



Self-Determination in Idaho

A Collaborative Project of the
Idaho Council on Developmental Disabilities
and
the Idaho Department of Health and Welfare

Report to the 2004 Idaho Legislature

“The promise of self-determination for both individuals and human service systems rests less on the *formula* for distributing public dollars and more on the increased *value* purchased by those dollars. Focusing on obtaining *better value* for public expenditures holds out real promise for more efficient human service systems and more meaningful lives for individuals with disabilities.”

Tom Nerney, Center on Self-Determination, October, 2001

WHAT IS SELF-DETERMINATION?

Self-determination is a movement by people with developmental disabilities and their families that seeks to give each person choice and control over the most fundamental aspects of their lives. A self-directed service system model expands upon the current system by enabling individuals to access needed services in a more flexible way and providing them with more choice and control over the supports and services they purchase. Traditionally, the control and responsibility for services rests with a service provider agency or an organization. With self-directed supports, people with disabilities and their families choose the services they want, hire staff, and control their budget. A self-directed system is implemented through the use of a Medicaid waiver.

BACKGROUND

In 2001, the Idaho Council on Developmental Disabilities convened a group of people with developmental disabilities, family members, providers, agency representatives and others to develop a framework for a self-directed service system in Idaho. The group spent several months developing the mission and principles by which such a system would be driven. The group outlined the following fundamental values upon which a participant-drive, efficient and cost effective system would be built:

- **FREEDOM** to plan their own lives
- **AUTHORITY** to control the resources allocated to them to acquire needed services and supports
- Opportunity to choose their own **SUPPORTS**
- **RESPONSIBILITY** for their fiscal choices and the consequences of those choices, and
- **RECIPROCAL RESPONSIBILITY** to participate and become contributing member of their community.

The Task Force also designed a set of quality indicators that could be used to measure consumer satisfaction and choice in a self-directed system, as well as a strategic plan to move Idaho toward a consumer directed approach.

At that time, the Task Force had hoped to demonstrate this model in one region of Idaho, but because utilization management was beginning to be demonstrated at the

same time, that effort was not pursued. The Task Force did, however, make a comprehensive presentation to policy makers and others in December of 2001.

In 2002, the Health and Human Services Subcommittee of the Governor's Blue Ribbon 2020 Task Force recommended that Idaho

"...endorse a pilot project based on the concept of self-determination. This project would include a modification of Idaho's Medicaid program to allow a specified number of individuals to utilize services under a participant-driven approach centered around the following essential elements: 1) Individualized budget; 2) Personal broker; 3) Fiscal intermediary; 4) Freedom of choice of traditional and non-traditional providers"

Acting on that recommendation, the Council on Developmental Disabilities drafted and submitted House Concurrent Resolution 29 to the 2003 Idaho Legislature. This resolution encouraged the Council, in collaboration with the Department of Health & Welfare and other stakeholders, to convene a task force to develop a waiver for a self-directed service delivery system. Upon passage of HCR 29 last March, the Council reconvened and expanded it's original Task Force on Self Determination to work on this project. This expanded group demonstrates the collaboration that has been a key component of this effort. At the table to work together on this project are self-advocates and parents from across the state plus representatives of the Department of Health and Welfare (Medicaid, Family and Community Services, and Welfare), the Department of Education, advocacy organizations (CO-AD, DD Council, Living Independence Network), the Office of the Governor, legislators (Sen. Fred Kennedy and Rep. Kathie Garrett), Idaho Parents Unlimited, the Center on Disabilities and Human Development at the University of Idaho, and a range of service provider agencies (DDAs, service coordinators, residential habilitation and supported living providers).

ACCOMPLISHMENTS TO DATE

TASK FORCE

The Self Determination Waiver Project Task Force began meeting in May, picking up where the previous group had left off with the design and development of a

self-directed service system model. The Council engaged John Agosta and Gary Smith of Human Services Research Institute (HSRI), a nationally-recognized consulting group, to assist in these efforts. Following the key design features of the *Independence Plus* framework – an initiative that follows the direction of the President’s *New Freedom Initiative* – the task force was divided up into four workgroups addressing these areas: Person-Centered Planning/Supports Brokerage, Individual Budgeting, Financial Management Services/Provider Choice and Quality Assurance and Improvement. The four workgroups met throughout the summer and fall, discussing and drafting recommendations for the design and implementation of a self-directed service system. A subcommittee of the full task is combining the recommendations into an outline of a proposed self-determined model and is presenting those recommendations to the full Task Force for discussion and action. A consensus approach is being used to help insure everyone’s understanding and buy-in through each step of the decision-making process.

