistants not showing up for work, quitting with little or no notice, being neglectful, a change in health status that would require a different type of support, or behavioral support issues.
- A description of risks if the personal assistant is unavailable to provide critical services. A critical service is a service without which the person would suffer an immediate risk to his/her health, safety or well being.
- Action that will be taken when situations arise that may jeopardize health and safety.
- Actions the individual or advocates can take to prevent risks to health and safety.
- A description of the type of support regularly scheduled staff provide.
- Skills and training a personal assistant needs to provide support to the individual.

The back up plan will include at least 2 individuals to provide back up support.

Activity: Quality Framework Services Monitoring

During face-to-face visits with individuals, the service coordinator monitors the provision of purchased services (e.g. personal assistant services) according to the Service Monitoring Guidelines outlined in Directive 3.020. Service coordinators document the service monitoring visit in a log note. The log note also includes any issues/concerns noted during the monitoring and the action taken to resolve these issues. The service coordinator will continue to monitor the issue(s) during routine visits, or more frequently as needed.

When the service coordinator identifies or learns of incidents of abuse and/or neglect during a visit, the service coordinator shall report the incident according to Department Operating Regulation 2.210. Service coordinators employed by approved SB-40 County Boards or Affiliated Community Service Providers follow 9 CSR 10-5.200.

Frequency:

- **Participants self directing with assistance from a personal advocate:** When entering the program the service coordinator will conduct service monitoring at least monthly. If it is determined that no significant issues exist, at the request of the participant or their advocate, monitoring may be conducted quarterly. Any time there is a change in the health status of the individual that puts the individual at increased risk the service coordinator will increase monitoring as needed.
- **Participants self directing without assistance from a personal advocate:** Individuals who do not have a family member or other individual to assist them in self directing may be at increased risk when entering the program. Therefore increased monitoring will be required. Service monitoring will be provided at least monthly for the first 3 months of

self directing. If no issues or concerns are noted, monitoring may be extended to quarterly.

Activity: Health Inventory Process

Participants who self direct without assistance from a personal advocate shall receive a health inventory as part of the planning process. The inventory will assist the participant in identifying needed medical supports. The health inventory shall be offered as part of the planning process to participants who have self direction assistance from an advocate.

The health inventory form contains a series of health indicators. Once completed it will provide information regarding health and safety concerns for which the person will need support. Individuals scoring over 30 points on the form will be offered consultation services from a DMRDD registered nurse. The inventory describes health care needs but supports that are currently in place are not identified. Therefore, individuals/families may not need or want these consultation services and may refuse them. Service coordinators will document that the services have been offered and the individual/family's response in a progress note. If the service coordinator feels that the consultation is vital to the health/safety of an individual, the support team will meet to resolve the situation.

Participant/Family:

Activities: Each participant/family member will complete training activities related to self directing services. Training will focus on an orientation of the project, self determination; person centered planning (which includes a section on back up plans), support brokerage, designing and selecting supports, budgeting and financial management and system monitoring requirements. Training includes how to contact service coordinators and other emergency response systems (911) and information that should be provided to service coordinators (i.e. when a back up plan failed to work and if there is a change in support needs).

Support Broker:

Activities: Each support broker will complete training activities related to the support brokerage role. Training will focus on an orientation of the project, person centered planning (which includes a section on back up plans), support brokerage expectations, community resources, budgeting and financial management. All support brokers must pass a background screening check. Brokers will be provided technical assistance by project staff.

Independent Plan Facilitator:

Activities: Each independent plan facilitator will complete training activities related to person centered planning. Training will focus on an orientation of the project, person centered planning (which includes a section on back up plans), roles of the various stakeholders and waiver expectations. All plan facilitators must pass a background screening check. Facilitators will be provided mentoring and technical assistance by project staff.

Division of Medical Services

Activity: Program Reviews

The Division of Medical Services, in cooperation with staff from the DMRDD Federal Program Unit, conducts random reviews of participants receiving DMRDD Waiver services, including individuals who self direct these services. Participants whose records will be reviewed are randomly chosen. The reviewers monitor records for compliance with waiver assurances including that:

- The individual is in need of an ICF/MR level of care.
- The plan addresses all the participant's assessed needs including health and safety, risk factors, supports provided and personal goals.
- Plans are updated and revised when warranted by changes in the participant's needs.
- Participants are provided choice between waiver services and institutional care and choice of waiver providers.

The DMS compiles a notification of the findings and sends it to the designated DMRDD Federal Programs Unit staff. The Federal Program Unit designee will notify regional center directors, regional center quality management team members and statewide quality team members of the findings. Each regional center must submit a plan of correction, if needed. Data from each review is entered into a database and tracked for local and statewide trends. Training is targeted to address negative trends, locally or statewide as appropriate.

Reviews are conducted on a bi-annual basis.

Activity: DMS Fiscal Reviews

The Division of Medical Services, in cooperation with staff from the DMRDD Federal Program Unit, conducts random fiscal reviews of the DMRDD Waiver Programs, including individuals who self direct waiver services. The DMS Program Integrity Unit ensures financial compliance by reviewing documentation that services were provided as authorized and described in the plan of care.

DMRDD conducts training based on trends found in these reviews.

Reviews are conducted on a bi-annual basis.

Regional Center Quality Assurance

Activity: Each regional center has a quality assurance team which provides consultation to service coordinators on an as needed basis. The service monitoring guidelines outline the process for identification, communication and resolution of issues of concern. When a service coordinator needs assistance problem solving or putting in place preventative strategies to protect the health and safety of an individual self directing services, the regional center quality assurance team provides expertise to the planning team.

Statewide Quality Assurance

Activity: The statewide quality assurance team will provide consultation and training to the DMRDD regional center staff when statewide trends are discovered. As monitoring of self directed services occurs, trends will be shared with statewide quality assurance team members for assistance with remediation and improvement.

**Attachment “F”
Original Independence Plus Task Force**

Purpose of the Task Force

Design, create, implement & evaluate components of a self-directed approach that leads to Missourians with disability and their families having choices and control of the resources via individual budgets, fiscal intermediaries, and support brokerage.

<i>Task Force Member Name</i>	<i>Representative of:</i>
Tracy DePriest Travis Anderson	MO People First
Lori Perdue Jessica Balters Debbie Stewart	MoCAN
Joann Noll Sharon Smith	MO State Planning Council
Richard Enfield	Parent
Amanda George	DMH-MRDD
Jeanne Lyod	Vocational Rehabilitation
Glenda Kramer	Division of Medical Services
Don Carrick or Tracy Lowery	Direct Support Professionals of Missouri
Gary Stevens	MOAIDD
Kirsten Dunham	Personal Independence Commission & Independent Living Centers
Donna Haley	MO Consumer/Family QA Team
Linda Allen	Senior Services
Mary O’Brien	Parent
Nan Davis	Parent, Region 2 RAC
Phil Fergeson	Parent
Alicia Neisen	MACDDS/MOANCOR
Kay Green	DMH

21 members with 12 members being either a self-advocate or a parent of a child with a disability. The names in bold are either self-advocates or parents.