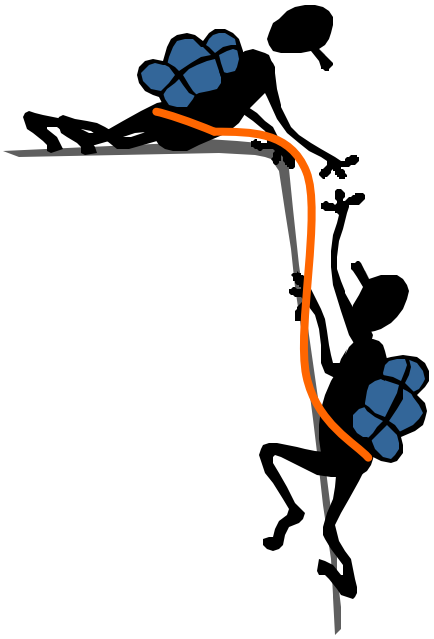
Quality: It's Everyone's Business

Great Expectations

Providing Choice – Minimizing Risk



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Service Systems Expectations

Irwin Siegel Agency, Inc.

ISA has been involved with the disabilities field for over thirty years, developing comprehensive insurance products and safety supports for agencies within the Human Service Field. Through our involvement, we

have become a leading insurance and risk management organization. Our commitment goes beyond risk protection and risk management. It ensures that our agency contributes in meaningful ways to support people with disabilities and the provider agencies who work with them. ISA works with local brokers throughout the United States, insuring over 2,500 provider agencies.

We are actively involved with national associations, such as AAMR, UCP and ANCOR. ISA has been chosen to represent the interests of people with disabilities on the National Safety Council Board of Directors. Through this involvement, ISA has received many awards like the National Safety Council "Distinguished Service to Safety Award". ISA also sponsors awards including: the United Cerebral Palsy (UCP) Commitment to Quality Award, the American Association on Mental Retardation's (AAMR) Robert Guthrie Award for Advances in Biochemical and Molecular Genetics, and the National Safety Council's (NSC) Award for the Improvement in the Quality of Life for People with Disabilities.

We understand the challenges facing providers and strive to provide quality services to all of our insureds. We are committed to:

Supporting Those Who Support Others^{TM}

Key Members of the ISA Staff

John Rose - Vice President of Risk Management

John has broad experience in the disabilities field and has presented on numerous topics nationwide. John began his career in the field of developmental disabilities in 1979 as a direct care worker. He has a master's degree in Public Policy. John is a past chair of AAMR's special interest group on Direct Support Professionals (DSP) which has now become a division. He recently received the AAMR President's Award for his leadership in promoting the importance of DSP. John currently serves on the Board of Directors of the National Safety Council. He is also a founding member of the Ontario Association on Developmental Disabilities in Canada.

Alan Kulchinsky - Assistant Vice President of Risk Management

Prior to coming to the Siegel Agency, Alan worked in various positions in the disability field and youth services. He directed youth services and was a childcare director for a residential program with developmentally disabled adolescents and was a teacher in a day program for youth with multiple disabilities. He has a B.S. in Psychology from the State University of New York. Alan networks with the Behavioral Health and Human Services markets, develops risk management resources, and assists our underwriters in developing an insider's perspective and understanding of elements unique to the human service environment.

Lynn Reno - Human Services Program Manager

Lynn has a master's degree in Health Services Administration from the New School of Social Research in NYC and has coordinated residential and clinical services for people with developmental disabilities for over 18 years. She currently works with providers around the country with risk management and has given presentations nationally. She is responsible for resource development, training, and provider association support.

Preface

There are many hopes and "**Great Expectations"** for a service delivery system that presents individuals with a diverse array of supports from which they can select, and that assures efficiency, effectiveness, and a degree of system safeguards.

As new and systematic ways to support people with disabilities emerge, driven by funding and philosophy, we will undoubtedly transcend this current period of confusion and uncertainty to embark on a new frontier of self-determination, known as Consumer Directed Service Delivery.

During this transcendental period, rife with ambiguities, there is one underlying certainty. The system of support that evolves into the 'new modality', must ensure quality consumer outcomes and reasonable safeguards, lest it be judicially revoked.

The Home and Community Based Waiver tends to be a freedom from the prescriptive controls of ICF/MR conditions, but does it really honor the sanctity of choice? This deregulation of sorts may make a provider even more susceptible to the 'jaws of a jury'. As providers enter the 'era of community membership' (Bradley) by supporting individuals in their 'right to risk', this litigious society of ours will be swift to admonish their slightest mistake. Armed only with good intentions (and ideally, a waiver, caring and properly trained staff, an ISP and plenty of documentation), providers will again take on the challenge, as they have in the past, to care for, support, nurse, educate, and integrate people into the community.

Individual Expectations

Quality assurance means:

- ✓ All people with disabilities will be treated like anybody else
- ✓ Rules and regulations should correspond with the needs of the individual
- ✓ The individual must be involved
- ✓ People get the support they need
- ✓ A person is allowed to choose where and with whom he or she wants to live
- ✓ Services are available to people wherever they want to live

Michael J. Kennedy – IN Quality Assurance for Individuals with Developmental Disabilities: It's Everybody's Business

The following highlight is one of the great success stories happening in the field.
(*Names have been modified for privacy.)*

Sara is the Job Coach for Mary who is 58 years old. Mary left a State center after over 25 years of institutionalization in the early '80's, determined to become independent, productive, and to gain all of the opportunities and rights of other citizens in her community. Mary arrived at the community agency with a diagnosis of severe mental retardation and a reputation for extreme behavior. Mary's Behavior Plan included placing her in four-point restraint and squirting lime juice in her face when she exhibited inappropriate behavior. Needless to say, the Behavior Plan was not implemented.

Mary now enjoys Supported Living with her housemate whom she met nine years ago. Six years ago Mary landed a job through a work services program and chose Sara to be her Job Coach. Mary meets Sara every day at a downtown bank. The bank is housed in the tallest building in the town and also provides office space to one of the largest law firms. Mary is nearly independent in her job, but her mobility challenges and the needs of a fellow worker continue to require Sara's presence.

Over the years, Sara has taught Mary how to independently access the building. She enters the elevator on the first floor, presses the

correct floor number; exits the elevator on the floor of her work site, and finds her office within the maze of offices. She punches in and hangs up her coat. From there, she takes the lunch that she made at home back through the office maze, and again rides the elevator and finds the luncheon area. Everyone in the law office knows Mary and they freely engage her in conversation. Mary's work habits are phenomenal, thanks to Sara's support and training. Her rather complicated job involves staple removal, counting, sorting, organizing, collating, and a number of other tasks, which she does independently with some support from her job coach when needed. In June 2000, Mary's colleagues held a five-year anniversary party to celebrate her successful work history.

In addition to her role as a job coach, Sara played a primary role in helping Mary reunite with her brother. Once, he visited Mary at work and tried out her shredding job, but jammed the machine. She taught him how to do it correctly. Sara and Mary share a unique understanding, best illustrated by this event during an airplane trip for the two of them to visit Mary's brother down south. Sara was the one afraid of flying, and Mary picked up on it. In a reassuring gesture, she took Sara's hand and said, "We'll be ok, don't be scared, you can hold my hand".

Sara has been an inspiration to her colleagues. She has first-hand experience with life's challenges, and has struggled with serious domestic issues, including divorce, supporting her children, and coping with her own mental illness. Mary's desire to live independently, and her ability to make wise personal choices that allow her to do so successfully are fueled by Sara's burning desire to help Mary realize her own potential and to be her best.

Service System Expectations

"If you have built castles in the air, your work need not be lost; that is where they should be. Now put the foundations under them"

Henry David Thoreau

There are multiple federal programs for people with disabilities, administered by different federal agencies. The largest federal programs are Social Security and Medicare/Medicaid. Within Congress, disability programs are scattered through a number of committees with no mechanism to promote coordination of policy.

"We must forge a national disability policy that is based on three simple creeds – inclusion, not exclusion; independence, not dependence; and empowerment, not paternalism."

President Bill Clinton, 1996

State programs generally reflect the categorical nature and complexity of programs at the federal level. There tends to be no single access point for people with disabilities to receive information or services. Some states have attempted to address these problems by consolidating programs at the state level. While consolidation may offer flexibility in service delivery, it may also risk loss of services as various recipient groups battle for their fair share.

A report by Scully et al, Coordinating Services with and for Persons with Disabilities: A Challenge for State Government, National Academy for State Health Policy, examined the states' experiences in administering disability programs and recommended consolidation at the federal level with a strong consumer and community focus, including a common intake process and a consumer-centered individualized plan.

The Changing Environment

We are at a crossroad in the delivery of services and supports to people with developmental disabilities. While we scurry to close institutions because we (professionals, self-advocates, parents administrators) feel that being in the community affords greater opportunity for integration, we realize an even greater concern for protecting those we support from risk within this open community environment. We also realize that as the people we support become more independent, their exposure to risk increases.

Efforts to deinstitutionalize, coupled with funding cuts, regulatory change, and Self-Advocacy/Self-Determination movements, are all motivators for greater independence and in turn, greater risk. **One must realize, however, that obtaining greater**

independence is a journey rather than a destination. It is not one outcome but a series of experiences. Individuals with developmental disabilities must have the opportunity to learn from experience without having that experience deter them from achieving greater independence.

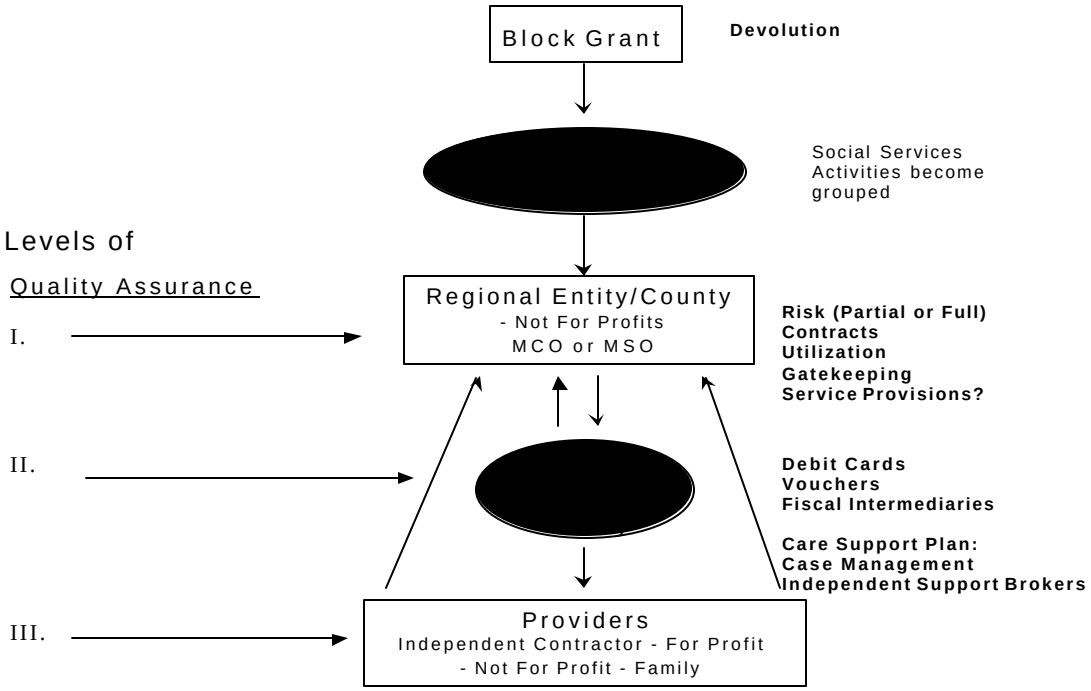
The field of developmental disabilities is not unlike any other field when it comes to change. We see change all around us on a daily basis, in the areas of technology and business. Change must be accepted as a way of life, it is inevitable. Several forces have led to the current changes in the field of developmental disabilities, including self-determination, devolution, funding, self-advocacy, waiting lists, and managed care.

