COMMUNICATING SELF-DETERMINATION: FREEDOM, AUTHORITY, SUPPORT AND RESPONSIBILITY

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The Tools of Self-Determination

With the vast extension of self-determination projects across the country and the wide adoption of the principles of self-determination, it may be helpful to step back for a moment and reflect on what we have learned thus far about some of the technical and structural issues associated with truly successful individual budgets, support brokering and fiscal intermediaries. Not every issue is yet crystal clear and it is anticipated that some ambiguity may remain especially in those projects that are still experimenting with systems change.

These three areas do not exhaust the range of system change issues but at this stage appear to be fundamentally necessary for the success of self-determination at the personal and family level. Typical human service systems find it difficult to make these fundamental changes. Other changes in personal planning and the restructuring of provider agencies also need to be addressed.

Addressing conflicts of interest in the present human service system has always presented itself as critical to the implementation of self-determination. If individuals with disabilities are ever going to attain a degree of freedom then those freely chosen to assist them will also need to be free. This simply means that no one gets to assist an individual/family unless that person is invited and remains totally committed to the individual with a disability and not to existing "services" or organizations. Those who assume these new roles will have to embrace the principle associated with rejecting overt or unconscious conflicts of interest. This is sometimes a long, arduous process.

One of the not so surprising results thus far reveals that creativity in planning appears to be very much related to avoiding conflicts of interest. Assisting individuals to achieve meaningful life goals (the goal of self-determination) appears to require both freedom and creativity. The same appears to hold true for cost effectiveness. Simply "buying back" existing services, with the option to move to another provider, doesn't meet the ultimate goal of self-determination nor is it cost effective. In fact, the federal Medicaid statute currently guarantees provider choice. That said, however, many individuals and families have little experience outside typical human services nor do they necessarily trust the current system to support them in meaningful ways outside typical human services. Developing trust between individuals with disabilities/families and human service system representatives, and gaining experience from those who pioneer self-determination, are important aspects of this change.

EMERGING BEST PRACTICE IN SELF-DETERMINATION

Two relatively innovative assumptions are beginning to under gird the self-determination movement for all individuals with disabilities. One is that all persons will "have their own place", and, two, that virtually all individuals can work in meaningful employment and/or produce income through the development of microenterprises. Folks with disabilities may indeed want to live with another person but that is always a freely chosen situation and one susceptible to re-negotiation when necessary. More and more projects across the country are gradually changing the goal from "getting a job" to one of "producing income". This enables everyone to understand that there are many ways to secure employment and to start a small business. Individuals within their budgets can (with assistance from a variety of sources) contract directly with employers for co-worker support, transportation and even training. Individual budgets can be used to help secure or pay down the cost of equipment necessary for a small business.

IDEAL STANDARDS FOR INDIVIDUAL BUDGETS, SUPPORT BROKERING AND FISCAL INTERMEDIARIES

INDIVIDUAL BUDGETS

Based on current best practice individual budgets meet ideal requirements for self-determination when the budget is actually controlled by the person and their freely chosen allies. Public dollars are now seen as an ongoing investment in the person's life and the obligation to be responsible as well as contribute to one's community becomes part of the budget development. In many demonstrations these ideal standards are only partially reached, but this represents an important step in the right direction. This means that the following is in place:

Individually created

The person with a disability and freely chosen family and friends create individual budgets. This includes the creation of unique line items that reflect the distinct dreams and ambitions of the person with a disability.

Authority over Personnel

Any person who works for the individual with a disability is hired and can be fired as well. In fact all employees and consultants work for the person and that person's social support network. Even if another organization assumes some legal responsibility to become the employer of record, all personnel and consultants work for the person with a disability.

Flexible

Within approved amounts, dollars can be reasonably moved from line item to line item as long as the essential supports are maintained. New line items may also be created as well as old ones erased.

INDEPENDENT SUPPORT COORDINATION

The linchpin to the success of creative, highly individual budgets and life plans is the function that is variously referred to as independent support coordination, personal agents, or independent brokering. What is important with regard to this function is the potential for conflict of interest. This is a person who may help with plan development, assist in organizing the unique resources that a person needs and even assist with ongoing evaluation of these supports. There are many ways that this function can be carried out from family members doing it to case managers assuming new roles. One creative project allows the person with a disability to select anyone they know and trust and pays them separately if necessary. Sometimes ongoing and regular support coordination is also required and some individuals are actually including this in their individual budget since it meets the test of a "service". The characteristics of an independent brokering function include:

Independence from Service Provision

It is important to keep this function separate from any form of service provision in order to avoid both the appearance and the reality of conflict of interest. Even those "brokers" who have great integrity should not be put in a position of divided loyalties. Current systems which feature service provision and support coordination may take years to accomplish the transition. Many individuals with disabilities and families have relationships and loyalties in place that need to be respected while this transition proceeds.

Real Authority

Whether the person is an independent contractor, or an independent agency is used, this function has to carry some state, county or publicly sanctioned authority if this person is going to adequately represent the person with a disability. Again, it should be clear that the person who carries out this function works for the person with a disability. It is always their choice who provides this function.

FISCAL INTERMEDIARIES

Fiscal intermediaries are simply organizations, places really, where an individual budget gets parked or banked. The functions carried out by a fiscal intermediary include, but are not limited to, check writing for all bills and personnel costs, tax withholding, paying worker's compensation, health insurance and other taxes and benefits that might be appropriate depending on the individual's budget. The fiscal intermediary works for the individual and remains accountable for insuring compliance with all federal and state laws. Minimum standards include:

Individual Budget Isolation

This means that every person's individual budget is isolated from any other and certainly from traditional provider contracts. The money is available upon receipt of an approved budget and is accounted for by the fiscal intermediary to the public funding authority as well as to the person with a disability.

Conflict of Interest Free

Fiscal intermediaries have no other duties that conflict with their role. This means that they are independent of service provision. If the fiscal intermediary is a government or quasi government agency, it has specific rules that prohibit the use of this money for any other purpose.

Close to the Person and the Community

Fiscal intermediaries, to the extent possible, should be generic, neighborhood, community organizations that enable the person with a disability to create relationships with personnel who work there in regular community settings. The closer this function moves to a "neighborhood bank" the better for the person with a disability.

These are ideal standards. Some human service systems can move faster to implement them. Others may take much longer. They deserve more discussion, examination and further demonstration. There are numerous ways to meet these ideal standards long term. Further demonstration and even experimentation will bring new knowledge and insight into improved ways to implement these ideal tools of self-determination.