



Guaranteeing the Promise of Freedom:

Creative Individual Budgeting

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Guaranteeing the Promise of Freedom: Creative Individual Budgeting

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• INTRODUCTION •

Guaranteeing the Promise of Freedom is a simple workbook organized to assist individuals with disabilities and those who respect and love these individuals. It sets in motion the realization of freedom. Finally.

We begin this workbook and concrete exercise with a reaffirmation of the principles of self-determination. We ask you to take a few moments and think deeply about the purpose of public funding. In our view this purpose is to assist individuals with disabilities achieve meaningful lives, rich in relationships and community, sharing with all citizens the opportunity to work and contribute as equal members of this society.

We challenge the notion of low expectations that characterize traditional human services. We ask you to rise above shallow notions of person-centered planning and recognize that with proper assistance all individuals can begin to craft at least a modest economic future and take their rightful place alongside all other hard working Americans. We need to stop substituting human services for real lives.

One of the foundations of self-determination rests on responsibility for the wise use of public dollars. Our notion of responsibility includes the exercise of those freedoms guaranteed to all citizens by the Constitution and the Bill of Rights. Self-Determination is at its heart about the restoration of full citizenship to all individuals with disabilities.

Tom Nerney, 2005
Center for Self-Determination

• DEFINING SELF-DETERMINATION •

Self-determination for citizens with disabilities is about freedom. **Freedom** to decide how one wants to live his or her life. It's also about organizing needed **support** with the person's support network— friends, family, those who care. Self-determination means having **authority** over resources and taking **responsibility** for decisions and action. True champions of self-determination honor the important leadership of persons with disabilities in changing our systems of support. **Confirmation** of the self-advocacy movement is a major principle of self-determination. We must not forget whose life is being lived.

The purpose of self-determination is to make it possible for individuals to craft personally meaningful lives in our communities. Principles of self-determination establish that individuals with disabilities are the planners and decision-makers in how they spend their days and in how they live their lives, with caring assistance available when needed. These decisions include financial responsibility for public funding and the generation of personal income with appropriate assistance.

Principles of Self-Determination

Freedom to decide how one wants to live his or her life.

Authority over a targeted amount of dollars.

Support to organize resources in ways that are life enhancing and meaningful to the individual.

Responsibility for the wise use of public dollars and recognition of the contribution individuals with disabilities can make in their communities.

Confirmation of the important role that self-advocates must play in a newly redesigned system.

Use these principles as your foundation for building self-determination. Let them be your guide.

The actual technical tools fundamental to the personal achievement of self-determination are:

- **successful individual budgets**
- **independent brokering**
- **independent fiscal management**

Sometimes we become confused about the purpose of self-determination: enabling individuals with disabilities to achieve a meaningful life deeply embedded in our communities. Some of the confusion arises from substituting the means to self-determination with the purpose. For example, hiring one's own support, controlling expenditures, are means (or tools). If these means do not result in the person *achieving a meaningful life*, then self-determination is in danger of becoming another program that does nothing to elevate the status of individuals with disabilities within our community. To guarantee the promise and avoid another superficial attempt at individual freedom for citizens with disabilities, we have to be clear. **Freedom. Support. Authority. Responsibility. Confirmation.**

• Notes

• PURPOSE OF PUBLIC FUNDING •

Public funding comes from tax dollars. The purpose of this funding is to assist citizens who need support. As taxpayers and people in need of support, it's important to understand what public dollars actually fund: congregate settings, clinically-based programs, segregated "home-like" environments, and rules and regulations that actually require poverty. Then examine what this all costs. Self-determination leads us to look closely at what dollars are purchasing in the name of human services. We need to ask ourselves, "What is this support for?" Looking beneath the surface, we find that money is often spent on promoting less than desirable lives.

The time has come to re-think public money.

Self-determination leads us to look at public funding as:

- **Investments in the lives of individuals with disabilities**
Investments should mean achieving something, gaining something in return, and not just allocating money without expectations.
- **Assets to every individual with a disability**
Assets are possessions to be used for identified purposes.
- **Individual budgets as a tool to emancipation**
Individual budgets allow the promise of freedom and acceptance of responsibility.