Self-determination is a consumer directed service delivery system and many states are rethinking this method of service provision. In a consumer directed delivery system, a provider markets the quality of their services and supports hoping to attract prospective consumers. There are as many factors influencing the need for change, as there are reasons to challenge current standards of quality assurance, safety, health, and fiscal accountability.

Devolution in a sense, is passing the buck from the federal government to the state level to the local entity. This local entity may be a county government or a selected not for profit organization. When we talk about change in the field of developmental disabilities, we often refer to a consumer-directed service system model. This was demonstrated at a November 2000 conference of State DD Directors in Virginia, that pertained to self-determination and system accommodations. This model basically has the family in the driver's seat in determining which services and supports the individual or family needs. Needs are determined through a care plan, which is then approved by the local government or provider organization. Once the care plan is approved, the regional entity, with family approval, would then contract with an independent not for profit provider, or perhaps even family members.

In this model, Quality assurance must have a multi-level approach to ensure customer satisfaction and compliance with various guidelines and mandates.

A State Model for Consumer-Directed Services

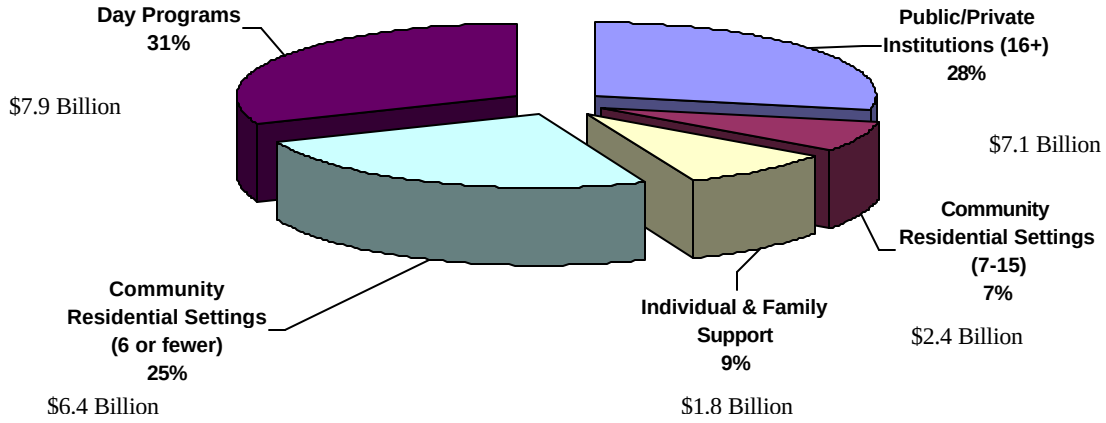


Rose '98

Irwin Siegel Agency Inc.

Funding has shifted from institutional to community support in many states, as documented by the research of Braddock (Institute of Human Development, University of Illinois) in The State of the States, which typically shows increased funding in the area of community services and individual family support, and a decline for institutional services.

United States Spending by Setting in 1998



Total Spending $25.6 Billion

*Day Programs include sheltered workshops, day care, transportation, case management, and other non-residential community services

Self-Advocacy, which started a little over 25years ago, has grown tremendously in the past several years. Many self-advocates echo David Scali of People First, who commented,

> ***"In the past staff made all the decisions, we would like to make our own decisions with staff's help, if needed, but not in a controlling way - just being supportive – really – that is part of the job".***

Self-advocates want to assume positions of leadership in agencies and government. Training programs are underway throughout the states that will prepare people with the needed leadership skills.

Top Ten Things You Should Do When You Support Us

- Forget the records: Get to know US as People
- Listen and Hear our voice: We've got a lot to say
- Treat us like you want to be treated -- with Respect and Dignity

- Ask us how we feel about stuff
- Make your goal to help us accomplish ours
- Take time to explain things if we don't understand something
- Put yourself in our shoes -- walk our walk
- Tell us the truth
- Believe in us and our Dreams
- Be good to yourself -- We need you to be healthy and energized!
- Thanks for the Great Work You Do in Supporting US!
  SABE Conference – Providence, RI, September 2000

Waiting Lists are a hot issue in most states, kindled by lawsuits to address the growing concern about providing support to some 60,000 people awaiting services. Many states have begun initiatives that will address this problem and NY CARES is a good example. The challenge lies in obtaining sufficient staff to accommodate the additional population from a workforce that is already depleted.

The principles of ***managed care*** and how they may impact on a consumer-directed service system include cost-containment, utilization and risk sharing. While managed care organizations are not seen as a current threat to long term care for people with disabilities, certainly the principles of managed care will be invoked in service delivery system change and at the local entity.

In the **New Services Paradigm**, Bradley provides a nice accounting of the evolution of services in the DD field. Between the 'era of institution' and the 'era of community membership' lies a transitional phase as individuals move from group living to their own homes, from custodial to individual support. A change also occurs in who controls the planning decisions formerly made by a professional (M.D.) or the interdisciplinary team. In the era of community membership, we see the changes of the highest priority moving from the institutional setting where basic needs were met, to self-determination. The objective is to move from limited control and custodial care, to changing the individual's environment and the community's attitudes. This evolution of change brings an increased degree of risk. Certainly quality of life is enhanced through self-determination, but supporting this quality of life may take on a different role. The institution was more clinically oriented, while the community-based program uses a team approach. In the era of community involvement and self-determination, it's the individual, with his or her circle of support who will make the choices and become responsible for the risk. Accepting responsibility is an important component of choice in the consumer directed service delivery system.

	Focal Questions	**Era of Institutions I**	**Era of Deinstitutionalization II**	**Era of Community Membership III**
A	Who is the person of concern?	The patient	The client	The citizen
B	What is the typical setting?	An institution	A group home, workshop,	A person's home, local business,

			special school or classroom	the neighborhood, school
C	How are services organized?	In facilities	In a continuum of options	Through a unique array of supports tailored to the individual
D	What is the model?	Custodial/medical	Developmental/Behavioral	Individual support
E	What are the services?	Care	Programs	Supports
F	How are services planned?	Through a plan of care	Through an individualized habilitation plan	Through a personal future plan
G	Who controls the planning decisions?	A professional (usually an MD)	An interdisciplinary team	The individual
H	What is the planning context?	Standards of professional practice	Team consensus	A circle of support
I	What has the highest priority?	Basic needs	Skill development, behavior management	Self-determination and relationship
J	What is the object?	Control or cure	To change behavior	To change the environment and attitudes

Adapted from "The New Paradigm" (Val Bradley, 1994, HSRI, PCMR Chair)

Accepting the principles of self-determination as discussed later, means accepting the need for a change in the service delivery system. However a person does not need to wait for those changes in order to exercise the right to choose.

	Level of Risk Exposure?	**Low-Moderate I**	**Low-Moderate II**	**Moderate-Severe III**
K	Management Oversight	Centralized	Decentralized	Negligible or Non-existent
L	Negligence potential	High	Moderate	*Low
M	Opportunity for Choice	Limited	Moderate	High
N	Protection	Excessive	Moderate	Minimal
O	Quality of Life	Diminished	Enhanced	Self-Determined
P	Risk Management	Clinician	Team	Individual with circle of supports
Q	Supports – Paid	Primary	Primary	Secondary
R	Supports – Natural	Limited	Secondary	Primary

*Needs further explanation

"Evolution of Risk" (Rose '98)

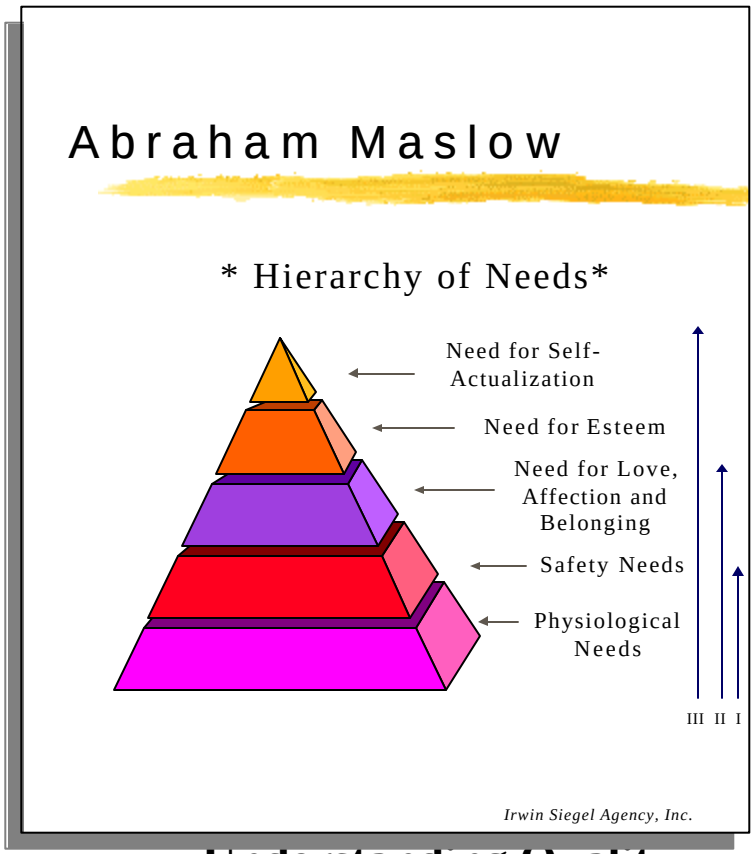
While greater opportunity for choice has its consequences and risks, there is much to say about the dignity of risk and the opportunity to experience life's rewards.

"In a era of individualized support environments, assuring quality will increasingly depend on the initial decision about the nature of the living environment and the extent of the supports required for each person. If the supports and connections required for real integration are not carefully put in place, there is a risk that harm will occur and remain undetected"

Clarence Sundram

Product of the Environment

It is interesting to note that 60 years ago humanist Abraham Maslow, in the early 1940s, wrote that we should focus on people and their potential and strive for an upper level of capabilities. He theorized that we are all products of our environments, and the right environment is necessary for each of us to reach our full human potential. In other words, environment is the key to unlocking each person's capacity to be and do all that he or she is capable of. Contrast his work in 'hierarchy of needs' against the institution-based model that only provides for physiological needs. In the era of community-based supports (III), Maslow's hierarchy of needs fits neatly into the context of self-determination, and further justifies the drive to give each individual the tools, circumstances, and opportunities they need to flourish.



Understanding Quality

What is quality? How is it defined? What determines a quality program? Someone once described quality by stating, "you'll know it when you see it". Does that mean that quality is a matter of perception?

- If I don't like the meal, but the chef went to all the best schools….
- If 9 out of 10 dentists say the bridgework is excellent, but it doesn't feel right…

Is quality more than customer satisfaction?

Quality can be defined as, 'the degree of excellence' or 'consistency in results' or the 'degree of customer satisfaction'.

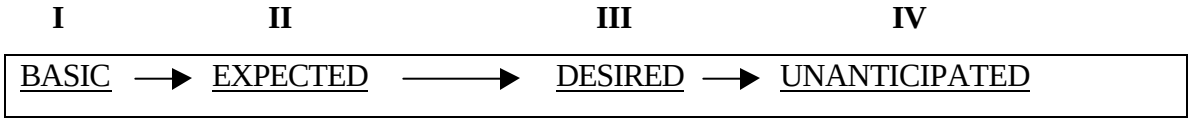
Gary Sluyter (TQM: A Paradigm for the 90s) says that there are two parameters necessary in defining quality:

- Technical – standards, clinical practice, overall organizational excellence
- Customer Perception – needs and wants

Sluyter goes on to say that what is critical in obtaining quality is first creating an organizational culture, "…defined by the constant attainment of customer satisfaction resulting in improvement to organizational process resulting in high quality services and products."

