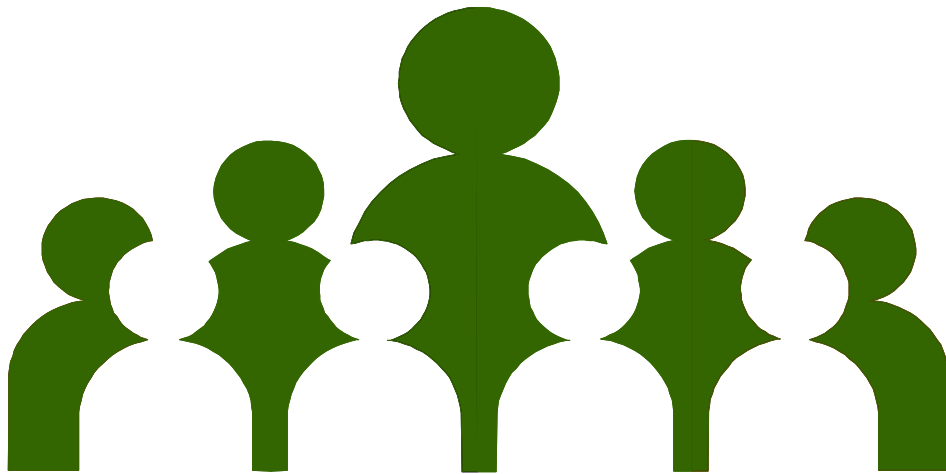


2002
Reinventing Quality Conference

Holiday Inn Chicago Mart Plaza
Chicago, Illinois
July 29 - 31



Balancing Freedom and Safety:
Quality Supports Lead to a Quality Life

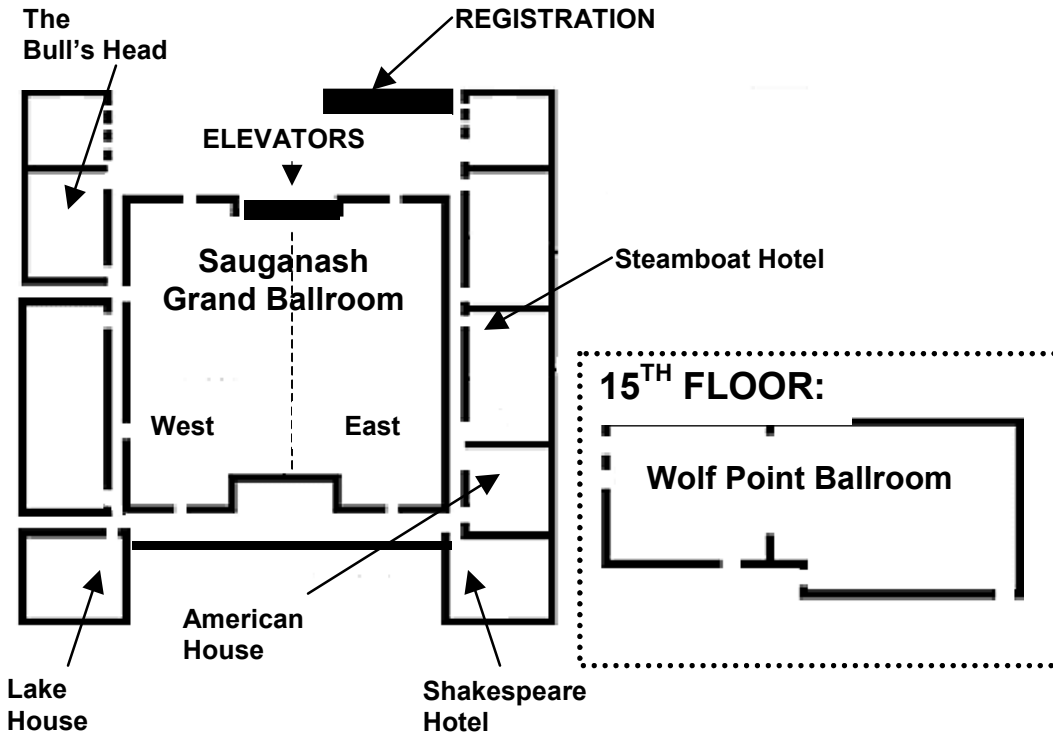
Freedom is not an ideal, it is not even a protection, if it means nothing more than freedom to stagnate, to live without dreams, to have no greater aim than a second car and another television set.

