



*Real Life
Quality
Standards*

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Real Life Quality Standards

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• INTRODUCTION •

Real Life Quality Standards is the fourth in a series of Center for Self-Determination produced guidebooks that focus on implementing self-determination for individuals across disability and aging. This guidebook is meant as an introduction to re-thinking what we mean by quality in human services and how we need to move to real quality assurance systems that treat individuals with disabilities as equals and not as human service subjects.

Contemporary quality assurance systems are gradually moving to issues of personal satisfaction with services and even personal outcomes that are individual and unique. However, we have to raise questions when individuals are asked if they are satisfied when they cannot exercise elementary freedoms; if they have personal outcomes they desire but no one held accountable for assisting in their achievement; and, finally, if they live in congregate settings, go to substitute environments for community and work and the human service system pretends that they are in and of the community.

People served by this system have become human service subjects within a system of long-term supports that has no expectations that

common life goals based on universal human aspirations can add great depth to the notion of addressing the health and welfare of individuals receiving supports. Present public policy inadvertently supports lives lost to programs and rules that deny or ignore our common humanity, our common aspirations and dreams, and our common sense of responsibility to become contributing members of this society. Our present public policy forces people served by the Human Service system into lives of personal impoverishment and frequent loneliness.

The purpose of public funding must move to a more noble goal of assisting individuals achieve lives of high purpose deeply embedded in their communities, engaged in meaningful relationships and pursuing both economic and spiritual goals.

Self-determination requires a fundamentally new foundation for defining quality. The goal of the self-determination movement has always been to assist individuals receiving supports to craft meaningful lives in their communities, rich in relationships and deeply connected to their communities and the world of business and commerce.

Tom Nerney, 2005, revised 2013

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 role 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 support 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 and 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 supports within our communities. To guarantee the promise of freedom, we must avoid any attempt at substitutes. We have to be clear. **Freedom. Support. Authority. Responsibility. Confirmation.**

NOTES

• PURPOSE FOR 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 result in and 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 the way we use 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, 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 served by the system.** Assets are resources available 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 publicly 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, good health, friends and economic security.

People want real lives – not human service programs.

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

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 real 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

• REAL LIFE STANDARDS •

These standards are premised on the need to design a quality assessment system that moves from “personal satisfaction with human services” to one that measures whether the person receiving supports enjoys a meaningful life in a way that is both culturally appropriate and normed on universal human aspirations. The foundation for this approach is to firmly imbed quality standards on outcomes associated with real freedom, long-term relationships, community membership, economic security and the production of income.

By universal human aspirations, these standards adopt the six following domains:

1. **Health and safety**, with an emphasis on features of communication, relationships and trust.
2. **Having a place of one’s own** (for those living outside of natural families), where people choose both the place and whomever else lives or provides support in their home.
3. **Community membership** that is grounded concretely in both participation and actual group membership.
4. **Important long-term relationships** that provide for reciprocity and safety.
5. **Economic security and the generation of private income** to what degree is appropriate. Protection of assets and the ability to generate and maintain income through typical jobs or self-employment.
6. **Control over issues of transportation** including, whenever possible, control over the means of transportation.

These domains are consistent with the ***Guaranteeing the Promise of Freedom*** budget template that can be used as an intervention tool. For purposes of this quality guidebook, individuals are assessed on all domains at the beginning and at the end of a specific planning period (usually six months to a year) after the budget guide is used to develop a real plan and budget. The principles of self-determination are incorporated directly into both guides and remain the foundation for this new approach to quality.

This new approach to quality requires both the collection of data, with an initial narrative summary explaining the scores, and an ongoing narrative. The initial information is collected through direct interviews with the person receiving supports and those who have important relationships with this person. Additionally the initial assessment summary records the issues that remain, the individuals who will assist and timetables for achieving better outcomes.

In addition to the data-oriented assessment and measuring system, personnel also keep an ongoing narrative. This narrative, which is updated at least monthly, recounts happenings, describes the changes, interventions and chronologically updates what is being done as a result of the initial assessment summary.