FEDERAL GRANT

As an additional part of these efforts, Council staff, in collaboration with the Idaho Division of Medicaid, responded to an opportunity through the federal Independence Plus Initiative to draft and submit a grant proposal to the Centers for Medicare and Medicaid Services (CMS) in July. The grant proposes systems change in multiple phases: 1) Development and cost analysis of a self directed Medicaid services and supports waiver (currently underway); 2) Submission of design to the Idaho Legislature and to CMS; 3) Statewide public education and training for consumers and providers (consumer education has begun); 4) Infrastructure development and implementation; and 5) Continuous quality management and improvement employing the CMS Quality Framework. In October, the Division of Medicaid received word that the grant had been funded in the amount of \$499,643 for three years. These funds will be used for many of the start up and infrastructure building costs associated with the waiver.

The grant is being coordinated by Medicaid, working in close partnership with the Council on Developmental Disabilities. Bi-monthly monitoring calls between CMS and Medicaid and Council staff and annual technical assistance meetings are helping to insure appropriate use of funds and provision of technical assistance to Idaho.

WAIVER DEVELOPMENT

The key to implementing a self-directed system is the application for and use of a Medicaid waiver. CMS has developed some templates for states to use to pursue these waivers. These templates guide the states as to the elements of the system that must be in development or in place in order for CMS to approve the application.

Idaho has been able to take advantage of the experience of nineteen states that implemented self-determination model projects with grants from the Robert Wood Johnson Foundation. Collectively, the states experienced challenges in the following areas:

- § New ways of allocating dollars had to be designed and put into place;
- § Fundamental business practices had to be developed and implemented; and
- § Accommodation of self-determination while continuing to operate predecessor systems side-by-side.

But it is also important to note that the states were able to design and put into place an infrastructure in support of self-determination. The fact that different solutions emerged furnishes evidence that addressing the mechanical aspects of self-determination hinge mainly on local considerations. It also supplies evidence that self-determination can work in a variety of structures.

The overarching experience of the RWJ states is that people had greater choice and satisfaction, that risk was no greater and generally less, and that in some instances, cost was reduced because people selected only those services and supports that they really needed and wanted.

The self-determination waiver in Idaho would initially be available to up to 200 adults with developmental disabilities. Participation is voluntary and eligibility will continue to be determined by the Scales of Independent Behavior – Revised (SIB-R). While the Task Force does not endorse the use of the SIB-R, especially on an annual basis, it is recommended for initial implementation to minimize additional administrative costs. However, the Task Force also recommends that other methods of assessment be reviewed during the initial implementation phase for use in the future. Among the tools discussed is the new Supports Intensity Scale that is currently being tested in Kansas and may be more appropriate for determining support needs as part of the planning process.

As envisioned by the Task Force, a self determination support system in Idaho would contain the following elements:

1. **Individual control over pre-authorized budgets** that can be used flexibly to accommodate the needs specified by the individual in his/her plan. Instead of relying on test scores and history, a comprehensive person-centered plan will outline the consumer's goals and needs and the projected costs of meeting those needs. If the budget amount falls beyond what a normal support range for that consumer, additional work will be done to either reexamine and modify the plan or change the budget. It is important to note that the costs for this waiver cannot exceed, on average per person, the costs for Idaho's other waivers for adults with developmental disabilities. Currently that average amount is \$45,000/person/year, but that can vary widely depending upon living arrangements, natural supports, transportation needs, available services, and goals of the person. For all of the waivers, costs must be no more than they would be in an institutional system. Given that institutional costs range from \$75,000 - \$150,000/person/year, they are far less.

2. **Personal Advocates or Brokers** who work for the individual to help him/her develop support plans and secure supports. This person assists the consumer in negotiating for the services they need and want at a price they are prepared to pay. The Task Force is proposing three alternatives for support brokers:

- § *Self-managed supports* where the consumer, with support from their planning team, hires, fires, and supervises all service providers. This means the person assumes all management responsibility and works directly with the fiscal intermediary in the control and decisions regarding their budget (within the parameters of their plan).
- § *Independent support brokers* who work directly for the consumer. They may help the person find and negotiate for services, negotiate a rate of pay, and locate complementary natural supports in the community.
- § *Support brokerage agencies* are similar to today's targeted service coordinator agencies but differ in that the broker's actions are directed by the consumer and the rate of pay is negotiated for each individual.

3. **A Fiscal Intermediary** or "business agent" assists individuals in managing their budgets and paying the providers of services; this entity operates like an accounting

service, receiving the bills for services from the provider (after they have been approved by the consumer), paying the bills, and billing Medicaid for reimbursement. They also provide monthly statements to the consumer to help them monitor their annual budget. Based on information gathered, the Task Force is recommending that Idaho have one statewide fiscal intermediary, making this part of the administrative cost for this waiver. All participants in the SD waiver would be required to utilize a fiscal intermediary. There is no comparable service in the current DD waivers, however at this time, the centers for independent living provide fiscal intermediary services for personal assistance services provided under the Aged and Disabled (A&D) waiver.

