

The cover features a central graphic of a globe held by two hands, with the title 'Real Life Quality Standards' overlaid in a teal, serif font. The background is a light teal with a fine grid pattern.

Real Life Quality Standards

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The logo consists of a stylized flag on a pole with three wavy lines representing the flag's stripes.

**Center for
Self-Determination**
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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 who experience disability. 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.

Individuals with disabilities 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 with disabilities. 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 individuals with disabilities 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 with disabilities 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

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 disability-led 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 individuals with disabilities 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 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 and controlling expenditures are means. 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 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: 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 with disabilities**
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 with a disability**
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 close 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 work.

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 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 real lives – not human service programs. The time has come to view universal human aspirations as the norm for quality for everyone.

People want real lives – not human service programs.

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 with a disability 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 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 with disabilities 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. **The generation of private 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 with a disability 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

This section emphasizes the importance of communication, relationships and trust and is designed to obtain information about medical care available to the person, as well as address issues that may exist with regard to safety. There is some evidence that for those without close allies and/or family members, for those who don't use traditional communication and for others with difficulty talking about medical concerns or safety issues, there is always the risk of inattention or even neglect. For this reason, questions about the person's relationships (for those with and even more importantly without family) are included in order to determine if the "reliable ally" is available to understand the person's communication and/or for whom the person will place enough trust in order to communicate any concerns about medical or safety issues.

There is growing concern that issues like staff turnover create (as one important example) a situation of jeopardy for the person. Without long-term committed relationships, all individuals with significant disabilities remain potentially unsafe. In addition, self-determination requires that all individuals who provide support of any kind work for the individual and that person's circle of support, if appropriate. In such a highly individual and personal arrangement, one of the key issues around contemporary quality approaches is better addressed. That is, instead of support staff having to assume multiple responsibilities for any number of individuals, under self-determination their commitment is to a single individual in a freely chosen arrangement.

If the person does not communicate traditionally or if the person is usually reluctant to address certain or all medical or safety issues, there are in the person's life family members, friends or staff always available who understand the person so well that they notice any distress or have the complete trust of the individual so that these kinds of communications occur.

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. If a minor, the person with a disability experiences inclusive education	yes		no	
3. If transition age, clear work/ higher education goals are established	yes		no	
4. 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 with disabilities 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 with a disability. 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		

• THE PRODUCTION OF INCOME •

What a person with a disability 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.

NOTES

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 with disabilities 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 with disabilities remain forever in jeopardy.

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 with disabilities. 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 with disabilities face the possibility of failure—failure at work or at self-employment. By addressing our connections to our communities people with disabilities 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.

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



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