Evaluation of the Maryland Self-Determination Initiative

BRIEF FINDINGS

August 2000

Prepared by
Madeleine Kimmich
and
Jody Becker-Green
Human Services Research Institute
850 Lancaster Drive SE
Salem, OR 97301

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Context of the Self-Determination Initiative

In February 1998, the Maryland Developmental Disabilities Council contracted with Human Services Research Institute (HSRI) to conduct a two-year evaluation of the state's Robert Wood Johnson Self-Determination Initiative. This report summarizes preliminary findings on the impact of the Maryland initiative.

Maryland's Self-Determination Initiative was a three-year collaborative effort (February 1997 - April 2000) of the Maryland Developmental Disabilities Administration (DDA) and the Arc of Frederick County, with active support of the Maryland Developmental Disabilities Council. The $390,000 initiative began as a pilot project in two DDA regions, encompassing four counties: in Central Region, suburban Howard County; and in Western Region, rural Allegany County, suburban Washington County, and rural Garrett County. Three groups of people were originally targeted: people currently receiving services but wanting a change, people on the waiting list, and youth transitioning from school to DDA services.

The Self-Determination Initiative seeks to create systems change in Maryland. The primary goals of the initiative are (1) to give people with developmental disabilities and their families greater choice and control over the services and supports they receive; (2) to increase the efficiency and cost effectiveness of DDA-funded services; and (3) to promote the principles of self-determination throughout the DDA system. Occurring within the existing DDA service system, the Self-Determination Initiative offers a model of system reform which encourages greater flexibility in policy and practice, and greater openness to consumer and family involvement.

Several events have had significant impact on the implementation of the Self-Determination Initiative: (1) the Self-Determination project director changed within the first year, somewhat delaying implementation; (2) in 1998, the Maryland Legislature passed a significant Waiting List Initiative, pushing to the forefront one of the three Self-Determination Initiative target populations and engaging the Arc of Frederick in a massive service coordination effort just at the time the Self-Determination Initiative was accelerating; and (3) in the fall of 1999, DDA was required by state procurement laws to rebid the service coordination contract; although they ultimately retained the Arc of Frederick, their actions caused the Arc of Frederick to lose staff and Maryland as a whole to lose momentum around Self-Determination service coordination activities.

Structure of the Evaluation: The evaluation explores the impact of the Self-Determination Initiative on the overall service delivery system and on the individuals being served. HSRI examined DDA policies and procedures, management information systems, regional office operations, and service availability, relevant to the initiative. Evaluation staff also assessed the experiences of key players in the Self-Determination Initiative, including consumers, families, service coordinators, direct support staff,

provider agency executives, and managers in DDA Regional offices and Arc of Frederick Service Coordination offices. The findings reported here draw from HSRI's on-site activities (community forums and interviews), telephone discussions, and review of written materials. In September, HSRI will integrate its findings with the Arc of Maryland's *Ask Me!* project, in a final evaluation report on the Initiative.

Outcomes of the Self-Determination Initiative

Maryland has been very ambitious in its Self-Determination Initiative, tackling meaningful systems reform rather than attempting a few changes for a small group of people. DDA has taken a leadership role in promoting the principles of self-determination through innumerable information-sharing events throughout the state, encouraging the pursuit of self-determination for the DDA system as a whole, not just for the two pilot regions. This philosophical commitment has gone beyond words to efforts to engage a wide cadre of stakeholders in policy discussions, giving individuals and their families, as well as providers, the sense that the system is indeed open to reform. Thus, not only has the Self-Determination Initiative improved outcomes for selected individuals, but also has laid the foundation for significant capacity-building toward more individualized service delivery.