*Adlai Stevenson (1900–1965), "Putting First Things First,"
Foreign Affairs (New York, January 1960)*



2002
Reinventing Quality Conference
Hotel Floor Plan

14TH FLOOR:



<u>ROOM</u>	<u>FLOOR</u>	<u>FUNCTIONS</u>
Sauganash East Foyer	14 th Floor	Registration, Continental Breakfast, Breaks
Sauganash East	14 th Floor	Opening & Closing Plenary Sessions
Lake House	14 th Floor	Breakout Sessions
Steamboat Hotel	14 th Floor	Breakout Sessions
Shakespeare Hotel	14 th Floor	Breakout Sessions
The Bull's Head	14 th Floor	Breakout Sessions
American House	14 th Floor	Breakout Sessions
Wolf Point Ballroom	15 th Floor	Welcome Reception & Luncheons

2002

Reinventing Quality Conference

Program at a Glance



Monday, July 29

4:30 PM - 6:00 PM	Registration	Sauganash East Foyer (14 th Floor)
5:30 PM - 7:00 PM	Welcome Reception	Wolf Point Ballroom (15 th Floor)

Tuesday, July 30

8:00 AM - 9:00 AM	Continental Breakfast	Sauganash East Foyer (14 th Floor)
8:00 AM - 5:15 PM	Registration	Sauganash East Foyer (14 th Floor)
9:00 AM - 10:45 AM	Plenary Session	Sauganash East (14 th Floor)
10:45 AM - 11:00 AM	Break/Refreshments	Sauganash East Foyer (14 th Floor)
11:00 AM - 11:45 AM	Plenary Session <i>continued</i>	Sauganash East (14 th Floor)
11:45 AM - 1:15 PM	LUNCHEON	Wolf Point Ballroom (15 th Floor)
1:15 PM - 2:30 PM	Breakout Sessions I	(See Program for Locations)
2:30 PM - 2:45 PM	Break/Refreshments	Sauganash East Foyer (14 th Floor)
2:45 PM - 4:00 PM	Breakout Sessions II	(See Program for Locations)
4:00 PM - 5:15 PM	Breakout Sessions III	(See Program for Locations)

Wednesday, July 31

8:00 AM - 9:00 AM	Continental Breakfast	Sauganash East Foyer (14 th Floor)
8:00 AM - 9:00 AM	Breakfast Discussions	(14 th Floor)
8:00 AM - 11:30 AM	Registration	Sauganash East Foyer (14 th Floor)
9:00 AM - 10:00 AM	Keynote	Sauganash East (14 th Floor)
10:00 AM - 10:15 AM	Break/Refreshments	Sauganash East Foyer (14 th Floor)
10:15 AM - 11:30 AM	Breakout Sessions IV	(See Program for Locations)
11:30 AM - 1:00 PM	LUNCHEON	Wolf Point Ballroom (15 th Floor)
1:00 PM - 2:15 PM	Breakout Sessions V	(See Program for Locations)
2:15 PM - 2:30 PM	Break/Refreshments	Sauganash East Foyer (14 th Floor)
2:30 PM - 3:30 PM	Plenary Session	Sauganash East (14 th Floor)



