The Johnson Foundation
Racine, Wisconsin 53401-0547

The Johnson Foundation is pleased to join with the Administration on Developmental Disabilities, American Association on Mental Retardation, American Association of University Affiliated Programs, American Network of Community Options and Resources, The Arc, Consortium of Developmental Disabilities Councils, The Council on Quality and Leadership in Supports for People with Disabilities, National Association of Developmental Disabilities Councils, National Association of Protection and Advocacy Systems, and National Association of State Directors of Developmental Disabilities Services in convening the Wingspread conference, “Measure for Measure: Person-Centered Quality Assurance” to be held October 19-21, 2000. We are very pleased that you will be joining these important discussions, and we look forward to a stimulating and productive meeting.

Wingspread was originally a private home, designed by Frank Lloyd Wright in the late 1930s. For 20 years it was a family residence, and since 1960 has served as The Johnson Foundation’s educational conference center. Over the years, many have found it to provide a setting supportive of undistracted and productive exchange. We believe you will find your time here to be well spent.

The Johnson Foundation staff and I look forward to greeting you at Wingspread.

Sincerely,

Christopher Beem
Program Officer
Democracy and Community, Family
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In the summer of 2000, representatives of nine national developmental disabilities organizations joined together to launch the Developmental Disabilities Quality Coalition (DDQC). The purpose of the DDQC is to prospectively address the public issues surrounding the quality and availability of community services for persons with developmental disabilities.

On behalf of the DDQC, The Council on Quality and Leadership in Supports for People with Disabilities (The Council) with funding from the Administration on Developmental Disabilities, organized a national invitational conference. With the support of the Johnson Foundation, the conference took place on October 19-21, 2000 at its Wingspread Conference Center in Racine, Wisconsin.

The Wingspread Conference was organized around a series of planned presentations and informal break-out group discussions. Self-Advocates began the conference with a commentary on a Pre-Wingspread self-advocacy caucus that took place at the Providence, Rhode Island Self-Advocates Becoming Empowered meeting in September, 2000. They presented a short video of the Providence meeting and discussed their perspectives on self determination.

Other participants representing a federal, state, provider, and service coordination/point of entry perspective also presented papers that were reviewed by panels of three other participants. Participants then broke into dialogue groups and discussed the paper and the comments of the review panel.
The participants then broke into four dialogue groups and identified priority issues. The participants returned from the dialogue groups and reported the group’s discussion and findings. The facilitator worked with the participants to identify the cross-cutting themes of the four dialogue groups. The themes that cut across all dialogue groups were:

- Quality improvement processes
- Workforce development
- Public awareness (making sure that we have a clear statement of values and purpose, and then communicating that message and purpose)
- Systems integration and alignment
- Self determination
- Leadership

Each of the four dialogue groups selected one of the cross-cutting themes and identified the key elements of a national initiative. The dialogue groups reported the following recommendations for national initiatives:

**Public Awareness**

Participants called for a multi-level public awareness campaign that results in the inclusion of all people as valued members of the community and that builds communities that embrace diversity. Family expectations have changed in the past two decades. Expectations were raised about the possible options and choices available for our constituents, and the constituents themselves began to speak out about how they wanted to be supported. The necessary local advocacy, for all persons who want and need it, has not kept pace with the growth in the system. The need for individual and systems advocacy is greater than at any time in the past twenty years, and the funding, as a percentage of the services and supports provided, continues to decline. Families, accustomed to an IDEA based system of public education, have adopted strategies that may be well suited to an entitlement program but do not work in a non-entitlement system.

Within five years we would expect to see the following:

- Kids will read about segregated classrooms in the history books and wonder how that could be;
- Employees will want to work in this field;
- People will have friends and neighbors involved in their lives.
Participants recommended that this public awareness campaign be conducted by a national public relations/advertising company and that it include key opinion leaders, power brokers, and media and entertainment leaders.

**Self Determination and Public Awareness**

The image of our constituents, and those direct support professionals who work with them, needs to be enhanced. This long-term effort must take place nationally and in every state. Attitudes that the people we support and those who support them are unworthy, or that staff do not need training, compensation, and support, have harmed our efforts to deliver quality services and supports.