> ***"Organizations must include multiple dimensions of service performance when defining quality: availability, appropriateness, effectiveness, efficacy, efficiency, safety, and coordination of disciplines, timeliness, and acceptability."***
>
> *Dennis O'Leary, President of JCAHO, 1992*

Karl Albrecht states that 'quality is present when the individual perceives a value'. "Quality is a measure of the extent to which an experience meets a need, solves a problem or adds value for someone". He goes on to say that there are four levels of value:



Following the above 'Value Continuum', where is our service delivery system today? Are we still at the Basic Level, ensuring only minimal needs as we struggle to provide a way to meet ones wants?

The Quest for Quality

Considering the aforementioned, quality can be achieved by ensuring that agency's mission embraces the following four areas:

I. **Customer Perception** - An individual's perspective, i.e. 'quality is in the eye of the beholder'. If the customer is satisfied, has quality been accomplished? How is satisfaction determined?

II. **Organizational Culture - A** lifelong commitment to continued improvement resulting in a totally satisfied customer. How are staff and stakeholders made a part of the quality culture?

III. **Compliance** - The traditional "meet the minimum standard" approach to quality assurance is abandoned in favor of one that strives to surpass what is minimally expected, i.e., driver's license (just having a license does not make you a good driver). What other assurances will help ensure organizational excellence (accreditation, risk management)?

IV. **Workforce –** There is more to quality than just a new and beautiful building. It's the human element in the field of human services that makes the difference. Is quality of outcomes equal to the quality of the workforce?

Customer Perception

Tell the customer what to expect. Give them time to think about what service standards would be most important to them. That is, convenient meeting schedules, timely arrival by staff who come to the home, prompt answers to questions about particular topics, and their rights to respect, courtesy, and enthusiasm, informed choice and Safety should be honored. The people who use the services or receive the supports must define quality.

Quality service systems should always have feedback and complaint mechanisms that are easy to use, i.e., a message system for phoning in complaints or concerns, an address to write to, a contact person, or even a suggestion box. Any system must be flexible enough to accommodate people with disabilities, including people who may not be able to put their complaint in writing. If there is no easy-to-use complaint (incident reporting) system, or process for feedback/input, then your programs will not evolve into quality programs.

The provider needs a clearly defined vision of the future: People working in the organization are united by a common understanding of the vision, and everyone in the organization cooperates to realize that vision. The organization sees itself as part of a larger system of services where teamwork and cooperation are valued. The organization also seeks information and feedback from staff and other key stakeholders (families, advocates, and funders) and listening to consumers is a priority activity. Decisions about

service improvements and development are made based on data about outcomes for people. Learning from success (as well as failure) is an important part of the service delivery process for everyone. The ability to gather, organize, and monitor information that measures staff performance and consumer outcomes is essential to any quality enhancement effort.

Organizational Culture

TQM (Total Quality Management) for service providers means that the organization's culture is defined by and supports the constant attainment of customer satisfaction through an integrated system of tools, techniques, and training. This necessitates the improvement of organizational processes in order to obtain high quality products and services.

TQM has at least five important elements. It should be customer-driven, have strong leadership, show constant improvement in the system of production and services, have action that is based on facts, data and analysis, and replace the traditional boss-centered hierarchical type of organization a customer-centered pyramid – the customer being on top.

According to quality management literature, a quality program features at least five important elements:

1. The program should be customer driven. People who depend on our services, our customers, should be able to expect more that a 'one-size-fits-all' system. We need to be responsive in identifying our customer needs. (Person Centered Planning).

2. The program must have strong quality leadership. Leadership needs to provide a clear understanding of the mission, and encourage employees and customers to be involved in important decisions.

3. The program must allow for continuous improvement. We must move away from, 'if it ain't broke, don't fix it', to 'it ain't broke but it could be better."

4. The program must take action based on facts and analysis. We need to abandon the 'shoot from the hip' approach to decision-making and rely on analyzing data in resolving problems, while keeping a broader focus on customer based outcomes.

5. The program must encourage employee involvement. Empowerment should apply to staff, particularly front-line staff (Direct Support Professionals) who are in positions to best support customers' satisfaction. Empowerment without management support and specific training (i.e., supporting customer choice) will not be effective.

Quality in human services has traditionally been defined by compliance with standards. Quality Assurance (QA) is only one part of TQM. QA needs to also be inclusive of performance (outcomes). Each improvement in quality lends support to the organization. "Getting it right" means providing the right support and following the right procedures while focusing on customer satisfaction.

Meeting the moment of truth means service based on courtesy and respect. 'Absence of quality is the essence of failure'. Quality not quantity is the true message of success.

Deming suggests that quality is "a life-long commitment to continuous improvement in customer service resulting in a totally satisfied customer"

Total Quality Management for service providers means that the organization's culture is defined by and supports the constant attainment of customer satisfaction through an integrated system of tools, techniques, and training. This cycle relies on improvements in the organizational process that result in high quality products and services.

Compliance

This is the traditional 'quality assurance' element: Compliance with federal and state regulations as well as local (community) ordinances.

For decades, bureaucratic compliance standards have outlined minimum requirements for running a licensed support program. Compliance standards are generally based on regulations. Quality service standards are not based on regulations and red tape. They are based on customers' realistic service expectations and standards of care and support. Quality, therefore, goes beyond regulatory compliance.

Service providers should ask customers what supports they need, how they want them provided, and what trade-off they are willing to make. Remember, quality does not necessarily mean customers will get everything they want. It means that what they do get will be more than they expected.

Experts, regulators, advocates, staff, and other partners can work with the customer to help figure out how to bend the rules or change the service delivery system so that supports will meet their needs. Sometimes, regulations are changed (through waivers) so services can be more flexible.

Workforce

Leadership begins with a clear understanding and articulation of governing ideas (mission, vision, and values). If the organizational culture says that only people in the top echelon can make important decisions or work on important problems, then any effort to involve employees in a systems change is doomed from the beginning. Frontline staff deal with the customer – empower them! Deming says, "the best efforts of workers are not sufficient. If a system does not permit quality performance, then it does not matter how hard people work".

> ***"How can you get the recognition that this position demands when the system rewards those furthest from the consumer"***
>
> *Michael Kendrick*

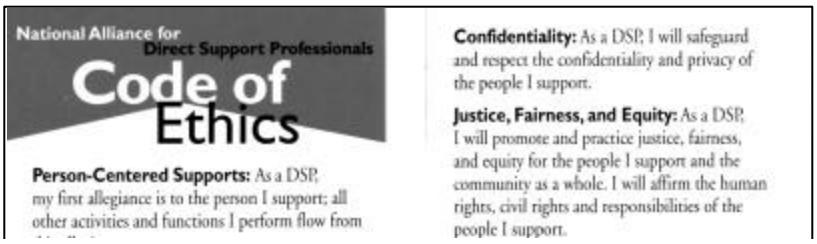
> ***"In the absence of competent dedicated frontline workers and supervisors, it is virtually impossible to furnish high quality resources on a consistent basis".***
>
> *DDQC*

Recall the rotten apple approach to management. It's much easier to issue a restrictive policy, throw money at the wall, or find a scapegoat after a crisis, then to look at changing the system. This is the point where TQM abandons the shoot from the hip approach and takes the time to collect, analyze and apply data in the resolution of problems.

The systems perspective tells us that we must look beyond individual mistakes or bad luck to understand important problems. We must look beyond personalities and events. We must look into the underlying structures, which shape individual actions and create the conditions under which these types of events are likely to occur.

The trend in developmental disabilities service delivery is obvious – focus services and supports around the customer, based on their needs and wants, and give them a degree of control (self-determination or consumer directed service delivery). But does this alone guarantee a satisfied customer? To a large degree, the answer is yes, but to be totally satisfied, at least one other component must be present...quality supports.

National Alliance for Direct Support Professionals Adopts a Code of Ethics.


National Alliance for
Direct Support Professionals
Code of Ethics

Person-Centered Supports: As a DSP, my first allegiance is to the person I support; all other activities and functions I perform flow from

Confidentiality: As a DSP, I will safeguard and respect the confidentiality and privacy of the people I support.

Justice, Fairness, and Equity: As a DSP, I will promote and practice justice, fairness, and equity for the people I support and the community as a whole. I will affirm the human rights, civil rights and responsibilities of the people I support.

Quality and the Workforce

Achievement of quality outcomes for people seeking supports and opportunities for community inclusion relies solely a quality workforce who can provide the appropriate and desired supports. Lack of adequate and competent direct support staff is a serious challenge to Bradley's era of community membership. Workforce is the single largest impediment, affecting growth (waiting list reduction), sustainability, and quality in community supports. The importance of finding and keeping direct support staff is well documented and discussed . This can no longer be viewed as a service provider problem but must be recognized as a threat to the viability of community services.

The shift to self-determination (individualized budget, choice) places a heavier burden on the shoulders of direct support workers. Service settings are smaller and expectations of the workforce are greater as their role grows in complexity.

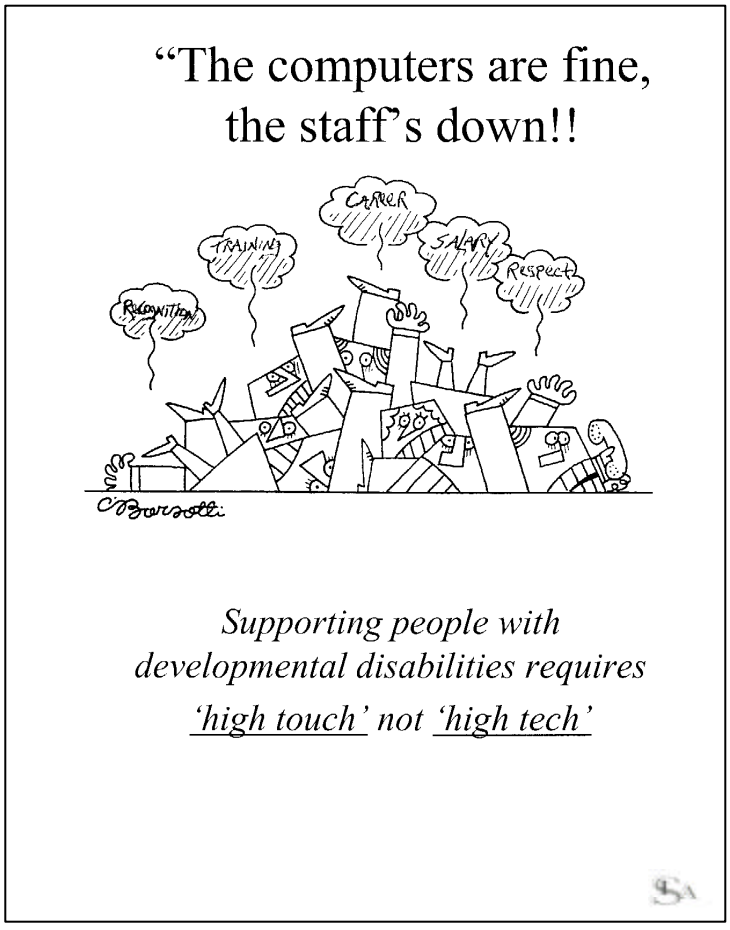
Research conducted by HSRI in their Community Support Standards (see appendix) documented the competencies necessary to guaranty the quality of outcomes by frontline staff. Training requirements for frontline workers have typically been confined to a minimum set of topics: CPR and first aid, consumer rights, introduction to disabilities and so on. While relevant topics, they by no means adequately prepare a person to properly provide supports that lead to meaningful outcomes.

Direct Support Competencies

- **Participant Empowerment*:*** Enhances the ability of participants to lead self-determined lives by providing the support and information necessary to build self-esteem and assertiveness, and to make decisions.
- **Communication:** Knowledgeable about the range of effective communication strategies and skills necessary to establish a collaborative relationship with the participant.