2002

Reinventing Quality Conference

Sessions at a Glance

Tuesday, July 30

	Lake House	Steamboat Hotel	Shakespeare Hotel	The Bull's Head	American House
1:15 PM to 2:30 PM	(I-A) <i>Can you Get There from Here?</i> Quinn & Picha	(I-B) <i>Changing Policy, Changing Outcomes</i> Stanton & Smith	(I-C) <i>It's Basic – Quality Staff Lead To Quality Lives</i> Hewitt & Perry	(I-D) <i>Transforming Consumer and Family Expectations</i> Jordan, Fox & Bottoms	(I-E) <i>Assessing Support Quality Across All Groups</i> Stahl
2:45 PM to 4:00 PM	(II-A) <i>Person-Centered Systems of Support</i> Bradley & Taub	(II-B) <i>OK, You Know About It</i> Feinstein, Sloyer & Coles	(II-C) <i>Role of Direct Support Professionals</i> Taylor, Tapp, Rhodes, & Zoeller	(II-D) <i>The Family's Role in Adult Quality of Life</i> Turnbull & Golden	(II-E) <i>Coordinating Medical, Health, and Dental Services</i> Morrow & Rimmer
4:00 PM to 5:15 PM	(III-A) <i>Balancing Risk and Individual Choice</i> Kunc	(III-B) <i>Quality Assurance and Self-Directed Services</i> Pelletier & Tuller	(III-C) <i>Supervisors of DSPs</i> Miller, Larson, Muchow & Spalla	(III-D) <i>Carpe Diem: Conversion</i> Saulino, Saulino, Dutton & Ficker Terrill	(III-E) <i>Listening So People Will Hear You</i> Gardner & Bomhoff

Wednesday, July 31

	Lake House	Steamboat Hotel	Shakespeare Hotel	The Bull's Head	American House
10:15 AM to 11:30 AM	(IV-A) <i>Following Core Indicators of Change</i> Taub, Garland, Jones, George & Lehr	(IV-B) <i>Authority, Risk and Responsibility</i> Duval & Finn	(IV-C) <i>Families with Young Children</i> Huwe & Herring	(IV-D) <i>College of Direct Support</i> Lakin, Hewitt & Tapp	(IV-E) <i>Minnesota Update</i> Cramer, Jordan, Ostrowski & Shoen
1:00 PM to 2:15 PM	(V-A) <i>Building a Circle of Support</i> Holmes, & Finn	(V-B) <i>Balancing Risks and Safety</i> Rose, Komoll, Ficker Terrill	(V-C) <i>Where You Stand Depends on Where You Sit</i> Jones & Lehr	(V-D) <i>College of Direct Support (Repeat of IV-D)</i> Lakin, Hewitt & Tapp	(V-E) <i>Microboards</i> Golden & Obermayer

2002
 Reinventing Quality Conference
Tuesday, July 30



<u>8:00 AM - 9:00 AM</u>	<u>Continental Breakfast</u>	<u>Sauganash East Foyer</u>
<u>8:00 AM - 5:15 PM</u>	<u>Registration</u>	<u>Sauganash East Foyer</u>
<u>9:00 AM - 10:45 AM</u>	<u>Opening Plenary Session</u>	<u>Sauganash East</u>
9:00 AM - 9:15 AM	<i>Welcome and Introductions</i>	
	Robert M. Gettings, Executive Director, NASDDDS	
9:15 AM - 10:00 AM	<i>“Are You Talkin’ to Me?” Listening to the Voices of Individuals and Families.</i>	
	Quality is, first and foremost, a subjective experience. Yet, many systems of support currently in use consider the “consumer” only as an afterthought. This session discusses the elements of a quality lifestyle and their relationship to quality services.	
	Presenters: Sue Fox, Institute on Disability, University of New Hampshire	
	Gail Bottoms, Self-Advocate	
	Liz Obermayer, Self-Advocate	
	Sherri Huwe, Parent	
10:00 AM - 10:45 AM	<i>The New Freedom Initiative: A New Approach or a New Name? The Federal Perspective on Service Quality.</i>	
	The Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS) has launched new initiatives to support self-directed services, improve quality, and strengthen system capabilities. What impact will these initiatives have on individuals, providers, and state systems?	
	Presenter: Glenn Stanton, Deputy Director, Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, CMS	
<u>10:45 AM - 11:00 AM</u>	<u>Break/Refreshments</u>	<u>Sauganash East Foyer</u>

Opening Plenary Session continued Sauganash East

11:00 AM - 11:45 AM

The Meaning of Quality

An internationally known speaker discusses the meaning of quality from the perspective of the people receiving support.