• Notes

• A NEW VIEW OF QUALITY •

Along with re-thinking how human services spend money, let's take a close look at how we've come to define the quality of the lives that are publically funded.

What's important in life is not so hard to define. Ask anyone you know what is important to him or her. Answers usually boil down to a very few responses. They are love, family, friends and work. Community connections, spirituality, deep personal relationships and a degree of economic security hold great importance in our lives. These desires are universal.

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For citizens with disabilities, what makes life important has been defined differently. We've come to judge quality based on artificial arrangements of human services. Yet, it's clear that people want lives – not programs. The time has come to view universal human aspirations as the norm for quality for everyone. This way we don't continue the segregation of people with disabilities paid for by public dollars.

• Notes

• ASSUMPTIONS FOR PLANNING AND BUDGETING •

Currently, many people in our human service system lack the basic freedom associated with self-determination because their “budget” is tied and mingled with others within an agency budget. The individual never has control. Costs assumed necessary for everyone else in the culture are denied (or simply not assumed) for citizens with disabilities. Costs associated with relationships, romance, being connected to one’s community, and fulfilling dreams are universal human aspirations. The individual whose budget is being developed (or someone who knows her/him very well) will relate information about present costs associated with typical services. All participants will understand how money currently gets spent and what it buys for the person.

There can not be quality in American society without freedom and equality.

At this point it is important to recognize the difference between an individual budget and an individual allocation. An individual allocation should be thought of as the amount of money available to use in the creation of an individual budget. That is, the “allocation” is the sum of money. The individual budget is a line by line expenditure pattern that represents the personal purchases that the individual with a disability will make in order to help create a meaningful life. This distinction seems obvious and a matter of common sense. Its importance lies in the fact that some federal and state agencies use the two terms interchangeably resulting in confusion (especially when meeting the requirements, e.g., of CMS under their Independence Plus Waivers) and bad compromises when individuals get an “allocation” called a budget and then never get to develop a personal budget while the funding source claims that the requirements for an individual budget were met.

The development of an individual personal budget is a first step towards real self-determination. Individual budgeting allows for free movement and free association by guaranteeing the promise of freedom made to all Americans at birth.

While developing an individual budget with individuals two new assumptions must be made;

- 1. Every person with a disability will have his or her own place to live.**
- 2. Every person with a disability will generate income.**

Additionally, each budget must

- **Be individually created and designed**
The person with a disability together with a trusted allies create individual budgets. This support circle includes the creation of unique line items that reflect the distinct dreams and ambitions of the person with a disability. No one-size fits all here!
- **Assure 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.
- **Be 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.

• BUDGET TOOL & TEMPLATE •

This budget tool and template lay out the steps to concretely implement self-determination. It brings clarity to the reality of actually planning and budgeting for an individual.

As each individual is unique, so must be his or her personal budget.

Please use the creative individual budget template as a guide only and as an opportunity to be creative, thoughtful and to assure the promise of freedom. Look at money as an investment in the life of a person with a disability rather than a mechanism with which to pay for services. Use the principles of self-determination to show you the way to set up a budget and as a checkpoint for staying focused. The Creative Individual Budget Template is not meant to be used as a form to obtain reimbursement. However, each category and line item can be transferred to a budget reimbursement form. Use this template to assist in translating the plans and vision for the person and then as a guide for completing appropriate reimbursement forms.

Each section of the personal budget form is designed to address critical human needs. Use the blank lines for line items that you've learned are the unique needs of the individual. **The Creative Individual Budget Template is not meant to be exhaustive.** You must consider health and safety throughout.

Each budget must be individually created, designed to assure authority over personnel, and have flexibility to move money from one line item to another.