- **Assessment:** Knowledgeable about formal and informal assessment practices in order to respond to the needs, desires, and interests of the participants.
- **Community and Service Networking:** Knowledgeable about the formal and informal supports available in his or her community and skilled in assisting the participant to identify and gain access to such supports.
- **Facilitation of Services:** Knowledgeable about a range of participatory planning techniques, and is skilled in implementing plans in a collaborative and expeditious manner.
- **Community Living Skills and Supports:** Has the ability to match specific supports and interventions to the unique needs of individual participants and recognizes the importance of friends, family and community relationships.
- **Education, Training and Self-Development:** Should be able to identify areas for self-improvement, pursue necessary education/training resources, and share knowledge with others.
- **Advocacy:** Knowledgeable about the diverse challenges facing participants (e.g., human rights, legal, administrative and financial) and able to identify and use effective advocacy strategies to overcome such challenges.
- **Vocational, Educational, and Career Support:** Knowledgeable about career and education related concerns of the participants and should be able to mobilize the resources and supports necessary to assist the participant towards each of his or her goals.
- **Crisis Intervention:** Knowledgeable about crisis prevention, intervention, and resolution techniques, and should match such techniques to particular circumstances and individuals
- **Organizational Participation:** Familiar with the mission and practices of the support organization and participates in the life of the organization.
- **Documentation:** Aware of the documentation requirements in his or her organization and is able to manage these requirements efficiently.

For additional information, please contact HSRI at 617-876-0426 or wqww.hsri.org



The workforce crisis has a broad range of detrimental effects on the lives of people with disabilities. It obstructs the ability to 'build bridges' to the community and provide services for those coming out of institutions or on waiting lists to do so, and also hinders efforts to reverse the alarming increase in abuse and neglect. **Where direct support staff find themselves working more over-time and turn-over and vacancy rates continue to rise, the level of quality will be diminished.**

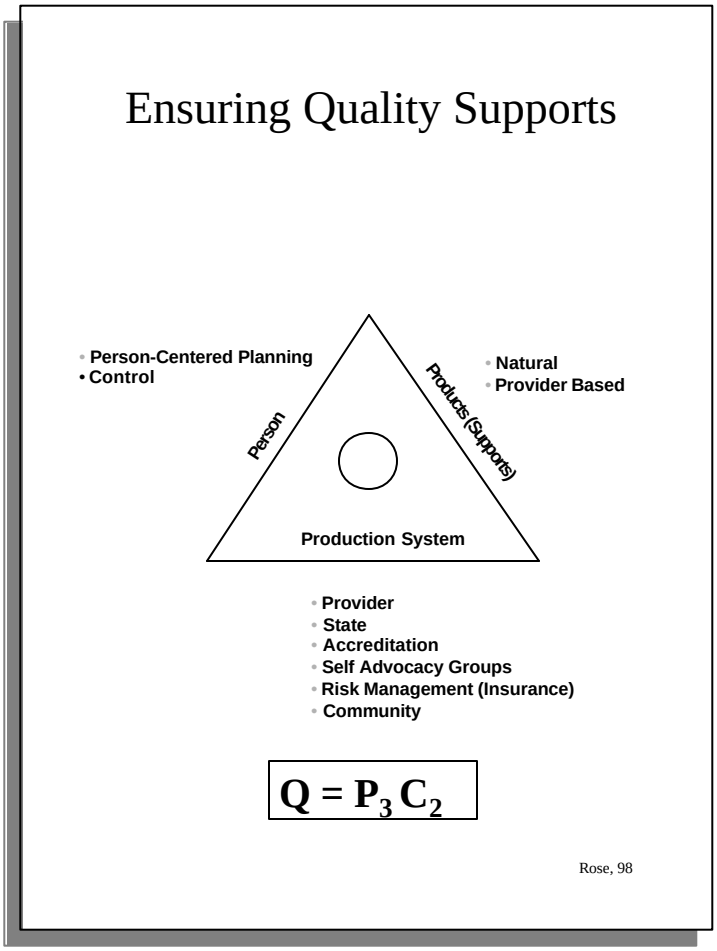
While this crisis will not disappear overnight, the first step, acknowledging its scope and severity, has been taken. All stakeholders are are vigorously pursuing solutions to the plethora of problems, and implementation will require a total commitment from all parties. Although the remediation process is still in infancy, there have been some encouraging advancements: defining a DSP career ladder and the competencies required for each rung, and opening educational pathways to attain them are all proof of progress.

As a national organization, AAMR (American Association on Mental Retardation) aamr.org, has brought its considerable clout to bear on the issues of frontline workers. Their original Task Force evolved into a Special Interst Group in 1995,comprised of John Rose, Chair, Dan Rosen, Bonnie Brooks, Pam Baker, Tom Sullivan and William Ebenstein, and is now a Division for DSP (Direct Support Professionals).

AAMR has been at the forefront in policy development and support to the field of frontline workers. Through AAMR, the National Alliance for Direct Support Professional, http://rtc.umn.edu/dsp/projects/nadsp.html was spawned. Today, Chapters in several states promote its goals and objectives – which are geared toward recognizing and rewarding Direct Support Professionals. Their newsletter, Frontline Initiative, is the only one of its kind that speaks to, is written by, and specifically addresses issues for the frontline worker. 'The Quality of the Outcome is Equal to the Quality of the Workforce'.

Quality Trilogy

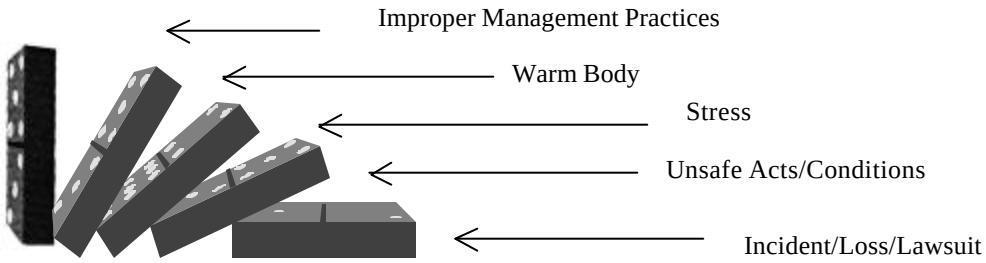
The Quality Trilogy reflects the unilateral importance of the three P's (Person being supported, the Product which is the support and the Production which is the system that provides the supports). The C's in the formula call for Continual Improvement and Customer Satisfaction



Price Pritchett writes in The Ethics of Excellence that, "Quality is a matter of individual values. The interaction between staff and the person receiving services tells a lot about the values of an organization". A 1985 Gallop Poll on the quality of American products and services demonstrated what was most important: Topping the list of desirable employee attributes were behavior, attitudes, and competence, followed by satisfying customer needs and ensuring that competent and compassionate staff are empowered to meet customers needs. Pritchett goes on to say that, "we cannot buy our way to excellence". Dykstra asks (Outcome Management, 1995), "has the organization born fruit? Despite all its cultivation efforts, has anything meaningful occurred"?

Frontline staff, the Direct Support Professional (DSP), plays a key role in assuring quality outcomes for people with development disabilities. In a consumer directed service delivery system - a more competitive environment for providers - the role of the DSP becomes even more critical, as outlined later in this monograph, in the Department Store Analogy *(see page 28)*.

'Quality Failure' – The Domino Principle



Improper Management Practices +"Warm body" + Stress + Unsafe Acts

= Incident/Loss

Rose '95

Note: The Domino Principle may be triggered by excessive mandate, lack of proper funding or other variables that are external to provider organizations.

As a field that provides services and supports to people with disabilities, we have always been obsessed with quality, particularly 'quality assurance'. Recently, there has been renewed fervor in both Quality Assurance (QA) and Quality Improvement/Enhancement (QI/E):

- CMS, formerly known as HCFA is developing a quality protocol
- States are issuing quality mandates
- UAP Minnesota has developed a Quality Mall (visit at **QualityMall.org**)
- A coalition for quality (DDQC) has been formed, and so on…

Is this renewed emphasis on quality being driven by an increase in incidents of abuse and neglect, in losses and personal injury? Are we, as a field, experiencing Quality Failure?

Quality Failure?

An employee of the insured filled the bathtub with hot water and placed the client in without checking the temperature. The client was nonverbal and could not feel pain. The employee realized that there was something wrong by the color of the client's skin. The employee removed the client from the water and called an ambulance. The client died in the hospital six days later from the severe burns that she received. The employee later admitted that he never checked the water temperature before placing the client in the water.

Quality Failure?

Oklahoma – state closed a provider program because it looked like a "battlefield of abuse".

Quality Failure?

Claimant age twenty-seven has a severe seizure problem and needs to be medicated to control the seizures. Insured's employee transcribed a lower dosage of medication than that required on the claimant's file, which caused a seizure. As a result of the lower medication dosage, the client went into a coma and never fully recovered. The employee admitted to the error after the incident and was charged with such. The allegations against the insureds are negligence and improper training on the distribution of medications.

Quality Failure?

"Investigators are considering whether to criminally charge a group home worker after a mentally retarded resident drowned Sunday"…(Wednesday, Hartford Courant 20 December 2000).

Quality Failure?

A child care worker at a state licensed school for troubled boys has been fired for allegedly using physical restraint to subdue a 15-year old boy who didn't want to follow his orders, state officials say." "The altercation left a bruise on the boy's shoulder and small cuts and

scratches on his neck…" (Hartford Courant 12 December 2000). The incident took place on 29 October 2000.

"Injustice anywhere is a threat to justice everywhere. We are caught in an inescapable network of mutuality, tied to a single garment of destiny. Whatever affects one directly, effects all indirectly."

Martin Luther King, Jr., letter from Birmingham Jail, 16 April, 1963

A recent article in USA Today (snapshots), gave examples of how we can be 99.9% sure that there has been quality, yet still have:

- 20,000 wrong prescriptions a year
- 106 incorrect medical procedures a year
- 15,322 pieces of mishandled mail an hour
- 2,000,000 documents lost by the IRS annually, and
- 12 babies to the wrong parents every day

How do you determine quality failure in the service delivery system?

- increase in incidents (perhaps 20 per month per average agency)
- increase in losses (perhaps a loss ratio over 40%)
- increase in turnover and vacancies in staffing

The workforce plays a key role in determining quality outcomes. Unless workforce issues are resolved, incidents and serious losses will continue to escalate.

Is there a correlation between outcomes and the workforce in the above scenarios?

Frontline Staff

I think most people would agree that quality must go beyond simple QA, which typically means just meeting 'compliance'.

Are you a good driver because you have a valid driver's license, or is it because you have a long history of driving accident-free (thanks to the training and support you get)?

Improving the skill level of the driver will greatly improve that driver's performance. If this is true, then the quality of the outcome is equal to the quality of the workforce. When discussing provider programs, the Department Store Analogy might have some relevance.

Department Store Analogy

Let's imagine for a moment that developmental disabilities service providers become new players in the market driven economy; department stores or retail outlets competing to provide you, the customer, with quality, cost-effective services and supports. As the customer, you decide at what store (provider agency) you want to shop. This may be based on a number of reasons, perhaps you shopped there before, and so you have established a preference. You choose a store because of the brand of products (services) available or perhaps the cost fits your budget. You alone decide where you want to shop because you have control in your spending – the charge card (voucher, etc.). Your choice of a store involves many factors, but of primary importance is the service you get. The knowledge, support, caring, warmth, and friendliness that you receive from sales clerks (frontline staff) may greatly influence your decision to shop or not to shop at a particular store. A department store that offers competitive pricing, quality merchandise, and all the guarantees will not have long term success if a non-caring, uninformed sales clerk is confronting the customer. Nordstrom, LL. Bean, and others realize that to be a retail leader, you need to empower and support your frontline staff. Organizational excellence requires many elements: one is a knowledgeable, caring, and dedicated staff that not only sells the services and supports but also ensures a totally satisfied customer.