Presenter: Norman Kunc

11:45 AM - 1:15 PM

LUNCHEON

Wolf Point Ballroom
(15th Floor)

1:15 PM - 2:30 PM

Breakout Sessions I

1:15 PM - 2:30 PM

Session I-A

Lake House

Can You Get There from Here?
System Change in Local Agencies.

Tim Quinn and Erv Picha are directors of private nonprofit agencies in Maryland and Indiana respectively who are leading their organizations through comprehensive system redesign processes. With the goal of instilling the principles of self-determination or self direction into the design and operations of all agency activities, each of these presenters has addressed a number of challenges in the process of “doing something different.”

Presenters: Tim Quinn, The Arc Northern
Chesapeake Region

Erv Picha, Noble of Indiana

1:15 PM - 2:30 PM

Session I-B

Steamboat Hotel

Changing Policy, Changing Outcomes.

Glenn Stanton and Gary Smith will discuss CMS’s current plans and activities regarding: (a) the development of a *Quality Framework*, the recommended components of a comprehensive quality management program for Medicaid-funded home and community-based services; and (b) the construct of a survey to collect baseline information from the states regarding their existing systems quality assurance/improvement programs and outcomes.

Presenters: Glenn Stanton, Deputy Director, Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, CMS

Gary Smith, Human Services Research Institute (HSRI)

1:15 PM - 2:30 PM

Session I-C

Shakespeare Hotel

***It's Basic. Quality Staff Lead To Quality Lives
– One Person's Journey To A Good Life.***

Amy Hewitt and Nathan Perry will discuss the relationship between the quality of support an individual receives and the quality of life he or she is able to access in the community. This session will share the results of a recent study in which self-advocates and family members of people with developmental disabilities who receive community supports were asked to describe how issues such as high direct support staff turnover, increased vacancies and poor training affect their lives. It also will share insights into how specific strategies used by one person to find, support and keep his staff have lead to a zero percent turnover rate, high staff satisfaction and amazing results in enhancing the individual's ability to get what he wants and needs out of life. It may be basic – but it works!

Presenters: Amy Hewitt, Institute for Community
Inclusion/University of
Minnesota (ICI/MN)

Nathan Perry, Self-Advocate

1:15 PM - 2:30 PM

Session I-D

The Bull's Head

***Transforming Consumer and Family Expectations
Into Quality Measures.***

A panel of parents and advocates will discuss the meaning of quality from the perspective of parents and self-advocates, with a particular focus on the impact of services on those who receive them.

Panelists: John Jordan, Minnesota Region 10 Quality
Assurance Commission

Sue Fox, Institute on Disability,
University of New Hampshire

Gail Bottoms, Self-Advocate

1:15 PM - 2:30 PM

Session I-E

American House

Assessing Support Quality Across All Groups.

This session will weigh the pros and cons of using a single quality assurance system for multiple populations such as

people with developmental disabilities, the aging, people needing rehabilitation, and people requiring mental health services.

Presenter: Frank Stahl, Kansas Department of Social and Rehabilitation Services

2:30 PM - 2:45 PM

Break/Refreshments

Sauganash East Foyer

2:45 PM - 4:00 PM

Breakout Sessions II

2:45 PM - 4:00 PM

Session II-A

Lake House

***Person-Centered Systems of Support:
Report on State Site Visits.***

Val Bradley and Sarah Taub from the Human Services Research Institute (HSRI) will review the preliminary findings of Reinventing Quality Project team visits to states with exemplary person-centered service delivery systems. This session will include reports onsite visits to Wyoming, Wisconsin, Connecticut, and Kansas.

Presenters: Val Bradley, HSRI

Sarah Taub, HSRI

2:45 PM - 4:00 PM

Session II-B

Steamboat Hotel

OK, You Know About It, What Are You Going to Do About It? Converting Information to Action.