4. **Individuals have a choice of service suppliers**, from traditional Medicaid providers or non-traditional providers, at a rate negotiated by the consumer (with help from the broker). The service must be one that will help the person meet their goals as outlined in their plan and be affordable within their annual budget. The Task Force is recommending that there be three services within the SD waiver: 1) fiscal intermediary services (although this may be an administrative cost instead), 2) support broker services, and 3) community supports. This last service category covers five components: employment supports, daily living supports, interpersonal supports, behavioral supports, and learning supports. These broad categories permit maximum flexibility and individualization. By contrast, in the current DD waivers, services must be provided by Medicaid provider agencies and selected from a menu of thirteen services at rates set by service category by Medicaid. The flexibility of service suppliers in a self-determination model may increase access to supports, particularly in rural areas where there are a limited number of traditional providers.

5. **Quality assurance will be imbedded throughout the process** from the development of a plan, to the achievement of the goals outlined in the plan, to annual reviews, and to periodic customer satisfaction surveys. Part of the initial plan development will be a risk assessment and a subsequent negotiated risk agreement that spells what is acceptable risk for the person to undertake and what is not. Each plan will also outline 3 back-up support systems, with the person-centered planning team convening at anytime the 2nd backup is utilized. Annual budgets will be monitored through monthly statements furnished to both consumer and broker by the fiscal intermediary. All providers will be required to submit to a background check, and all

support brokers will participate in training specific to their responsibilities. Consumers will also receive training on how to use the waiver, in addition to the generic consumer education on the concept of self-determination that has already begun. Individual waiver participants will be surveyed at enrollment and periodically throughout the project thereafter regarding satisfaction, independence, choice, and safety. This information will be routinely incorporated into the ongoing training of providers and the education of current and potential participants and family members in order to take advantage of lessons learned.

The Division of Medicaid has compiled some preliminary cost information based on current waiver costs and estimates from other states and CMS. The initial costs for consumer and provider training, computer system changes and development of quality assurance measures will be largely covered by the Independence Plus grant with additional support provided by the Council on Developmental Disabilities. The Center on Disabilities and Human Development at the University of Idaho was named in the grant application as the subcontractor for initial provider training. Budgets for consumers cannot exceed the level of care cost in an institution and are expected to be equivalent to those on the other two DD waivers, approximately \$45,000/year. The fiscal intermediary costs may reduce that amount slightly but that may be offset by the consumer's ability to negotiate a price and amount for services that is just what they need rather than having to take additional services in order to be served by a provider.

The design development process for this waiver in Idaho has been thorough, deliberative and inclusive. Significant time and effort have been expended to ensure that stakeholders or their representatives were at the table from the beginning. Concerns have been expressed, particularly with regard to how service providers will fit in a self-directed model, but the Council and other partners have made concerted effort to accommodate differing perspectives while holding true to the Independence Plus requirements and the values of consumer direction and choice.

In order to see how a self-directed Medicaid system will work for adults with developmental disabilities in Idaho, it will be necessary to try it out. That means applying for a Medicaid waiver, developing the consumer awareness and provider capacity (both traditional and non-traditional), and enlisting the voluntary participation of up to 200 consumers. These consumers and their families will be partners with

Medicaid, advocates, providers, and policymakers in determining the desirability and success of such a service model in Idaho.

CONSUMER AWARENESS AND EDUCATION

The key to the success of this project is a coordinated effort to educate individuals with disabilities, their families and service providers about self determination and the possibilities afforded through access to self-directed supports. The DD Council has contracted with consultants from HSRI to provide training for consumer teams in two regions of Idaho. On January 14, 2004, these teams, known as the Self Advocates Leadership Network (SALN), made a presentation at the Statehouse to legislators and others. Their training will be completed in March. At that time, they will develop plans and begin comprehensive educational outreach effort in their areas of the state. Two new teams of consumer trainers will be identified and training will begin in two additional regions. By the spring of 2005, all regions of the state will have trained teams of self-advocates who will not only provide ongoing consumer education but serve as a resource for training of consumers on how to use the self-directed waiver.

NEXT STEPS

Prior to submitting a waiver application to CMS, additional research and planning will be done. After submission, it is expected that CMS will have questions about Idaho's application that will need to be addressed. Modifications of the application may have to be made. During that time, the Council will continue with not only consumer education but also outreach and presentation to providers and families. A public awareness campaign, in which we hope to engage the legislature as a partner, is scheduled for late 2004 or early 2005. A consumer tool-kit will be developed by Medicaid and the Council and used by teams of self-advocates and Department staff to train consumers in how to manage their own services and supports in the self-directed model. Qualifications of and training curriculum for support brokers will need to be developed and a plan put in place for implementation by the Center on Disabilities and Human Development. An RFP will be developed and a contract let for fiscal intermediary services. And a consumer satisfaction tool will need to be selected and resources identified for using it to determine the quality of services being provided through this model.