What follows for each of the six domains is an introduction and clarification of the domain, the standards that are proposed with a simple rating scale, yes or no answers and, in some instances, simple data and the expectation for the ongoing narrative.

NOTES

HEALTH AND SAFETY ASSESSMENT

- 1 – No, Not Available or Not Present
- 2-4 – Represents a Small or Large Compromise
- 5 – Yes, Always Available or Always Present
- N/A – Not Applicable

Rating scale	1	2	3	4	5	N/A
1. This person has an annual check up						
2. This person has his/her freely chosen doctor						
3. This person has his/her freely chosen dentist						
4. All medical professionals are freely chosen and supportive						
5. This person communicates medical issues freely and easily with one or more allies						
6. This person has regular check-ups, as appropriate, that evaluate issues common to the person's gender						
7. Who does this person trust and understands him/her the most?						
Family						
Friends						
Support Staff						
8. The home is assessed for any safety issues						
9. The home is modified to address these issues						

10. Emergency fire and tornado shelter exit plans are in place	yes		no	
11. An emergency back-up plan is developed and operational	yes		no	

NOTES

• A PLACE OF ONE'S OWN •

For those who live outside their family homes, there is an explicit assumption under self-determination that they have a place to call home and that place is their own. This means, as well, that they exert complete control over who comes through the front door, who provides assistance and who, if anyone, they freely choose to live with in this home. There is also an assumption that the home is typical housing for the general population and that both the home and the neighborhood are acknowledged as safe.

For older Americans remaining at home and receiving supports from people they know and trust is key to feeling safe and independent. Much depends on that familiar face and mutual respect within these arrangements.

Unless all of the five categories or standards (1-5) are substantially met, the initial assessment summary records the issues that remain, the individuals who will assist and timetables for achieving better outcomes. The ongoing narrative documents and chronologically updates how this is being done.

NOTES

A PLACE OF ONE'S OWN ASSESSMENT

- 1 – No or Never
- 2-4 – Represents a Small or Large Compromise
- 5 – Yes or Always
- N/A – Not Applicable

Rating scale	1	2	3	4	5	N/A
1. The home is a typical home, apartment or condo						
2. The home is in a typical and safe neighborhood						
3. The home is freely chosen						
4. Anyone who provides paid support to the person works for that person, including companions						
5. Anyone who lives with the person is there by mutual agreement or at the request of the person						

For those who live within family homes and are supported with public dollars

1. The family has its needs for supporting the family member taken into account	yes		no	
2. Caregiver supports are in place	yes		no	
3. If a minor, the person experiences inclusive education	yes		no	
4. If transition age, clear work/ higher education goals are established	yes		no	
5. If transition age, real work experience is accomplished through the school	yes		no	

• COMMUNITY MEMBERSHIP •

Real membership in one's community takes place through active participation in the ongoing life of that community. Just as with relationships, being known and understood in one's community adds a measure of safety to the person's life as well as addresses issues of quality that are common to all. This means, in practice, that individuals are equal members of any number of civic, recreational, social, religious or political organizations and clubs.

These categories represent freely chosen activities based on the person's interests and relate in important ways (*as do many of these items*) to the potential for facilitating relationships. Many individuals have little interest in some of these activities. Some may not express their spirituality by formal religious affiliations. However, many individuals never get the experience of joining diverse community groups in order to find out if their interests may be peaked. In fact, this section is designed to ascertain if the person is at all connected. In some ways, this is an "isolation" profile.

The initial summary assessment explores this issue. The ongoing narrative documents what is being done to lessen this isolation or increase this person's connections.

NOTES

COMMUNITY MEMBERSHIP ASSESSMENT

- 1 – No or Never
- 2 – Infrequently
- 3 – Sometimes/Episodic;
- 4 – Frequently (at least 6X/year)
- 5 – Weekly or Monthly, whichever appropriate
- N/A – Not Applicable

Rating scale	1	2	3	4	5	N/A
1. The person attends a place of worship						
2. The person shops at typical neighborhood stores						
3. This person attends community/generic recreation/sporting events						
4. The person attends community cultural, educational or social events						
5. The person is a member of a cultural, political or social organization or club						
6. The person votes						

7. Name the organizational affiliations/events

• LONG-TERM RELATIONSHIPS •

All good relationships are reciprocal in some ways. They form the foundation for much of our social, personal and spiritual lives. Individuals served by the system who generally remain impoverished often have few close relationships. Those without close family are even more likely to remain lonely. This section seeks to gauge the degree to which individuals can and do enter into and/or sustain long-term relationships as well as romantic and simple friendship-based associations.