Celia Feinstein, John Sloyer, and Steve Coles will discuss the efforts underway in Pennsylvania to develop a management information system that supports the state's quality improvement goals. Although all states have quality assurance systems, it is frequently the case that there is no effective means of converting the information collected into effective actions that result in measurable changes. The presenters will discuss different mechanisms to collect data on quality and effective approaches to putting the information to use.

Presenters: Celia Feinstein, Institute on Disabilities,
Temple University

John Sloyer, Pennsylvania Office of
Mental Retardation

Steve Coles, Bucks County,
Pennsylvania MH/MR Program

2:45 PM - 4:00 PM

Session II-C

Shakespeare Hotel

The Role of Direct Support Professionals (DSPs) in Decision-Making.

Every day, support staff and consumers are faced with decisions. Some decisions may seem minor, but can have larger ramifications; others have immediate, serious consequences. How do the respective roles of the consumer and his or her direct support staff change when the person directs the support received? Who has the final say, and who should have the final say, especially if decisions involve potentially dangerous consequences? How can the consumer-DSP relationship be organized in order to ensure the appropriate balance of freedom and safety in decision-making (and what is the “appropriate balance?”)?

Presenters: Marianne Taylor, Human Services Research Institute (HSRI)

Bill Tapp, Institute on Community Integration at the University of Minnesota

Levetta Rhodes, Community Learning Centers

Kim Zoeller, Community Learning Centers

2:45 PM - 4:00 PM

Session II-D

The Bull’s Head

The Family’s Role in Adult Quality of Life.

The family of a person with developmental disabilities often has a significant role to play in the large and small decisions he or she makes. Families can have a tremendous impact on quality of life. This presentation focuses on ways families can help their relatives achieve their quality of life goals, and considers the roles the family can and should play in the decision-making process that ultimately determines quality of life.

Presenters: Ann Turnbull, Beech Center, University of Kansas

Jackie Golden, Inclusion Research Institute

2:45 PM - 4:00 PM

Session II-E

American House

Coordinating Medical, Health, and Dental Services: A Nibble is Not Enough.

Drs. Jill Morrow and Jim Rimmer will discuss the effects of low rates of Medicaid reimbursement, access to hospitals

and a number of other specific barriers that make it difficult for many people with developmental disabilities and their families to readily access the specific health and wellness services they need. This session will discuss the issues, the problems and potential solutions.

Presenters: Dr. Jill Morrow, Pennsylvania Office of
Mental Retardation

Dr. Jim Rimmer, National Center on Physical
Activity and Disability

4:00 PM - 5:15 PM

Breakout Sessions III

4:00 PM - 5:15 PM

Session III-A

Lake House

***Balancing Risk and Individual Choice:
A Personal Perspective.***

Norman Kunc will address the specific challenges that confront people receiving support and those who provide it when making decisions that involve risk and personal choice. Who is in charge of what decisions? How does one balance the need to assure an individual's health and welfare with the need to support self-determination, freedom, the development of a sense of responsibility and independent decision making skills? What is the impact of diffuse authority and responsibility for decision-making that impacts on people receiving support, providers, and families?

Presenter: Norman Kunc

4:00 PM - 5:15 PM

Session III-B

Steamboat Hotel

***Quality Assurance and Self-Directed Services:
Who Calls the Shots?***

Self directed approaches to service delivery require significant changes in decision making processes, the allocation of responsibilities, and the determination of who holds the authority for ultimate action. This session will describe the goals and challenges of providing the support necessary to enable people to actually take charge of their lives.

Presenters: Sandy Pelletier, Area Agency for
Developmental Services of
Greater Nashua, Inc.

Jean Tuller, Oregon Technical Assistance
Corporation

4:00 PM - 5:15 PM

Session III-C

Shakespeare Hotel

Supervisors of Direct Support Professionals.