In several specific arenas, the Self-Determination Initiative has already shown dramatic effects:

REGULATIONS AND QUALITY ASSURANCE – Under strong leadership, DDA has improved regulations and quality assurance standards, moving the DDA system toward more individualized supports, flexibility, and an outcome focus. New program regulations are more outcome-oriented, and greatly increase the flexibility of service coordinators: the individual plan is now the centerpiece of services, and service coordinators/resource brokers have more flexibility in how and how often they interact with individuals. The new regulations also include significant changes in quality assurance activities, to make the process more outcome-oriented and more focused on consumer satisfaction. Further supporting its movement toward self-determination, DDA submitted its Medicaid 1915 Waiver renewal, expanding Maryland's capacity over five years to obtain federal funds for an additional 5,000 individuals with developmental disabilities. As part of the renewal package, DDA made modifications to its Waiver Plan, to assure that the expansion would occur in individual and family supports, and requiring use of person-centered planning.

INDIVIDUAL OUTCOMES – Many Self-Determination Initiative participants have experienced improvements in their personal outcomes, making real the vision of self-determination for individuals with disabilities. HSRI interview data, which is designed as supplementary to the Arc of Maryland's *Ask Me!* study, indicates that Self-Determination Initiative participants are being treated with more dignity and respect, are making more decisions about the direction of their lives through the planning process, have more choice and receive more flexible services. The dramatic increases in the use of non-traditional supports presage the movement toward a service delivery system that truly meets the unique needs of an individual. Reliance on natural supports is growing in

acceptance and in practice, although it is challenging to service coordinators, families, and direct support staff due to the amount of time invested in building and sustaining dependable community relationships.

While changes are occurring, barriers to individualized services and supports still exist. Despite providers' efforts to enhance employment opportunities for individuals in their communities, widespread concerns remain about the lack of meaningful and individualized day services for individuals. Building service capacity in this area will prove challenging for providers as well as for the larger service delivery system. Viable strategies must be developed that take into consideration the current investments in bricks and mortar, direct support staff shortages, and funding limitations.

SERVICE AVAILABILITY – In both of the Self-Determination pilot regions, the array of available services expanded between FY97 and FY99, especially non-traditional supports. This expansion occurred within the existing provider network, with several agencies in each pilot region adding new support services (CSLA, ISS) to their offerings. While the Self-Determination Initiative had the potential to attract new providers to the pilot areas, existing providers appear to have risen to the challenge of meeting changing service delivery needs. Between FY97 and FY99, no new providers came forward, and none of the existing providers ceased providing services. This speaks to the flexibility of the current providers, responding to the changing service preferences of consumers.

The Self-Determination pilot counties experienced steady growth in all service areas between FY97 and FY99, but expansion in the less traditional support areas was noticeably greater. As the charts below indicate, the largest service growth in the pilot counties occurred in support services (including ISS and FSS) and CSLA. Between FY98 and FY99 in Howard County, the total number of individuals served in support services increased from 96 to 209, a growth rate of 117%; at the same time, the total number served in CSLA nearly doubled from 50 in FY98 to 92 in FY99. Similarly, the most substantial service growth in the three pilot counties in Western Region occurred in support services and CSLA. Between FY98 and FY99 the total number of individuals served in support services increased by approximately 50%; the total number served in CSLA more than doubled from 20 in FY98 to 46 in FY99. Although these individualized support categories still are dwarfed by the more traditional day and residential service

Chart 1: Services Delivered in Howard County

Chart 2: Services Delivered in the Western Region Pilot Counties
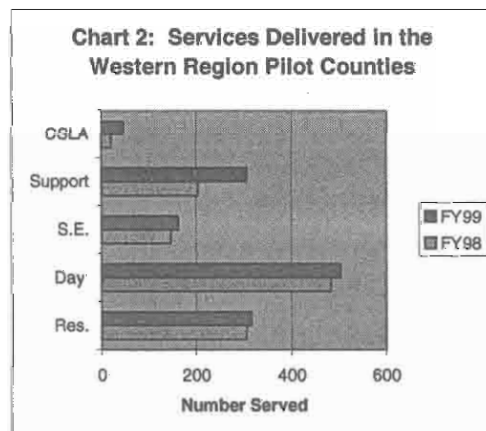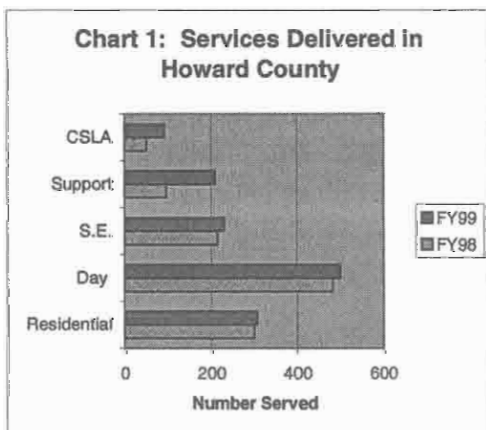
categories, the trend is significant, and may foreshadow a more dramatic shift in the near future.