As we move towards a consumer directed service delivery system, the ideal of customer satisfaction will become pre-eminent among determining factors. Customers can choose where to purchase goods or services, and they will avoid a beautiful store with wonderful merchandise (supports) if it is staffed by clerks who are not properly trained to assist them, or who don't uphold the quality culture.

Deming, the guru of quality management has emphasized the role of the consumer in measuring the effectiveness of outcomes. He also noted the importance of eliminating barriers that prevent the workforce from taking pride in what they do. Training and teamwork are emphasized, as are continuous monitoring and improvement.

Quality Improvement

A model for gauging quality and customer satisfaction is the Litmus Test for Quality, developed by People on the Go in Maryland (410-571-9320). It is a series of questions with suggested appropriate responses.

- Did you ask me?
- Will I be safe?
- Is my health protected?
- Do I have privacy?
- Are my rights and individuality protected?
- Am I spending time the way I choose?
- Help me be a part of the community
- Does the service make sense?

People on the Go is a statewide self-advocacy group supported by the Arc of Maryland. It is composed of self-advocates who believe all people with challenges should be included in school, work, and independent living. They conduct leadership training for new self-advocacy leaders, quality assurance training for providers, and disability awareness presentations for schools and community organizations. For the past four years, People on the Go has received a grant from the Maryland Developmental Disabilities Council called Leadership Now! During that time they have mentored 17 local self-advocacy groups. They also host a yearly Self-Advocacy Legislative Reception to meet and talk with elected officials, and an annual Statewide Advocacy Conference.

The Two Faces of QA: One: Control

Function	Characteristics	Mechanisms
Quality control: to assure minimum performance	**Protection from harm**	**Licensure**
	Clear indicators	**Certification**
	Immediate response	**Incident reporting & review**

Human Services Research Institute

The Two Faces of QA: Two: Enhancement

Function	Characteristics	Mechanisms
Quality enhancement to encourage optimal performance	Related to personal outcomes	Training
	Non-standardized interpretation	Technical assistance
	Taken seriously	Performance based contracting

Human Services Research Institute

Quality Enhancement must not be driven by the mandate to meet regulations. It should be geared towards motivating self-improvement and providing opportunities for growth and development. It is used to bring about continuous quality improvement, as measured by consumer and workforce input about outcomes generated.

Customer Outcomes

Community Inclusion
Choice/self-determination
Independence
Relationships
Quality of Life Rights
Services/Supports Coordination
Access
Satisfaction
Employment

Human Services Research Institute

Valued Outcomes

Individualization	Personal Growth
Integration/Inclusion	Self-determination
Relationships/Social Connections	Dignity
Health & Safety	Consumer Satisfaction

In a system of self-determination, quality assurance requires more than regulatory compliance or accreditation. It requires a multi-faceted approach to ensuring quality outcomes as well as participant safety. Peer groups, providers, families, and other stakeholders (insurance companies, the state or regional entity) all must play an active role. They must be certain that their new support system, enhanced by managed care components, and driven by the consumer, will surmount all obstacles in order to provide recipients with the opportunity to experience their chosen futures, and to enjoy self-determination.

Service providers will play a pivotal role, since their position on the frontline of service delivery will enable them to monitor outcomes as well as balance choice and risk.

It will be necessary to use roadblocks to prevent the Dominos from falling. The key domino is the staff domino, as illustrated below.

MANAGEMENT

Finding solutions that enhance frontline supervision, create a quality culture, and ensure proper policy and procedure implementation

STAFF

Finding solutions that lead to recruiting and retaining a quality workforce – recognition, career ladders, competencies, ethics, respect…

BEHAVIOR

Finding solutions that reduce stress, improve job satisfaction…

UNSAFE ACTS

Finding solutions that help to control losses, improve & monitor quality, and minimize risk…

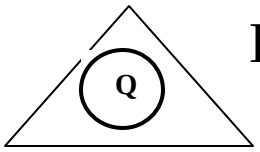
LOSS

First Aid
Public Relations
Legal/Insurance Issues
Incident Investigation/ Reporting

Risk Managers rank risk:
1) Human Capital (Retention, turnover)

Risk Managers rank risk:
1) Human Capital (Retention, turnover)
2) Technology (Security, Back-up)
3) Operations (Business interruption, supply disruption)

Source: Risk and Insurance 8/00



Do You Provide Quality Services?

- Do consumers think they are treated with courtesy, respect and enthusiasm?
- Do consumers say that they are asked what they want?
- Do consumers feel your services are reliable?
- Do you measure how well your organization performs against benchmarks for timeliness and reliability?
- Do you regularly ask consumers whether their supports are working for them?
- Do you track how consumers' needs are changing?
- Do you measure whether consumers think information is easy to understand?
- Are staff members trained and empowered to make processes easy for consumers?
- Are staff members cross-trained and empowered to solve emerging problems in other "departments".
- Do consumers say you have an easy-to-use complaint system?
- Do you help potential consumers find out whether they are eligible for services?
- Do consumers say it's easy to change their services or providers?
- Do consumers feel they have input into how they get their services?
- Can consumers turn down services they don't value?
- Do you publish your own service standards (beyond legal compliance regulations)?
- Do you provide performance data to help consumers compare services?
- Do you use alternative dispute resolution, such as mediation, instead of litigation?
- Do you publish who consumers and families should call if they suspect abuse or neglect?
- Do you share responsibility with partners, ie, other organizations in the system to effect system change?
- Do you measure key performance results?

"Shaping Our Destiny" - AAMR

Liability

Families and consumers may be assuming more than control in a consumer-directed service delivery system. They will find themselves also assuming a greater responsibility for obtaining and directing the supports they require. This risk could bring not only lament and anguish but also exposure to liability and litigation.

That old adage rings true, 'beware of what you ask for because you just might get it' - and then some! This should be taken as a precautionary statement only. It is not intended to discourage people from the opportunities that a well-planned service delivery system can provide.

Charles Dickens once said, "These are the best of times – These are the worst of times". These are the best of times for many reasons. Opportunities for people with developmental disabilities have never been greater (although we are still far from the Promise Land). The ADA has created a much better environment for people with disabilities, from greater accessibility in the community to the opening of doors to increased job opportunities. Reform in Social Security will hopefully allow for maintaining health coverage while working a fuller work schedule (WIIA-H.R.1108/S.331).

Technology has made life better for all people through new or improved medications, computerization, assistive devices, and more. But these are also times when people tend to shift the blame and pass the responsibility to others. This is evidenced by the litigious society in which we live–spill a hot cup of coffee on yourself and blame someone else! As families and consumers find themselves with greater opportunity to direct their needed supports by hiring personal care attendants or direct care staff, they should also gather all the information they can about the responsibility that this entails. This may include but is not limited to, issues relating to IRS, care attendant training, workers compensation, consultant agreements, employee hiring/firing, and most other employer-related concerns.

In order to address these issues, the following risk management checklist will be helpful to the person/family acting as a quasi-employer.

Risk Management Checklist (Sample)

Activity/Responsibility	Provider Agency 'C'	Contractor'B'	Employer'A'
Background Checks	Primary	None	Primary
Training	Primary	Credentials	Primary
Relief Staff	Shared	None	Primary
Insurance	Primary	Verify	Primary
Disciplinary Action	Shared	Agreement/Contract	Primary
Contracts – Employment agreement state/county agreement	Shared	Yes	Primary
Incident Investigation	Shared	Shared	Primary

As an 'employer', you assume all the responsibilities associated with that of a provider and/or contractor. Note: The IRS has a set of questions that help determine your status.

Protecting yourself and your assets in the event of a lawsuit is a primary consideration for any employer. This is traditionally done through insurance. The first thing you want to do is discuss your coverage with your insurance broker. It may be best to get his opinion in writing. You may need to seek additional sources for appropriate coverage, i.e., state associations, etc. Minimizing your liability is the basis for completing a Risk Management Plan.

Lawsuits

People can sue for anything, and given our litigious society, you need to accept and plan for this. Following proper risk management guidelines as mentioned earlier will minimize the possibiity of being sued and of outrageous settlements. In order for a lawsuit to be successful, you must be proven liable. To be proven liable, four conditions must be met:

Duty – There must be an obligation to conform to a particular standard of conduct towards another. In your situation, who defines your obligations and the standard of care?

Breach of Duty – Failure to fulfill an obligation or uphold a standard of conduct.

Damages – As a result of this breach of duty, the person was harmed or suffered a loss of property.

Foreseeability – The defendant could reasonably be expected to have foreseen the possiblity of risk.

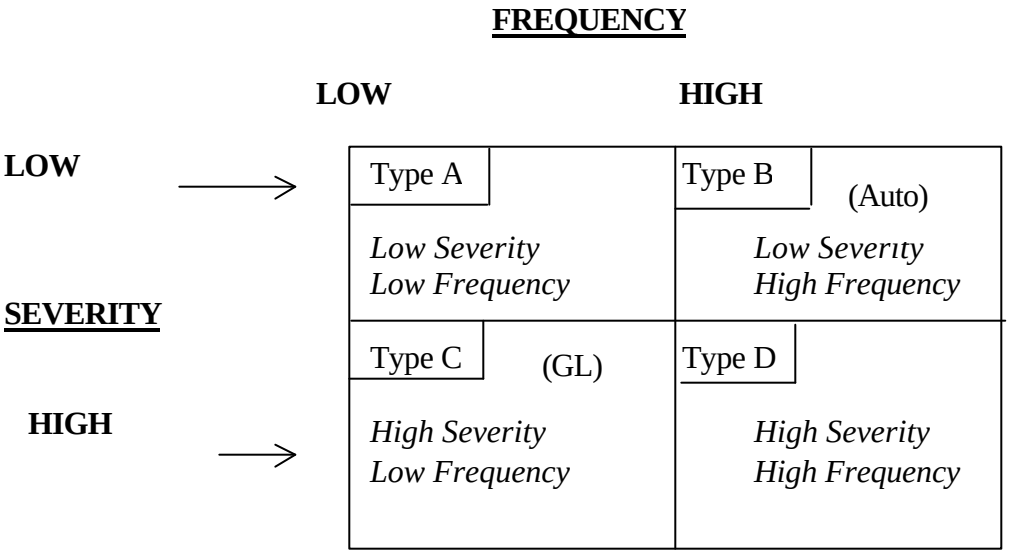
Working with a knowledgeable provider organization will better prepare families and consumers for appropriate decision-making regarding risk management. "Only a person who risks is free" but not free of responsibility and lawsuits!