• Income Template

	Operations	Capital	One-time only
SSI			
SSDI			
Targeted Waiver Amount			
Vocational Rehabilitation			
Ticket-to-Work			
Special Education			
Private Work			
Micro-Enterprise			
Family/Friends			
Individual Development Account			
Other Assets			
TOTAL			

• **INCOME KEY** •

There are six individual line items for use of possible public dollars and six line items for use of possible private dollars that can become part of the individual budget. A renewed emphasis on income from work (job and/or micro-enterprise) is central to the development of an individual budget. These dollars are also the most unrestricted in terms of what you can purchase. This freedom becomes extremely important. Government dollars always come with some restrictions.

It is anticipated that government in the future will pay a lot more attention to contributions from family and friends, trust dollars and hopefully Individual Development Accounts (IDA). IDA's are simply savings accounts that are matched on a dollar for dollar (or better) basis and can be used for particular purposes such as home ownership and business development.

It is important to try and create some balance between public dollars such as Medicaid Waiver dollars and private income. Medicaid is likely to be the main source of public support for the future but state Medicaid budgets are already under severe strain. This is likely to worsen in the future.

SSI/SSDI are predictable sources of monthly income. State Vocational Rehabilitation resources are sometimes crucial in order to enter the world of business and commerce even if the funds are only granted on a one-time basis. In the long term, it is hoped that Ticket to Work dollars will also become available to individuals as cash, if the federal law is ever changed.

• **Notes**

• **SECTION ONE** •

• **Creative Individual Budget Template: A Place of One's Own**

		Investment Costs	Monthly Costs	x12	Annual Costs
Home	Rent/Mortgage				
	Utilities - Cable				
	Insurance				
Companionship					
Personal Assistance					
Emergency Back-up					
Wardrobe					
Grooming	Barber				
	Beauty Shop				
	Other				
Mealtimes					
Training					
Transportation					
TOTAL					

- **A Place of One's Own Individual Budget Template Key**

Home

As a rule of thumb, it is wise to consider size when brainstorming the kind of home a person might desire. The larger the better, especially for creating enhanced support packages for companions and others who might provide various types of support. Cost is also an issue but dollars saved on companionship approaches may offset additional costs for housing. (See also Companionship and Transportation.)

Companionship

While it is more labor intensive to seek out individuals who are willing to be in-home companions, the long term results may justify this approach. Even for individuals with disabilities who also need hourly paid staff, this approach offers some benefits that may provide less overall cost, more potential for relationships, and more stability in the person's life. Organizing unique compensation packages in return for live-in supports is key to making this successful. Just as with paid hourly staff, it is important to seek individuals who are willing to bring their own family and social network with them. Without spending another dollar, this offers a way to facilitate potential relationships and promote more natural activities.

Personal Assistance

Depending on the level of support needed, this is the place to budget hourly paid staff, taxes, worker compensation and benefits. Once an hourly rate is established there is an "overhead" dollar amount-typically ranging from 20 to 30% – that must be included here. Funding agencies and provider agencies are good sources of information on what this figure ought to be based on both the hourly rate set, the number of hours to be worked per week, and the type of benefits proposed.

Wardrobe, Grooming and Mealtimes

These categories are named to replace typical food and clothing line items. This will trigger discussion of the important social issues surrounding mealtimes for any individual and the importance of wardrobe and grooming for personal as well as social reasons. Although this may require increasing the amount from typical human services budgets, these issues go to the heart of reciprocal relationships, real work, and generating income. The additional funds may have to come from wages or earnings from the world of business and commerce.

Training

There may be two separate issues regarding training of companions and direct support workers. Some issues are generic, such as CPR or basic safety and disease prevention strategies. Others will be germane to the specific individuals being served and may include unique medical or behavioral issues. Under the rubric of self-determination, typical behavior programs may be eschewed in favor of more humane and personal approaches.

Transportation

Transportation is such a key component that it occurs in every section of the budget template. There may be a capital cost associated with buying or leasing a vehicle as well as ongoing monthly/annual payments. Insurance is always a category that needs to be addressed. This is especially true for individuals who do not drive but need to have a vehicle available with insurance for whomever will be driving. Solving the transportation problem for an individual at home may also solve it for the work or day/ weekend needs. Conversely, solving the transportation problem for work may solve it for personal and social needs. Without controlling transportation, self-determination loses a lot of meaning.