This movement toward non-traditional supports may receive further impetus from an efficiency perspective. DDA Regional Office data suggest that in FY99, the average cost of providing support services was one-fifth that of residential services; and the average cost of delivering CSLA was roughly half that of residential services.

Figures showing the shift toward individualized supports mask the enormous challenges that regional offices and service providers have faced and continue to face. On-site interviews revealed that the increase in service demand generated by the Waiting List Initiative has overwhelmed many provider agencies. Overall, the system has not been able to respond quickly enough to expand capacity, leaving providers unable to meet all of the individualized consumer desires. Provider agencies acknowledge the positive changes occurring in the service delivery system as a result of the Self-Determination Initiative, yet grapple with some significant barriers, including:

❖ how to restructure internally to meet changing demands;

❖ how to recruit and retain staff in a booming economy (see discussion of direct support staff below);

❖ how to match staff schedules to individuals' times of need; and,

❖ how to assure that consumers know what services and supports are available.

TRAINING – Training and technical assistance have been one of the strongest elements of the Self-Determination Initiative. The original Maryland proposal stated that DDA would spend approximately $28,000/year on training efforts. In FY98 training allocations, the DDA Director asked each Regional Director to earmark 25-50% of training funds for self-determination related activities; all regions were supportive of this and exceeded the original training targets.

From inception, the Self-Determination Initiative has provided an extraordinary amount of training and technical assistance for service coordinators, service providers, Regional Office staff and other interested parties on a wide range of topics related to the principles, philosophy and implementation of self-determination. Training efforts were not solely targeted to the Self-Determination pilot areas; rather, they occurred statewide. Throughout the course of the project, training activities progressed naturally from a philosophical base to operationalizing the values of self-determination in the delivery of services and supports. Initially, the project struggled in reaching consumers and their families; however, over the course of the project, strategies were developed and implemented to increase their participation in training efforts.

DIRECT SUPPORT STAFF – Recruiting, training and retaining high quality direct support staff is paramount in the delivery of self-determined services and supports. The direct support staff currently working with Self-Determination Initiative participants are seen as skilled and committed, but need to be better supported in their role. The majority of individuals and families interviewed were complimentary about their direct support staff. They described positive help-giving relationships, felt that staff were an

integral part of accessing community resources, and sensed that staff were instrumental in facilitating self-determined lives. Direct support staff were genuinely concerned about and committed to providing individualized services and supports to the individuals with whom they work.

Provider executives expressed serious difficulties in recruiting, training, and retaining direct support staff. They commonly attributed the staffing crisis to (1) low direct support staff wages, (2) high turnover rates, (3) lack of "hands-on" self-determination training for direct support staff, and (4) an inability to hire individuals to work both limited and flexible shifts in order to meet the individualized needs of consumers. Direct support staff echoed these concerns. In addition, they expressed confusion over their roles and responsibilities as they try to build natural supports and also to be ready to fill in when those don't come through. Further, staff believe that it is difficult to advocate for and promote self-determination for others when they themselves feel undervalued and underpaid. Logically, as people move into more individualized supports, the reliance on traditional staffing models will decrease. Providers are beginning to see this movement and must continually strive to develop creative strategies to address this change.