In ways that are similar to being connected to the community, individuals vary considerably in their interest and pursuit of these relationships. Some people are more social than others. However, the initial assessment summary can relate more information here that will put these "scores" in a better context. Low scores indicate a degree of isolation that, when correlated with low scores in terms of community connections, frequently spell trouble for the individual. Again, the ongoing narrative documents interventions being used to increase real connections and build relationships that may stand the test of time.

NOTES

LONG-TERM RELATIONSHIP ASSESSMENT

- 1 – No or Never
- 2 – Infrequently
- 3 – Sometimes/Episodic;
- 4 – Frequently (at least 6X/year)
- 5 – Weekly or Monthly, whichever appropriate
- N/A – Not Applicable

Rating scale	1	2	3	4	5	N/A
1. The person has friends over to his/her home						
2. The person person visits with friends						
3. Those who visit are friends with disabilities	Yes			No		
4. Those who visit are friends without disabilities	Yes			No		
5. Number of friends with disabilities	Number					
6. Number of friends without disabilities	Number					
7. The person has visits from family						
8. The person visits family members						
9. The person indicates an interest in dating/romance						
10. The person is able to have support to have friends over	Yes			No		

• ECONOMIC SECURITY AND PRODUCTION OF INCOME •

Economic security gives deeper meaning to the notion of freedom and is a cornerstone of self-determination. Effectively securing and managing financial resources prevents impoverishment and empowers people. To what degree is appropriate protection of assets and the ability to maintain a level of income needed to provide for one's life needs and desires is the hallmark of transitioning from total dependence on public funding, to public funding, supplementing the person's life in meaningful way.

What a person does during the day goes a long way toward increasing self esteem, facilitating potential relationships and being an important part of the community. Just as important, the production of some private income gives deeper meaning to the notion of freedom that is a cornerstone of self-determination. Near total impoverishment relegates individuals to dependent relationships, if at all, shallow connections to the community and little hope for dreaming and ambition.

INCOME TEMPLATE

	Operations	Capital	One-time only
SSI			
SDDI			
State Supplemental Income			
Medicare			
Vocational Rehabilitation			
Ticket-to-Work			
Special Education			
Private Work			
Micro-Enterprise			
Family/Friends			

	Operations	Capital	One-time only
Individual Development Account			
Veteran Benefits			
Housing Subsidies			
Food Assistance			
Utility Assistance			
Medicaid Funding			
Long-Term Care Insurance			
Other Assets			
TOTAL			

ECONOMIC SECURITY ASSESSMENT

1 – Excellent 2 – Good 3 – Average
4 – Below Average 5 – Poor

Rating scale	1	2	3	4	5	N/A
1. The person can afford their living expenses						
2. The person changes their own finances with good results						
3. The person has received assistance securing benefits, entitlements and/or resources.						

NOTES

PRODUCTION OF INCOME ASSESSMENT

1. The person works in competitive/independent employment	Yes		No		N/A	
2. The person, with necessary assistance, is self-employed	Yes		No		N/A	
3. The person works through a supported employment program	Yes		No		N/A	
4. The person has a plan for self-employment	Yes		No		N/A	
5. The person makes minimum wage or higher	Yes		No		N/A	
6. The number of hours per week the person works	Number					
7. The amount of money the person earns weekly/monthly	0-50	50-100	100-200	200-300	300-400	
8. The person has a bank or belongs to a credit union	Yes		No		N/A	
9. The person has a checking and/or savings account	Yes		No		N/A	
10. The person has an ATM card	Yes		No		N/A	
11. The person has a credit card	Yes		No		N/A	

12. This person uses his/her private income in the following ways:

• CONTROL OF TRANSPORTATION •

Personal control of transportation represents a critical element in the development of a self-determined life. After the loss of elementary freedom through typical human service arrangements, transportation has emerged as a problem that is almost universal for individuals across disability and aging. It is cited, together with impoverishment, as a major barrier to both employment and community connections as well as to relationships.