Risk Continuum

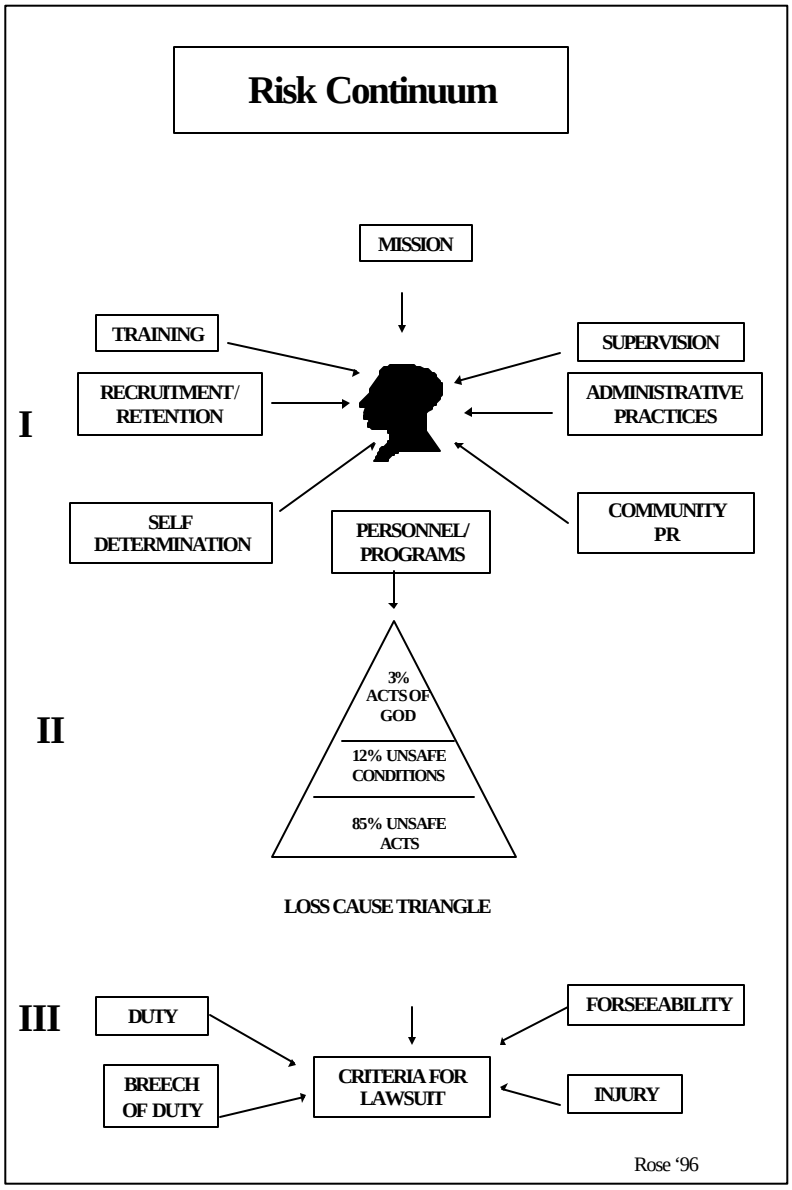
Before we go further in the discussion of supporting choice for an individual, it's important to address the concern many providers express in regard to the liability they face. Comments range from one end of the continuum to the other: "well it's their choice so we support whatever they want to do" to "we are too concerned with harm to the individuals, and liability and lawsuits to the agency to support choice".

Risk is the chance or possibility of a loss. Agencies face risk everyday, through the operation of vehicles, to the professional care provided to the people they support. While autos incidents account for the largest percent of claims (frequency), general liability claims are larger in terms of dollars paid out (severity).

Loss Potential Rating Matrix



After risks have been identified and evaluated, the next step is to classify them. The loss potential rating matrix is a useful tool for planning a risk retention policy. The matrix classifies risks by frequency, how many times a loss is expected to occur in a certain time frame, and severity, gauged by the dollar amount assigned to a loss. Only after all risks have been identified, evaluated for severity and frequency, and classified, can the most effective method(s) of treatment be determined. (see Dollars and Sense of Risk Management – Irwin Siegel Agency, Inc.)



Let's briefly look at the three areas that are defined in the Risk Continuum:

I. Organization Management
II. Loss Cause Triangle
III. Judicial Process

In **Section I**, an organization is involved in many different programs, all of which have the propensity toward risk. Whether it is advocacy or residential services, personnel matters or administrative practices, you are subject to a potential loss. For example, the driver of an agency vehicle attempts an illegal turn, which results in an accident with another vehicle. Aside from the violation of agency procedure (no use of agency vehicles until completion of driver training program) or the negative impact on community public reaction, the potential of personal injuries (consumers) could lead to a lawsuit (as well as the reporting of a serious incident to the state).

MANDATES DO NOT ENSURE QUALITY -

MANAGEMENT DOES!

Rose, 99

In comparing similar agencies (Budgets, Programs, Geographics), we have found that one agency had a low loss ratio and turnover ratio, while the other was quite the opposite with high frequency of losses and high turnover.

In **Section II**, the Loss Cause Triangle (based on the National Safety Council data) represents the idea that losses result from only three causes (Acts of God, Unsafe Acts, Unsafe Conditions). Acts of God would be things like lightning and flooding. While it is difficult to predict with any great certainty, the date, location or the degree of a natural disaster, there are preventative measures that should be taken (One Step Ahead of a Disaster/ISA).

The triangle shows that Unsafe Acts (vehicle incident above) are the primary cause of losses. These are generally attributed to improper or lack of staff training, usually coupled with other human characteristics, like stress or curiosity. The key to successful loss control/risk management (achieving desired outcome with minimal or no loss) is properly trained and supervised staff.

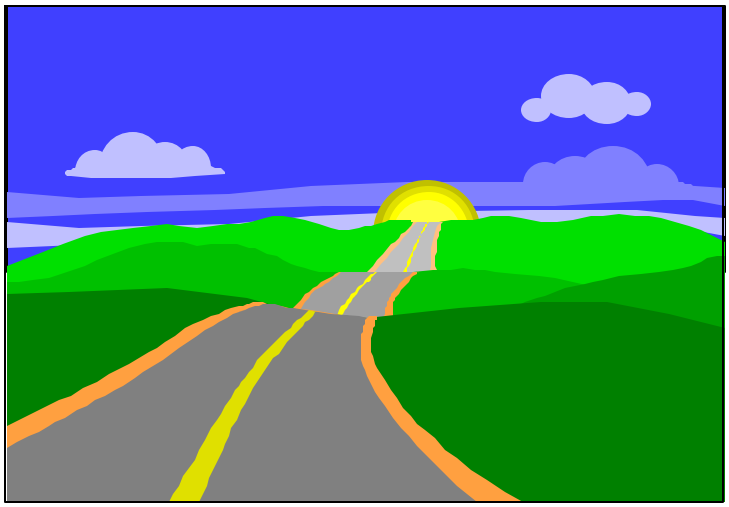
"Quality of the Outcomes is equal to the Quality of the Workforce"

In **Section III**, we are aware that almost anyone can bring a lawsuit for almost any reason. Whether a lawsuit can continue depends on the four conditions that must be present:

- **Duty:** an obligation (agreement or contract) to provide and/or perform
- **Breech of Duty:** the failure to meet the obligation
- **Foreseeability:** the injury or loss of property should have been anticipated, possibly avoided, and resulted due to the failure to act or to act in the manner that caused the harm
- **Injury:** a loss either personal or financial

It is not realistic to expect that individuals who have limited experience with options and choice will glide effortlessly down the road of self-determination and not encounter the bumps, pot-holes, and even the dangers that accompany a more independent lifestyle. It is our responsibility as care givers to provide environments where people have multiple options, to help them develop their own decision making processes, and to support them as they meet the joys and challenges of lives grounded in self determination and guided by choice.

However, we need to take an incremental approach in doing this. We need to be able to have the person experience the journey in a way that is appropriate for them. Experience is the best teacher; unfortunately, it is usually bad experience that we learn from or as I like to say, 'experience is something you don't get until just after you needed it'.



Road to Self Determination

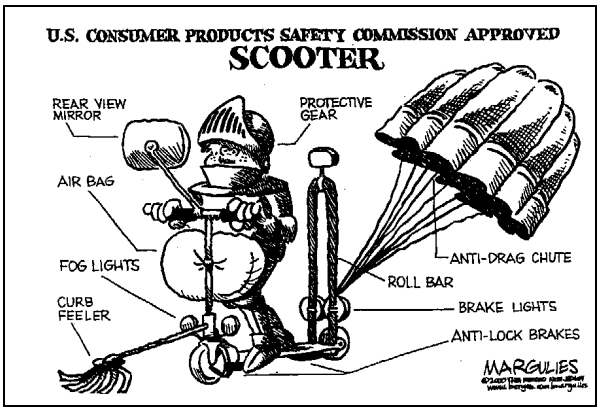
"Life is a Journey not a Destination"

The Challenge of Choice

Provider agencies hold the key that unlocks the door of choice for individuals with developmental disabilities. But, before that individual passes through that door, he or she must be able to make 'informed choices' and accept responsibility for those decisions. The challenge then for providers is to properly support individuals so that they can make their own decisions while facing minimal exposure to risk. In other words, providers must be prepared to manage risk where individual choice is involved. While choice may enhance the quality of one's life, so does the assurance of a reasonably safe environment.

Service Provider Dilemna

"Provide Choice - but Ensure Safety"



Providers must find the balance between choice and risk

Choice - the act of choosing, the power or opportunity of choosing, options, the best part, a person or thing selected, a variety offered for selection.

Understanding and Supporting Choice

The principles of self-determination have been presented in numerous documents and at numerous conferences. These principles of freedom, support, responsibility, and authority represent the vision of the Robert Wood Johnson grant programs:

> **Freedom** talks about a plan of life, a person's desires and goals. **Support** addresses formal and informal resources, and how to integrate those services into each individual's life plan. **Responsibility** is basically about accountability. **Authority** is the control of dollars in order to purchase those supports.

Other terms are frequently used but pretty much define choice as preference, opportunities, and control. These terms have been defined by the works of Michael Smull.

Preferences include not only what people like but also their desires and dreams.

Opportunities are the available occasions when people can spend their time as they prefer, doing the things they choose to do, and going to places they chose to go. Preference reflects what people want, while opportunities reflect what is available.

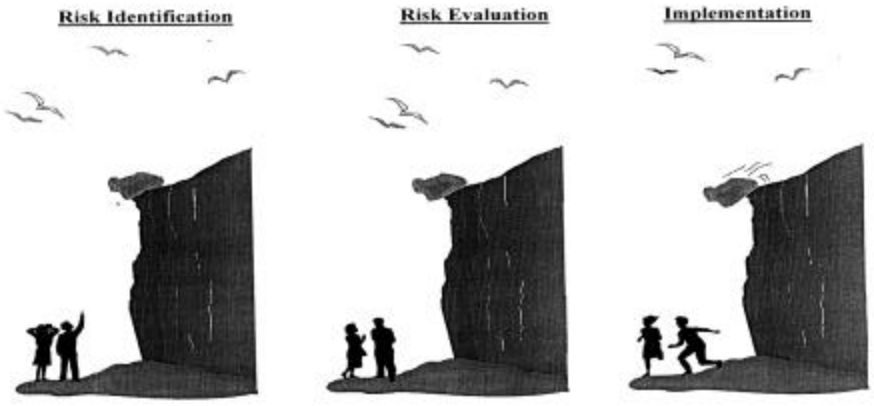
Control is the authority to make use of an opportunity to satisfy the preference.

We learn that Risk is the chance for personal or financial loss and that Risk Management is a structured process for controlling risk. The risk management process that supports choice is an individualized process that weighs the risk with the individual's ability to make choices. Each individual's support needs (both natural and contrived) will vary depending upon that person's life experiences, skill and environment. Provider agencies must find that balance between choice and risk. The Individual Risk Management Process (IRMP) can aid the provider agency and the individual in finding that balance.

Four Components of the Individual Risk Management Process

The following four components are taken from traditional risk management and applied on an individual basis

- Identification – knowing the individual's abilities and desires and also the potential risk associated with those desires
- Assessment – evaluation of choices - 'informed choice'
- Treatment/Implementation – selection of the best choice
- Monitor – to ensure safety and individual satisfaction



Risk Management is a structured process for controlling losses and reducing uncertainty about risks. The following four components explain how traditional risk management can be applied to benefit the individual being supported regarding choice and risk.

I. IRMP - Identification

Identification is a two-part analysis involving the individual and the environment. The first and most important step in developing the IRMP begins with the individual. Here, it is necessary to really know the individual whom you are assisting and supporting. By using a person-centered and futures planning tool, you will identify the individual's abilities and ambitions and become familiar with the person's values and goals. Objectives of person-centered planning should include (Mount & Zuernick, '89):

- a review of the personal file
- a review of trends in the environment
- finding desirable images in the future
- identification of obstacles and opportunities
- identification of needed system change

While ‘Futures Planning’ focuses on opportunities for people with developmental disabilities to increase control of their own lives, it also generates an ongoing problem-solving process. To ascertain the level of risk and in turn develop the IRMP, we must be able to determine the exposures individuals will be facing based on their desires and strengths. Futures Planning should complement the habilitation plan to provide a comprehensive game plan that is best suited to the individual's goals.