COMMUNICATION – In the initial stages of the Self-Determination Initiative, stakeholders at various levels of the service delivery system benefited from increased opportunities for discussion and communication around implementation of the initiative. Evidence of the quality of this communication can be found in the level of participation in the pilot county focus groups, improved relationships and information exchanges between the DDA Regional Offices and Arc of Frederick Service Coordination, and heightened involvement of families as a valuable resource in the planning process. Changes in the planning process have led to enhanced communication among members of the service delivery teams. Initial pockets of resistance within the provider community have lessened as (1) providers have had opportunities to give input and receive feedback through the Regional Focus Groups; (2) communication has improved among the DDA Regional Offices, service coordinators and provider organizations; and (3) providers have participated in training opportunities and provider fairs.

While communication has increased, there is still need for more effective ongoing communication and greater stakeholder involvement. The Regional Focus Groups gave voice to a wide range of local stakeholders, but the groups struggled with their identity and desired more control in the actual creation and direction of the local project. At the state level, the DDA Steering Committee offered visionary leadership and a forum for policy discussions, but their actions did not systemically impact the day-to-day operations of the Self-Determination Initiative. Ultimately, these groups appeared to have had only modest impact on the Self-Determination Initiative as it played out in the pilot counties. In addition, providers continue to feel excluded. They articulated uncertainty over the future of self-determination beyond the life of the initial grant, expressed concerned about the shifting roles between DDA and Service Coordination, and continued to feel "left-out" of key decision making processes.

FISCAL PROCEDURES – Among the weakest threads in the self-determination fabric is the state fiscal management system. One of the primary goals of the Self-

Determination Initiative is to increase the efficiency and cost effectiveness of DDA-funded services, through changes in the way funding flows through the DDA system. In particular, Maryland stakeholders are interested in whether funding patterns and practices have changed, leading to an increase in the number of people served. Addressing these questions has been much more complex than expected, due to difficulties in identifying and analyzing service expenditures per individual. HSRI is in the midst of collecting and analyzing fiscal data on a selected sample of individuals. However, it is already clear that DDA's fiscal tracking capacity and the requirements of the current procurement and funding systems seriously limit DDA's ability to manage and analyze resources at the individual level.

From the perspective of self-determination, individualized budgeting remains elusive. Thus far, no real change has occurred in how money flows: some limited budget responsibility was shifted to service coordinators, but not without significant confusion, tension, and a need to carefully re-examine relationships and roles.

The proposed shift is not an easy one for any of the parties, not the least of which is service providers. Giving budget development to service coordinators threatens to disrupt established relationships between providers and DDA regional staff, and raises uncertainties for providers regarding what will be approved, how quickly and smoothly the new process will be implemented, and, ultimately, how the change will affect provider payments. In addition, early discussion of potential cost savings only fueled provider fears about decreasing payment rates; it took two years for that fear to abate.

The new DDA regulations promise to increase fiscal flexibility, but this is only a partial solution. In practice, a meaningful shift in budget authority will not happen until all the parties get together to address liability and risk issues, which are at the heart of many states' reluctance to consider shifting fiscal control to individuals or their designees.

The transfer of budget authority has significant implications for how risk is distributed and managed among all participating parties. These risks are tied to liability concerns (e.g. tax liability, civil liability), concern related to budget allocations and whether support plans are adequate, the capacity of providers to compete for business, and other factors that inject uncertainty into the system. To begin to tackle these concerns, state bureaucratic and procurement issues need to be resolved, since a sound and rational procurement system can help to reduce risk.

Another problem arising from the lack of reliable fiscal data is the dominant perception of inequitable funding between current services recipients and new recipients of service through the Waiting List Initiative: the widespread belief that those entering services under the Waiting List Initiative are getting more generous service budgets, while those already in services are constrained by their present budget. The reality is more complicated: new service recipients may have different levels of service need, and certainly face a different range of service and support options, than do current service recipients. It may or may not be the case that the actual support costs of entering people are higher than previous support budgets, but they are certainly lower than the budgets of people in residential services. When data are available on budgets for all people served through the Self-Determination Initiative and Waiting List Initiative, this issue will perhaps be clarified.

Unquestionably, the biggest benefit that has come from efforts to shift budget responsibilities has been to highlight the problems with the current state budgeting and financial management processes, and to create urgency for addressing these issues.