• **Income Generation Individual Budget Template Key**

This section is predicated on the belief that all individuals with disabilities can generate private income irrespective of the degree of disability they may have. In keeping with the need for innovation, cost effective ways of obtaining employment must be pursued. This is a complex undertaking but with great potential, especially for those with significant disabilities and those who may not be interested in traditional jobs.

Costs Associated with Jobs

- Employment Agency/Broker: this is a fee for the support of an individual or agency who will work to negotiate a desired job with a potential employer. This may include any of the categories below.
- Co-Worker support: paying the employer or co-worker directly.
- Employer Training: paying the employer the cost of learning the job
- Subsidized wages: where this is allowed, paying to subsidize one’s own wages until the job is learned.
- Wardrobe, Transportation, Other: all other costs associated with getting to and holding the job.

Business Ownership

- These are central categories essential to the development of a micro-enterprise. Micro-enterprises range from very simple to fairly complex. Not all micro-enterprises require these categories, but it is wise to consider all of them when planning for this type of venture. It is also wise to pay particular attention to the changing role of direct support staff, new job descriptions, and the potential for both the support staff and the person with a disability to benefit financially from the business enterprise.

• **Creative Individual Budget Template: One-time Investment Costs**

		One-time Costs	Monthly Costs	x12	Annual Costs
Investments	Communication Technology				
	Mobility Technology				
	Other				
Capital Costs	Down payment on a home				
	Vehicle purchase/lease				
	Education				
	Home modifications				
	Business equipment				
	Other				
Other	Security Deposit				
	Other				
TOTAL					

See following Individual Budget Template Key

- **Additional Support Individual Budget Template Key**

- **Management & Administration**

Support plans and budgets require attention to both the development and ongoing administration of supports of various kinds. It is wise to earmark at least 10% of total authorized funds for administration and management of these supports. Always include emergency back-up in planning. This figure can frequently be negotiated depending on the complexity of the planned support.

- **Independent Support Broker**

Typical case management and support coordination systems frequently do not have the personnel, the time, or the expertise to help an individual with a disability arrange the desired supports. For this reason a line item in addition to management and administration has been added to draw attention to the potential need to hire specific individuals to provide one or more of the arrangements or negotiations necessary for the successful implementation of the person's plan. These are usually small fees for specific tasks that need to be carried out, or even a fee for the extra coordination necessary to successful implementation. (For more information see Center for Self-Determination guidebook "Supporting the Promise of Freedom: The New Broker.")

- **Notes**

Housing

- Rent/Mortgage
- Application Fee
- Insurance
- Property Taxes
- Repair and Maintenance
- Renovation/Modifications
- Security Deposit
- Other

Utilities

- Gas
- Electricity
- Cable
- Water/Sewage
- Garbage Pickup
- Other Utilities

Other Household Needs

- Household Supplies
- Household Furnishings
- Adaptive Equipment

Transportation

- Gas
- Insurance
- Lease Down Payment
- Lease Payments

- Auto Insurance
- Auto Maintenance
- License and Registration
- Public Transportation
- Other Transportation
- Education and Training
- Transportation
- Wardrobe
- Other

Health and Medical

- Prescriptions
- Over the Counter Medication
- Dental Care
- Nursing Services
- Psychological Services
- Speech
- Dietician
- Psychiatrist
- Physical Therapy
- Occupational Therapy
- Support Coordination
- Other

Vocational/ Employment/ Education

- Vocational Costs
- Employment Agency/Broker
- Co-Worker Support

Business Ownership

- Business Plan
- Materials
- Equipment
- Accounting
- Legal Expenses
- Insurance

Personal Expenses

- Mealtimes/Food
- Wardrobe
- Grooming
- Community Involvement
- Contributions
- Gifts/Cards
- Church/Synagogue/Mosque
- Activities (Cultural and Recreational)



• ORDER FORM •

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