Sherri Larson, Howard Miller, Linda Muchow, and Catherine Spalla will discuss the crucial role direct support professionals (DSPs) play in enabling consumers to achieve the quality of life they seek. Supervisors of DSPs are integral to this process, providing their staff with the training, support, and guidance they need to successfully acquire the skills necessary to direct their own supports. This presentation examines the role supervisors play in supporting the efforts of consumers and DSPs toward achieving an enhanced quality of life.

Presenters: Sherri Larson, Institute for Community Inclusion/University of Minnesota (ICI/MN)

Howard Miller, REM Minnesota

Linda Muchow, Ray Graham Association for People with Disabilities

Catherine Spalla, Ray Graham Association for People with Disabilities

4:00 PM - 5:15 PM

Session III-D

The Bull's Head

Carpe Diem: Conversion – Taking Advantage of the Opportunity!

Community Interactions, Inc., an agency based in the Philadelphia suburb of Springfield, is directing its resources and corporate culture to focus on enhancing the lives of its consumers and families. Staff and consumers of the agency's services will describe their plans and the journey so far. Cathy Ficker Terrill will share similar experiences from Ray Graham Ray Graham Association for People with Disabilities.

Presenters: Marian Saulino, Community Interactions, Inc.

Paul Saulino, Community Interactions, Inc.

Dale Dutton, CARF

Cathy Ficker Terrill, Ray Graham Association for People with Disabilities

4:00 PM - 5:15 PM

Session III-E

American House

Listening So People Will Hear You: Obtaining Feedback from Self-Advocates on Quality of Life.

The Council on Quality and Leadership has developed an extensive information base from interviews of people with developmental disabilities conducted in communities throughout the country. Jim Gardner, The Council's President and CEO, will discuss the potential uses of such data to drive quality improvement efforts. A similar approach taken by the Self-Help Network of Kansas documented the perspectives of people with disabilities in Kansas. The presenters will discuss what has been learned from the interviews they have conducted and what services mean to the individuals who receive them.

Presenters: Jim Gardner, The Council on
Quality and Leadership

Kevin Bomhoff, Self-Help Network of Kansas

5:15 PM

ADJOURN FOR THE DAY



2002
Reinventing Quality Conference
Wednesday, July 31

8:00 AM - 9:00 AM **Continental Breakfast** **Sauganash East Foyer**

8:00 AM - 9:00 AM **Breakfast Discussions** **14th Floor**

Continental breakfast and informal roundtable discussions on topics organized and led by conference participants and presenters. Eat with a small group discussing areas of interest or relax on your own.

8:00 AM - 11:30 AM **Registration** **Sauganash East Foyer**

9:00 AM -10:00 AM **Keynote** **Sauganash East**

***Striking the Balance Between
Freedom and Protection***

Presenter: Dr. Pat Morrissey, Commissioner of ADD,
US Department of Health
and Human Services

10:00 AM - 10:15 AM **Break/Refreshments** **Sauganash East Foyer**

10:15 AM -11:30 AM **Breakout Sessions IV**

10:15 AM - 11:30 AM **Session IV-A** **Lake House**

Following Core Indicators of Change.

The Core Indicators Project (CIP) is supported by NASDDDS through a contract with the Human Services Research Institute (HSRI), for the purpose of developing of a set of performance indicators that can be used across states to assess each state's progress on identified outcomes. Sarah Taub, Olivia Garland, Bob Jones, Janet George, and Connie Lehr will discuss approaches that have used to integrate CIP results into the overall quality assurance and improvement activities in participating states. Problems, successes, and areas for further development will be discussed.

Presenters: Sarah Taub, HSRI

Olivia Garland, First Health Services Corporation

Bob Jones, First Health Services Corporation

Janet George, Massachusetts DMR

Connie Lehr, Massachusetts DMR

Commission (MN Region 10) will discuss their respective experiences thus far with a grass roots initiative in Minnesota to improve the quality of supports made available to persons with developmental disabilities. The presenters will discuss the history of this initiative and provide an update on the activities of system stakeholders since last year's conference in implementing this project.