RESOURCE AGENCIES – The resource agency concept is being piloted in both Western and Central Regions, but with little effect on the local service delivery system. The pilot resource agencies were given little independent authority, especially in fiscal arenas, and the relationship between the pilot agencies and DDA is poorly defined, not only in financial management but also regarding eligibility determination, training and technical assistance, quality assurance, and strategic planning.

A primary objective of the Self-Determination Initiative was the establishment of pilot resource agencies in Central and Western regions. According to the plan, the Resource Agency would be a consumer-driven and consumer-focused entity, empowered to administer DDA funds on behalf of all DDA recipients in a geographic region. In particular, it would be the organizational home for resource coordinators who conduct person-centered plans, maximize informal supports, help people obtain services and supports, and assist providers to develop individualized services and supports.

This vision has not yet been realized. Prior to implementation, Regional Focus Groups engaged in tremendous discussion and planning, a process generally seen as frustrating because it was very time-consuming and ultimately had limited impact on the plan. Actual implementation of resource agencies in both pilot areas did not begin until July 1999, at the same time service coordination services were being rebid. No distinct entity has yet taken shape independent of the existing service coordination contractor. Since the Resource Agency concept in Maryland has been considered the key to effecting a shift to individualized budgets, DDA needs to clearly decide how it wants to proceed beyond the limited pilot effort.

MANAGEMENT INFORMATION SYSTEMS – Current DDA management information systems do not adequately support the current service system nor the effort toward systemic reform. In the course of the Self-Determination Initiative, both the Arc of Frederick and DDA made plans for new management information systems, the former to handle individual-level data on the various people served by Service Coordination, the latter to address the data needs of not only the Self-Determination Initiative but also the Waiting List Initiative. Neither system has yet been implemented sufficiently to provide accurate and complete data on people served through the Self-Determination Initiative, greatly limiting HSRI's ability to evaluate the initiative's programmatic and fiscal effectiveness. DDA Regional as well as Central office staff have worked hard to try to tease out of the system the needed information – people entering DDA services, people currently being served, people awaiting DDA services, people with approved case plans under the Self-Determination Initiative, financial allocations for selected Self-Determination Initiative individuals, etc. These efforts remain largely unsuccessful, because the data systems are simply not built to answer such questions. To at least partially compensate for the insufficient cost data, HSRI will conduct a small primary data collection effort during the summer of 2000.

Recommendations for the Future

✓ Keep critiquing the self-determination/ systems change process, acknowledging and fully understanding the barriers, and then systematically addressing them.

✓ Appoint someone to spearhead the reform effort – designate a *change agent* who is independent of the local service delivery system, has sufficient influence to effect policy changes, and effectively utilizes the Steering Committee.

✓ Address procurement and bureaucratic barriers that hinder implementation of self determination, so that service coordination activities and budgeting processes become more smooth.

✓ Overhaul the DDA information systems, both fiscal and programmatic, to support ongoing practice and policy reform.

✓ Stay accountable by systematically addressing quality as well as quantity issues, through monitoring and ongoing reporting to stakeholders.

✓ Make a decision about the Resource Agency concept.

✓ Give attention to the factors that enhance and inhibit the increased use of non-traditional day supports (including supported employment and individualized day supports), to expand system capacity to provide these desired options.

✓ Support direct care staff, people with disabilities, and families, especially through training and meaningful opportunities for input to practice.

✓ Sustain the parts of the initiative that are working well, such as retaining experienced service coordinators and direct care staff.

✓ Consolidate the gains made through the Self-Determination Initiative, and make sure the reform reaches those originally intended as the target group, those currently in services.

HSRI will report more complete findings on Maryland's Self-Determination Initiative in Fall 2000, in the final report of the evaluation. In particular, HSRI staff will work with DDA to obtain more reliable data on service costs. We will collaborate with the Arc of Maryland to merge HSRI's analysis of the Self-Determination Initiative with the findings of the *Ask Me!* interviews with Self-Determination Initiative recipients, regarding their relationship with service coordinators and their individual outcomes. We will also prepare a consumer-friendly summary of the evaluation findings, appropriate for distribution to self-advocates, family members, direct care workers, and others interested in the future of self-determination in Maryland.