Frequently, the only viable long-term solution is for the person receiving supports to "own" the means of personal transportation. However, under self-determination it is also possible to require any support staff to provide transportation as part of their job requirements. In some places, public transportation is available, although not always for evening or social events.

CONTROL OF TRANSPORTATION ASSESSMENT

1. Can the person reliably get to and from work daily?	Yes		No		N/A	
2. Can the person spontaneously decide to "go out"?	Yes		No		N/A	
3. Can the person plan an evening/weekend/overnight trip?	Yes		No		N/A	
4. Can the person usually decide to give a ride to a friend?	Yes		No		N/A	

NOTES

• RISK AND REAL LIFE •

Free men and women take risks. The very notion of freedom implies the possibility of risk. Human service discussions of risk center on issues of health and safety. As if with newfound freedom individuals across disability and aging are somehow predisposed to create situations that will jeopardize their well being. Self-determination is not about doing whatever one pleases with public dollars. It is not about creating additional risks to health and safety. In fact it can be argued persuasively that self-determination properly implemented better addresses issues of health and safety. Self-determination at its core promotes long-term committed relationships. Without these relationships individuals served by the system remain forever in jeopardy.

“Self-determination at its core promotes long-term committed relationships.”

Vulnerable people especially, but not unlike most everyone else, need someone to rely on and in whom they can place their trust.

But self-determination properly implemented does increase risk for individuals. It seems important to recognize these risks and even to encourage them. What are they? By addressing universal human needs and desires and aspirations, self-determination poses several risks not usually contemplated by traditional or typical human service systems. By addressing forced impoverishment people face the possibility of failure financial —failure at work or at self-employment. By addressing our connections to our communities people face possible rejection. By focusing on the universal human need for friendships and even intimate relationships, self-determination poses the risk of heartbreak.

These are the risks that define us as human beings, make us strong and reflective and carry the promise of true community and family membership. With every one of these risks there is now hope.

With assistance individuals across disability and aging including those with neurological diseases and intellectual and cognitive disabilities need to face the risks associated with membership in the human race. They need to accept responsibility for the exercise of freedom. They need to understand that the dignity of risk is what makes us human. The possibility of hope prevailing outweighs the fear of failure in a system of supports that truly values every person and finally aims to re-capture lives lost. This proposed approach to quality then is designed to address key issues in the lives of all people in ways that help focus these very same important issues for any person served by the system. Health and safety are paramount. But, if you are elderly or have a disability, you are even more vulnerable than most and the presence of trusted individuals who have a deep commitment to you is essential to both access to health care and safe homes and work.

The ability to pursue both real community membership and long term relationships are central to our notions of what makes us important and human. This should be no different for those receiving public supports. The promise of income is closely linked with the freedom all people desire. The present human service system conspires to make this difficult for those who rely on public support. No matter. The creation of economic futures for all needs to become part of a future framework of support. Control over the means of transportation is vital to all individuals in this society and this is even more true for those with disabilities. And, in a future system of public support, accountability must play a central role for those who work and benefit from the provision of supports to individuals across disability and aging. The system of the future needs to rest firmly on the equality of those who experience aging and disability and the possibility for their attainment of the same quality of life that is universally sought by all of us.



• ORDER FORM •

NOTES

Multiple horizontal lines for writing notes.

GUIDEBOOK	PRICE	QTY.	TOTAL
Crafting the Instruments of Freedom: Tools of Self-Determination	\$10		
Guaranteeing the Promise of Freedom: Creative Individual Budgeting	\$10		
Supporting the Promise of Freedom: The New Broker	\$10		
Real Life Quality Standards	\$10		
COMPLETE SET OF FOUR	\$34		
TOTALS*			

* Receive 20% off for orders of 100 or more handbooks.

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Organization: _____

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E-mail: _____

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