Top Ten Things You Shouldn’t Do WhenYou Support Us

- Don’t think we don’t think
- Don’t change your tone of voice when you see us or we come into a room
- Don’t touch our property or move our equipment without asking us
- Never ask someone else what we want (“Does he take cream in his coffee?) ASK US!
- Don’t make decisions for us
- Don’t have meetings about us without us
- Don’t talk to us in an authoritative way or with a “sing-song” tone of voice
- Don’t discount our abilities
- Don’t think that those of us with disabilities are all the same. We’re different, including you
- Don’t partonize us.

SABE Conference, RI, September 2000

The environment and circumstances to which the individual will be exposed while pursuing his/her goals must also be evaluated. Exposures can be viewed as opportunities to experience risk. There are basically four categories of exposure: home, work, community and personal.

It is impossible to address and prepare for all potential risks that one may encounter in life. In supporting people with developmental disabilities, the initial focus should be on developing or enhancing reactive safety responses, followed by proactive safety response. These safety response concepts should be applied to any activity that can affect a person’s health and well being.

While it is essential to provide training and safety awareness on the most immediate exposures in any environment, expanding that awareness to include the broader concept of reactive/proactive response is also beneficial. "Catch me a fish and I eat today - teach me to fish and I can eat on my own"- or in the case of safety,"teach me to be safe and I will be safe on my own."

As noted by Seligman (75) in his research, “people in positions of dependence are likely to develop ‘learned helplessness’ due to insufficient opportunities for decision-making and absence of appropriate learning experiences.

The reactive safety response comes into play during an emergency or risk situation. For example, the fire alarm goes off. A typical reactive response would be to calmly go to the nearest exit. During a proactive safety response, the individual can assess a given area or situation to identify potential risks, recognize abatement options, and understand their consequences. The reactive safety response is generally a trained response or can be a

conditioned response, whereas the proactive safety response relies more on judgement and the ability to make informed decisions.

Good risk management strives to minimize exposure to risk. From a practical standpoint, the primary objective would be to eliminate the risk, but in fostering 'choice' and 'decision-making', experience is the best teacher. Therefore, the challenge is to minimize the risk (hazards), rather than eliminate it all together as that would contradict the philosophy of self-determination.

"Only those who risk going too far will ever know how far they can go"

Anonymous

No training or educational program is better than first hand experience. While classroom type training can supplement or provide a general understanding of a certain topic or activity, practical experience is the best teacher. Incorporate all training methods to give individuals the greatest possibility of learning. We must start early to provide experiences to individuals with developmental disabilities. If we can anticipate that an individual will fall, we can also provide a soft landing and caring hands to pick them up.

II. IRMP - Assessment

In the first section, we looked at individuals in terms of their values and goals. Their goals would indicate the level of risk. Fully understanding each individual based on their 'personal file" and input from friends, family, and support givers is essential in determining their ability to make a choice. We also weigh their goals and possible choices within the context of their given environment. Assessment measures the compatibility of one's choice with one's goal and one's ability to handle the risk associated with that particular choice.

The use of tools like the IRPA (Individual Risk Preparedness Assessment) in conjunction with other factors like staff and friends and family input are essential in evaluating a person's risk potential in respect to their environment.

IRPA is an assessment tool designed to assist the service provider in determining where Risks of daily life activities may lie and enable foresight to plan necessary supports for the individual served. It identifies the individul's Risk Preparedness, as well as the risk associated with each activity.

Individual Risk Preparedness Assessment (IRPA)

Personal Safety in the Community/Emergency Preparedness (Sample Chart)

Knows the location of emergency phone numbers	NA	A	D	CR	AR	S	P	Comments
Uses emergency numbers appropriately								
Communicates all pertinent information when placing call								
Accesses police, ambulance, hospital , doctor when needed								
Communicates names of important others								
Contacts the appropriate person for assistance with needed repairs								
Recognizes and deals appropriately with harassment								
Understands what assault is								
Demonstrates assault prevention								
Gives personal information discretely and never to strangers								
Explains whom to contact in the event of an assault or emergency								
Keeps keys on person when leaving home								
Locks doors, windows and safety storage areas appropriately								
Reads and responds to survival signs and simple directions								
Responds appropriately to emergency personnel								
Responds appropriately to evidence of fire and fire alarm								
Responds appropriately to severe weather								
Responds appropriately to emergency news and warnings								
Tests to determine if home smoke detector is in working order								

Legend:

NA = Not Applicable

A = Ability (0 = Unable/Refuses; 1 = with Physical Assistance; 2 = with verbal/gestured assistance; 3 = independently)

D = Desires to do Activity (U/0 = unable to express choice; 0 = no; 1= somewhat; 2 = yes; 3 = yes, very much)

CR = Comprehends Risk Inherent to Activity (0 = no, 1= somewhat; 2 = yes)

AR = Accepts responsibility for risks involved in activity (0 = no; 1= somewhat; 2 = yes)

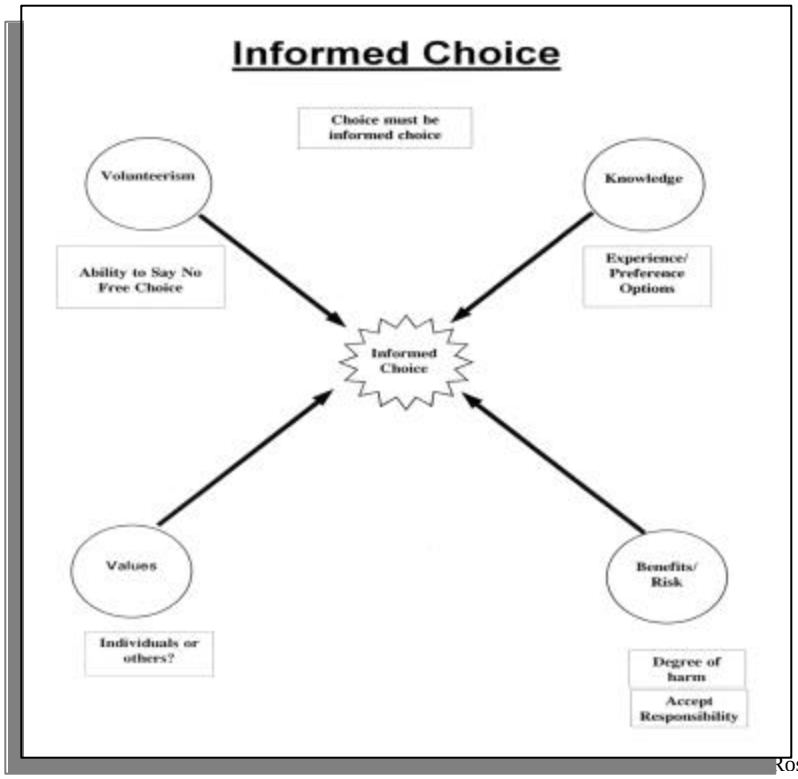
S = Severity of Potential Harmful Occurrence (1 = mild; 2 = moderate; 3 = severe)

P = Probability of Potential Harm Occurring (1 = low; 2 = moderate; 3 = high)

(Contact the Irwin Siegel Agency, Inc. for the complete program)

With Choice Comes Responsibility!

If someone asked you if you wanted an ice cream cone you might reply, "Yes," and instantantly think about a particular flavor. Your experience over the years of tasting different flavors allowed you to make an 'informed choice'. Informed is the key word, since there exist many types of choices (coerced, spontaneous, and so on)



Rose '96

All four components are necessary to ensure 'informed choice'

Nonetheless, being informed about one's options is critical in dealing with risk situations. There are several steps that make up the decision process. Once choices are established for any given situation, they must be evaluated to determine their potential effect upon the individual. Remember that choices are generally based on life experiences. Without having experience to fall back on when we are faced with a particular situation that requires a decision, we may first begin to panic. This panic will in turn cause us to make a decision based on 'impulse' or something other than an informed choice. In other words, the lack of experience, ('experience poor' or situational challenged), will increase our risk potential. Other factors that influence choice process include:

- Ability
- Experience
- Liability
- Consequences
- Funding - pertaining to supports
- No decision
- Poor decision making ability
    - lack of clarity of available options (experience)
    - lack of awareness of one values
    - limitation on cognitive processing

Certainly, the challenge facing support providers will be to offer individuals the opportunity to experience various situations based on their abilities and desires, and present them with enough options so they can make an informed decision.

> ***".... choices require options to choose from that are the product of our experience with both the rewards and consequences . . . many of the people now going into IRA's have not had those experiences and know neither the consequences nor the rewards inherent in the choices they are being ask to make . . . to suddenly place people with such experience in an unstructured environment without guidance is to preclude the idea of freedom of choice and to shirk the responsibility of service providers . . . "***
>
> *Newsletter of the NYS Commission on Quality Care,*
> *excerpt of a letter sent to the Commission by a provider,*
> *October-November 1994*

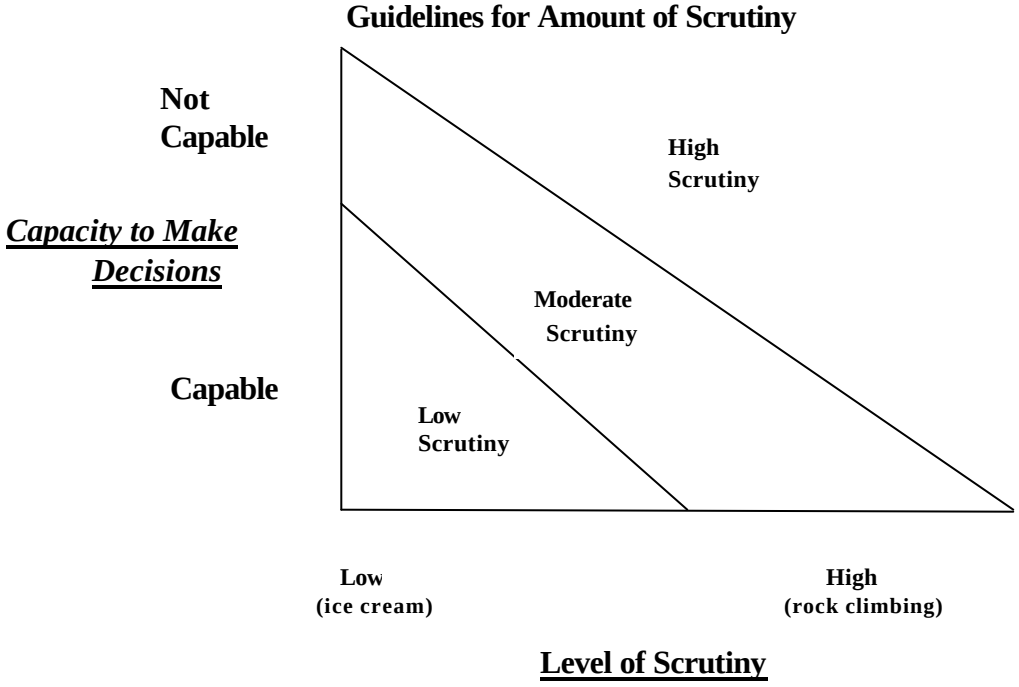
It is the support provider's obligation to advance the individual appropriately through the decision making process, to higher risk options only when the individual can make informed choices and understands the consequences of his or her decisions. Remember, the first obligation of parental power (parens patriae - regarding provider agencies and the state) is to protect from harm. However, this can also be a roadblock to self-determination.

"Judgement" is a product of understanding the environment in which one is working, the values that are important, the risks that are present, and the outcomes that are desired"

Clarence Sundram

III. IRMP- Treatment

In Section II, Assessment, we looked at one's ability to make choice. Realizing that the less capable a person is in making a choice (considering all the influences on choice) and the higher the risk to that individual, then the greater the scrutiny should be.