Presenters: Tom Cramer, MN Region 10
John Jordan, MN Region 10
Cindy Ostrowski, MN Region 10
Matt Shoen, MN Region 10

11:30 AM - 1:00 PM

LUNCHEON

Wolf Point Ballroom
(15th Floor)

1:00 PM - 2:15 PM

Breakout Sessions V

1:00 PM - 2:15 PM

Session V-A

Lake House

Building a Circle of Support.

Circles of Support are a part of the lives of more and more people with developmental disabilities. This presentation examines the role of a Circle of Support in achieving quality of life for the person it is supporting. How can a Circle of Support best contribute to quality of life? How should it interact with the consumer, any direct support professionals, and others in working towards quality of life?

Presenters: Steve Holmes, Self-Advocacy Association NYS
Chester Finn, New York OMRDD

1:00 PM - 2:15 PM

Session V-B

Steamboat Hotel

Balancing Risks and Safety.

No other issue in the field today can influence the outcome of person-centered supports more than the 'Right to Risk'. Given the current movement of the service delivery system toward an even less restrictive direction, general liability claims are sure to increase. It will become imperative for providers to have a greater understanding of general liability and how to better protect themselves from financial claims and possible lawsuits. The key to successful outcomes will be largely the result of a competent workforce. By examining 'case studies' this session will look at how recent court cases influence the DD field and impact provider agencies. It also will address who determines the ability of an individual to

accept the responsibility of choice: the direct support professional? the parent or guardian, the clinician?, the individual?, the courts?

Presenters: John Rose, Irwin Siegel Agency, Inc.
Mike Komoll, Irwin Siegel Agency, Inc.
Cathy Ficker Terrill, Ray Graham Association
for People with
Disabilities

1:00 PM - 2:15 PM **Session V-C** **Shakespeare Hotel**

***Where You Stand Depends on Where You Sit:
Roundtable on Quality.***

Sue Jones and Connie Lehr will discuss the need for states to emphasize approaches to quality improvement that take into account the meaning of quality from differing perspectives and involve people with disabilities in the QA process.

Presenters: Sue Jones, Wisconsin Bureau of DD Services
Connie Lehr, Massachusetts DMR

1:00 PM - 2:15 PM **Session V-D** **The Bull's Head**

College of Direct Support.

Charlie Lakin, Amy Hewitt, and Bill Tapp of the Institute on Community Integration at the University of Minnesota (ICI/UMN) will describe a new multi-media training program for direct support professionals that offers exciting opportunities for increased education, training, and support. The College of Direct Support is an Internet-based, multimedia, interactive national training program for direct support staff. The presenters will demonstrate the program; discuss the framework of the course, and the involvement of other professionals. (*Repeat of Session IV-D*)

Presenters: Charlie Lakin, ICI/UMN
Amy Hewitt, ICI/UMN
Bill Tapp, ICI/UMN

1:00 PM - 2:15 PM **Session V-E** **American House**

Microboards.

Self-directed Support Corporations (SDSCs), a concept based on British Columbia's Microboards model but adapted for the United States. Self-directed Support Corporations (SDSCs) are legally developed not-for-profit corporations

developed to provide a legal entity to manage the support system for a person with a disability through the establishment of a board of directors, and designed to contract directly with the Home and Community-Based Waiver Funding (Medicaid).

Presenters: Jackie Golden, Inclusion Research Institute
Liz Obermayer, Self-Advocate

2:15 PM - 2:30 PM **Break/Refreshments** **Sauganash East Foyer**

2:30 PM - 3:30 PM **Plenary Session** **Sauganash East**

***Bringing It All Together:
Report of the Investigators***

Three individuals will take the role of *investigators* during the conference to identify the ideas, conversations, and issues that are emerging from the presentations and between session conversations. Investigators will interview conference participants and presenters and will present what they have heard during this closing session. An open mike discussion of the issues involved in the establishment of an enduring quality improvement system will follow.

Presenters: Angela Amado, Inclusion Research Institute
Liz Obermayer, Self-Advocate
Jean Tuller, Oregon Technical Assistance Corporation

3:30 PM **ADJOURN FOR THE MEETING**