



*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 across aging and disability and those who respect and love these individuals. It sets in motion the realization of freedom.

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 across disability and aging to achieve meaningful lives, rich in relationships and community, sharing with all citizens the opportunity to achieve financial stability 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 limited 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.

*Tom Nerney, 2005, revised 2013
Center for Self-Determination*

• DEFINING SELF-DETERMINATION •

Self-determination for citizens across disability and aging 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 roles individuals play 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 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 individuals 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 crafted from individual allocations**
- **independent brokering**
- **independent fiscal management**

Sometimes we become confused about the purpose of self-determination: enabling individuals 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 receiving support within our communities. To guarantee the promise of freedom and we must avoid any attempts at substitutes. 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: facility based, 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 across disability and aging.** An investment achieves something and gains something in return. The current system funds services without high expectations. It does not invest in lives of high quality and great purpose.
- **Assets to every individual.** 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 closer 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 economic security.

Community connections, spirituality, deep personal relationships and a degree of economic security hold great importance in our lives. These desires are universal.

. . . love, family, friends and economic security. Community connections, spirituality, deep personal relationships and a degree of economic security hold great importance in our lives.

For citizens who need support, 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 human service 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 paid for by public dollars.

• Notes

• ECONOMIC SECURITY AND INCOME GENERATION

For those with disabilities, the assumption is they cannot work. There are many reasons why individuals with disabilities don't work. Some think they can't. We know better. Some think that those who can obviously work should have a choice to work or not. We think this is insulting to people. Data clearly reveal that the vast majority of individuals with disabilities want to work but find it difficult to find jobs or generate income. Virtually all of the economic incentives in the present system favor congregate non-work or below minimum wage sheltered work. In fact individuals with disabilities and prisoners are the only two groups not actually protected by the minimum wage law that protects every other hourly wage worker in America.

But the most common reason the majority of individuals lack financial stability or don't work has to do with the overly complicated benefit structure, especially for the Medicaid and Social Security income programs. Fear of loss of essential benefits and differing and complex rules for various federal and state programs create a nightmare of laws and regulations that few understand. Fewer still can navigate the benefit structure.

It is important for freedom to be meaningful that individuals have some discretionary income and, if possible, contribute to the costs of support. For this reason the Creative Individual Budget Template includes only line items that relate to obtaining jobs creatively or beginning a very tiny business called a micro-enterprise. Individuals learn how to manage protected assets and learn how to assist others to creatively obtain jobs. When individuals cannot do the labor associated with traditional jobs or lack the interest, then the possibility of creating micro-enterprises is fully explored.

The production of modest private income can be a realistic goal for any individual no matter how significant their disability.

It may require re-structuring the jobs of direct support workers or require other changes to the system. However, it is possible to begin within the present system.

One of the primary implications of freedom is a renewed sense of economic freedom and economic justice.

Even for those with significant disabilities who have never contemplated being part of the world of business and commerce there can be a transition from a life with no expectations of an economic future to one where new possibilities emerge.

To what degree is appropriate, protection of assets and the ability to generate and maintain a level of income needed to provide for life's needs and desires. For older individuals financial stability is key to assuring needs and desires are met. Financial stability should not exclude people from receiving public support they need.

• **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 receiving supports.

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

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.

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 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 will have his or her own place to live.**
- 2. Every person will have financial stability and the opportunity to generate income.**

Additionally, each budget must

- **Be individually created and designed**
The person receiving supports together with a trusted advocates create individual budgets. This support circle includes the creation of unique line items that reflect the distinct dreams and ambitions of the individual. No one-size fits all here!
- **Assure authority over personnel**
Any person who works for the individual is hired and can be fired by the individual. 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.
- **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 receiving supports 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 financial stability and 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, protected assets and 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 receiving supports 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.

• SECTION THREE •

• **Creative Individual Budget Template:
Income Generation**

		One-time Costs	Monthly Costs	x12	Annual Costs
Jobs	Employment				
	Agency/Broker				
	Co-Worker				
	Support				
	Employer				
	Training				
	Subsidized Wages				
	Wardrobe				
	Transportation				
	Other				
Business Ownership	Business Plan				
	Materials				
	Equipment				
	Accounting				
	Legal Expenses				
	Insurance				
	Vehicle Costs				
	Transportation				
Other					
TOTAL					

See following Individual Budget Template Key

• **Economic Security and Income Generation
Individual Budget Template Key**

This section is predicated on the belief that all individuals can achieve financial stability and have protected assets or 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 to benefit financially from the business enterprise.

• SECTION FOUR •

Protected Assets:

- To the degree associated, planning for financial stability through protection of assets that meet state and federal guidelines is key to economic security (examples are income only trusts, transfers of assets, estates etc.)
- **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

• **One-Time Investment Costs Individual Budget Template Key**

These categories are representative but do not comprise a complete list. Simple investments in technology can reach to the issue of productivity as well as quality. Some of these one-time costs may not be covered under state or Medicaid regulations or interpretations. State Vocational Rehabilitation agencies are frequently a good source of funding and support for many of these items.

• **Notes**

• SECTION FIVE •

• **Creative Individual Budget Template: Additional Support**

	One-time Costs	Monthly Costs	x12	Annual Costs
Management and Administration				
Fiscal Management Agency				
Other				
Independent Support Broker				
Long Term				
Short Term				

• **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 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 guide book "Supporting the Promise of Freedom: The New Broker.")

• **Notes**

• OTHER EXPENSES TO CONSIDER •

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

Business Ownership

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

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

Personal Expenses

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

• COMPLETE BUDGET SHEET •

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

Complete Budget Sheet	One-time Costs	Monthly Costs	x12	Annual Costs
Section One: A Place of One's Own				
Section Two: Community and Relationships				
Section Three: Income Generation				
Section Four: One-Time Investment Costs				
Section Five: Additional Support				
INCOME				
TOTAL				



• ORDER FORM •

• Notes

Lined area for notes.

TITLE	PRICE	QTY.	TOTAL
Guaranteeing the Promise of Freedom: Creative Individual Budgeting	\$10		
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