



Texas Parent to Parent

# The Tools of Self Determination

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Self-Determination has three primary, interrelated meanings for people with developmental disabilities:

1. Self-determination is a collective effort, by which individuals and those important to them work to create a life in community, regardless of the political, cultural, or bureaucratic constraints that limit where people live, how they spend their day, and the options considered to be within their capabilities and reach;
2. Self-determination is a political movement by which people with disabilities, their families and their allies are working on the political, bureaucratic and cultural changes needed for people with disabilities to be fully accepted as citizens and members of their communities; and
3. Self-determination refers to a redesign of key structural elements of the public/private system of services and supports to people with developmental disabilities and their families.

The “Tools” of Self-Determination described below relate most specifically to the 3<sup>rd</sup> meaning of the term, though all three meanings are essential and interrelated. Self-determination as a collective effort by which individuals and those important to them create a meaningful life in community, and self-determination as a political movement provide the energy for the hard and equally creative work of applying the tools of self-determination to redesign a human service system.

As redesigns the system of services and supports to people with developmental disabilities, key structural elements of the system are added or adapted. Essential “Tools” of Self-Determination include individual budgets , independent support coordination , and fiscal intermediaries . These three areas do not exhaust the range of system change issues that need to be addressed, but changes in how these aspects of the system are structured are at the heart of success of self-determination at the personal and family level. They begin to address the conflicts of interest inherent in our historic design of services to people with developmental disabilities, and are at the core of creating a structure that provides the needed flexibility in providing supports and services for both individuals and those who choose to work in support of them.

The ability to plan with and manage flexible individual budgets provides individuals with disabilities the opportunity to create or purchase tailored supports and services. Independent support coordination provides conflict-of-interest free advice and support to enable individuals with disabilities and families and friends to translate “How can I create the life I want to live?” into “How can I draw the support I need from the human services system, in concert with my own gifts and the help of others, to create the life I want to live?” Fiscal intermediaries are simply a means to enable funding to flow smoothly.

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## *DESIGN PRINCIPLES FOR INDIVIDUAL BUDGETS, SUPPORT BROKERING AND FISCAL INTERMEDIARIES*

### **INDIVIDUAL BUDGETS**

Individual budgets are best designed for self-determination when the amount of funding allocated for services for a person 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, with a concurrent obligation for the individual receiving those dollars to use those dollars effectively in obtaining supports and contributing to community. This requires the following design features:

#### **Individually created**

The person with a disability and freely chosen family and friends create individual budgets within the service funding and personal income available. This includes being able to create unique “line items” that reflect the distinct ways in which each person wants to live.

#### **Authority over Personnel**

Individuals with a disability have the authority to hire people who work for them, whether as independent workers or employees of a provider agency. 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 funding**

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. It is important in designing this function to attend to potential conflicts of interest. This function 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, to various combinations of each.

#### **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 support coordinators who have great integrity should not be put in a position of divided loyalties. Many individuals with disabilities and families have relationships and loyalties in place that need to be respected while this transition proceeds.

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### **Independence from Public Authority**

It is also important that this function is provided in a manner in which individuals and families are able to receive advice and support independent from the agency that is responsible for funding. Again, even those support coordinators with the greatest integrity and experience are placed in a position of divided loyalties when they are working for a public authority that has overall fiscal responsibility for the system. This potential conflict is even greater when the county also is a provider of services.

### **Real Authority**

In whatever ways the independence from the public authority is designed, this function has to carry some state, county or publicly sanctioned authority if the support coordinator or personal agent 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. Some fiscal intermediaries can provide a range of related services, such as recruiting and training of workers hired by individuals and the support network. The fiscal intermediary works for the individual and remains accountable for insuring compliance with all federal and state laws.

There are numerous ways to create fiscal intermediary functions, but all include at minimum:

#### **Individual Budget Isolation**

This means that every person's individual budget is isolated from any other, separate from traditional provider contracts. The money is available upon receipt of an approved request or "invoice" 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, as much as possible like a "neighborhood bank."

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