In the above graph you can pinpoint the amount of scrutiny necessary by assessing the amount of risk in a choice and plotting it on the horizontal line. On the vertical line, plot how capable a person is of giving informed consent. The intersection of the lines will show the amount of scrutiny you must give that choice.

Remember, ***"A decision to protect can always be undone, but a decision to permit a person to make a decision that caused harm cannot be reversed."***

Massey and Thompson 1995

Therefore, be prepared to assess your treatment options if the risk outweighs the benefit of the experience or opportunity.

Action or choice is based on the assessment of a particular situation. Therefore, the treatment or implementation of a particular choice will follow one of at least four courses of action:

P **Protect** - the choice is congruent with the individual's values or goals, however the degree of risk is too high without developing supports that minimize risk exposure.

A **Avoid** - the choice is not congruent with the individual's values or goals, and the degree of risk is too high.

C **Continue** - the choice is consistent with the individual's goals or values, and the risk is low.

E **Educate** - the choice is not consistent with the individual's goals or values, but risk is low.

Note: Treatment options spell PACE. This is how we need to provide experience, at a pace that is appropriate for the individual supported.

Whenever supports are indicated, the preference should be for natural supports. Natural supports will guaranty safety more readily and protect individuality. This is not to say that formal supports are inappropriate. In many cases, formal supports may be the primary support mechanisms.

Guiding this treatment process is the principle that dignity, confidentially, rights, and choice must be respected while ensuring safety. It is very difficult to strike a balance between choice and risk. It can be a long and difficult journey, but it's also the one most likely to bring both provider and consumer to the desired destination of successful outcomes

Condeluci suggests a four-step process to connect a person to the community by bridging an interest or passion (Cultural Shifting). "Bridges are interesting structures as they blend two important notions: the simplicity of connecting two points (the person and the community) and the complexity of the engineering necessary to make the connection".

- Step One: Find the Passion
- Step Two: Find the Venue
- Step Three: Understand the Elements of Culture
- Step Four: Find the Gatekeeper

Essence of Interdependence, Al Condeluci, Ph.D., Executive Director, UCP Pittsburgh, 412-683-7100

With the ever-changing program environment (waiver, managed care, consumer-

directed), an individual may be at greater risk than ever before. Responding to the concerns of parents/guardians further complicates the balancing of choice and risk. While, from a risk management standpoint, all involved parties should participate in the choice process, the ultimate decision-makers must be the individuals to whom supports are provided. *"We can see how the greatest obstacles to independence and self protection can be the caring parents who over-protect their children and discourage independent activities."* (Briggs, 95)

As the individual experiences opportunities for decision-making, the support giver is best able to ascertain that person's ability to make choices, that proper supports are in place, and that they are adequate to minimize dangers or harm. A person does not go through life in a vacuum, and all people progress at different levels. Be prepared to adjust for the changes in the life of the individual being supported.

Meeting the Challenge

The Field faces several challenges to providing the quality of care they and the people they serve envision. Meeting Great Expectations for individuals and the support they desire will require serious discussion, productive debate and effective action.

- Individuals we serve are 'experience poor'. We must, therefore, provide them with the opportunity to experience all they can in relationship to their values and goals. We must strengthen their 'circle of support' to be sure of a safety cushion when their journey towards independence becomes a little rocky. We must ensure that their experiences, for the most part, are good ones. We must realize however, that they will also have bad experiences and when this happens, we must ask ourselves, "Was there informed choice?" Families as well as consumers may be assuming more than they anticipated. We must rely on current Early Intervention Programs to be certain that Choice and decision-making are part of the curriculum.

- Another challenge is within the workforce. We must support direct support professionals in meeting the requirments and competencies their jobs entail by offering career path options, access to continuing education, and encouraging them to pursue those opportunities. For IRMP to be an effective process in supporting choice, we first need to properly support our frontline staff. Sustaining the frontline staff is pivotal, since the quality of outcomes hinges directly on the quality of the workforce. Issues surrounding workforce in the field of human services are many and well documented, with recruitment and retention considered top priorities. The quality of the outcomes can be tied directly to the quality of the workforce. The success of an individual in a more independent environment will depend on many factors, with frontline staff support bearing the greatest weight. The overall quality of an organization is directly tied to its frontline staffs' ability to satisfy customers (Department Store Analogy).

- Agencies need to take proper action not only to minimize exposure to the individual being supported, but also to the agency in terms of liability. Provider agencies should

consider making waivers a part of the annual IPP or ISP, and to obtain signatures of parents, legal guardians, and others involved in natural support capacities. Every agency should have written policies and procedures of which all staff are aware, and that they implement consistantly. These procedures should address informed consent, program planning to include person centered planning, team participation, parent/guardian involvement and sign-off and follow-up, as well as staff and participant training. Good documentation is often overlooked, but it is crucial to minimizing liability. State associations along with providers should undertake efforts to institute tort reform legislation within their respective states. Some examples would be good here. Like capping liability???

- States allow for stakeholders' input in service delivery design with consideration for operating a dual service system; one of individualized budgets and one of traditional, program based budgets. This will allow individuals to choose type of service delivery, risk, and responsibility that an individual is willing or prepared to assume. States must allow for safety nets within an individualized service system without overriding the concept of 'right to risk'.

- Changing community perception about people with developmental disabilities is one of the more difficult trials facing the field. This begins with educating the community at large regarding the 'right to risk', and the value of contributions people with disabilities make to the community. Keep in mind that community members will be on the jury of cases that can influence the future of service delivery.

- Case Management (Support Broker) - consideration should be given for this position to be independent of state and provider. While a similar role for QA purposes could be maintained by state and/or provider, the independent nature would allow for greater consumer focus. The postion should be one that is liscensed and meets a set of compentencies.

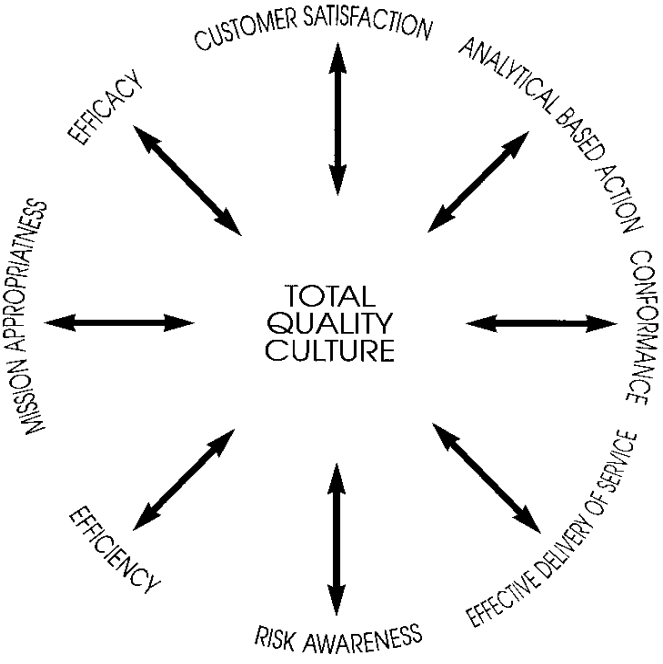
- Other Safety Nets could include:

    - Peer Advoisory Council (PAC's) comprised of a self- advocates available to assist and monitor services.
    - Third party assessment of the services – this would include accreditation entities and other similar organizations to include insurance companies.

- Risk Management training should be available for consumers and parents and/or guardians, regarding the liability, risk and safe guards that a person should be familiar with. This could be offered through state P&A organizations, or through other sources like insurance companies, and risk management consultants.

Appendix

Quality Circle



Met ☐ Not Yet ☐

Customer Satisfaction

Gauging the level of customer satisfaction can be accomplished both directly and indirectly. Meeting with the customer and those who have an interest in the customers' well being is imperative in determining satisfaction. How do you know the customer is satisfied? **ASK!** Measure the customer's satisfaction and react to feedback.

Analysis Based Action

☐ ☐ It is important to monitor outcomes and support activities and implement corrective actions to confirm conformance and that customers' wants and needs are being met. Several tools can assist in the analysis. These include: data collection, graphs, charts and diagrams. This quality element replaces the `Band-Aid approach` to problem solving with an organized system for gathering and interpreting the information that tells us if our Quality Circle is complete.

Met	Not Yet	
☐	☐	**Conformance** This is the traditional 'quality assurance' element. Compliance with federal and state regulations as well as local (community) ordinances is required. Quality assurance alone, however, does not ensure a quality program. Have you surpassed the minimal standards of compliance? Have you earned accreditation or other recognition and/or achievements?
☐	☐	**Effective Delivery of Service** Services are delivered effectively when the goals established with the involvement of professional staff during the planning process (IISP & PCP) are achieved. Is your service system the best it can be? How can it be improved? Do you follow 'best practices' and industry accepted standards?
☐	☐	**Risk Awareness** The completion of a hazard assessment is necessary to identify potential hurdles to the achievement of the intended goal – person-centered planning or timely and reliable training. Incorporating a risk management plan and ensuring the safety of employees and customers is paramount.
☐	☐	**Efficiency** The achievement of results in a prudent and cost-efficient manner is the goal of any business or organization. For example, are administrative costs less than 15% of budget? Are there any areas for collaboration?
☐	☐	**Mission Appropriateness** Your mission is your purpose! The mission statement must be periodically reviewed to ensure that it's being implemented. All interested parties should be involved with the development of the mission statement in order to be certain of on-going support. Leadership must provide a clear understanding and articulation of governing ideas, the mission, the vision, and the values.
☐	☐	**Efficacy** Empowerment. The ability to breath life into the mission statement by engaging in those activities necessary to satisfying customer wants and needs. Consumers and front-line staff must both be imbued with power.

Met ☐ Not Yet ☐

Quality Culture

As an agency brings the above eight elements of the 'circle of quality' into place, its quality culture will evolve. Quality culture is a product of employee involvement, a strong leadership, and a consensus of commitment to achieving customer satisfaction.

Steps for Implementing a Quality Program

- ✓ The organization's leading management team makes a commitment to apply the principles and techniques of quality for a specific period (suggest a minimum of two years).

- ✓ They arrange for training in total quality management for themselves and all members of the organization.

- ✓ The management team appoints a 'Quality Committee'. This group will oversee and provide support for the quality process. It may be composed of the management team itself, but will be stronger if it represents a cross-section of the organization.

- ✓ The Quality Committee makes recommendations to management on what types of quality projects will be supported, and the limits of each team's authority less complex issues with a high probability of success should initially be addressed by the team.

- ✓ Team process may or may not come easily to employees. It is suggested that the Quality Committee make sure that there is a cadre of well-trained facilitators available to work with the various departmental quality teams.

- ✓ Teams may be formed in a number of ways. They may be natural work groups (i.e., all of the organization's service coordinators) or they may be cross-functional. The Quality Committee should play a direct role in supporting all the teams.

- ✓ The Quality Committee should sponsor a 'Quality Fair' to allow each team to spotlight its accomplishments for employees and stakeholders.

- ✓ The Quality Committee should report (Quarterly newsletter) on all aspects of development, with emphasis on 'positive outcome' stories.

Pinnacle

"A Quality Assessment Tool"

isa1.com/Pinnacle/PinnacleDemo.htm

- A proactive approach to risk management quality improvement.
- A "dynamic" resource that is continually updated and provides national benchmarking.

Notes

Notes

Notes

Suggested Reading

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Worthington, O.H., Jaskulski, T., and Ebenstein, B., 1996, Opportunities for Excellence: Supporting the Frontline Workforce, President's Committee on Mental Retardation, Washington, DC.

DSP Resources

- AAMR (American Association on Mental Retardation) aamr.org
- NADSP (National Alliance of Direct Support Professionals) rtc.umn.edu/dsp/projects/nadsp.html