Participants cited the need to facilitate and support people to obtain the support they need to create the life they want, and be connected to, and supported by others, in the community.

Within five years, we would expect to see the following:

- People with disabilities have direct access to money and resources; and
- The values, financing, and structure of the support and service system facilitate self determination.

Participants recommended a clear statement of mission and purpose in supporting people with developmental disabilities. The group stressed the need for working with professional marketing organizations. Finally, the participants recognized the need to work in coalitions and through alliances and partnerships with other organizations.

**Workforce Development**

Group members cited the need for a comprehensive approach to workforce development that included recruitment, selection, training, retention, and compensation.

This comprehensive system would be state-wide, based on labor market planning, and include as partners such organizations as the Department of Labor, the National Alliance of Direct Support Professionals, Welfare to Work initiative, and the American Association of Retired Persons.
The system of community-based supports and services has been largely built on an entry-level workforce. In the current economy, that strategy has caused a great deal of disruption, ranging from high turnover, to the inability to attract workers, to a different workforce. There is no systematic effort to train, recruit, support, and promote the direct support workforce in any single state, though there are local efforts in many parts of the U.S. It is clear that enhancement of the skills, compensation, training, and support of this workforce will be a necessary component of any system portending to offer quality supports and services.

Within five years, we would expect to see the following:

- A public service initiative that offers young people education credits and stipends in return for employment in the field of disability services and supports.

The participants recognized that workforce development would require alliances with other organizations and a working model such as Americorps.

**Quality Management System**

State and local systems of quality management must be developed and implemented. While some states have made progress on this issue, most state systems have slowly evolved from those in place at the beginning of the deinstitutionalization effort in the 1970s. Few local systems of quality management exist. There are many systems, structured after institutional models of quality assurance, that are focused on monitoring and compliance. But monitoring and compliance are only two elements of the quality assurance and improvement requirement. In addition to monitoring for compliance, states must develop other quality improvement and assurance models that promote quality in services and supports 24 hours a day, seven days a week.

Participants identified the core components of a quality management system. These included an incident reporting tracking and management response system. They also identified the need for a system that would facilitate analysis of consumer outcomes, provide for consumer and family monitoring, and address questions of risk analysis. The quality management system would also include comprehensive systems for mortality review, complaint reviews, and public reporting. Finally, the system would both promote best practice as well as set standards and monitor performance.
Within five years we would expect to see a quality management system based on the following principles:

- Feedback loops;
- A culture of improvement with a willingness to admit mistakes;
- Available training and technical assistance based on best practice;
- Incentives and rewards for quality performance;
- Upper level management commitment and responsibility for quality;
- Person-centered quality assurance based on responsiveness to the person served rather than compliance with process;
- Quality management that is integrated into all levels and systems within the organization.

This quality management system would be based on the principles of quality improvement rather than on the inspection model of most quality assurance systems.

The Conference closed with the identification of long range strategic issues. Strategic action issues included the following:

- **THINK MORE BROADLY.** In identifying and addressing issues we need to look beyond our traditional structures, organizations, and solutions in the field of developmental disabilities. Long range solutions are going to be found at the intersection of developmental disabilities systems with those of public relations, marketing, economic development, and workforce development.

- **TAKE ACTION THROUGH DEEPER THINKING AND ANALYSIS.** There was a recognition that existing models and assumptions may be fatally flawed and that an incremental model of improvement becomes an exercise in suboptimization. We need to ask second level questions such as *what are the forces and circumstances that will inhibit success? What do we do if we can’t solve a problem? What are the different strategies for making this happen?*

- **FIND PARTNERS AND OPPORTUNITIES.** We need to be opportunistic in our strategies and find allies who bring resources and opinion leaders to our cause. We need to find initiatives, opportunities, and energy that we can seize and direct toward our goals and objectives.
Organize Locally. Participants were unanimous in their call for replication of this consensus conference at the state and county level.

Act Now. Our leadership must create a sense of urgency and immediacy. The people at Wingspread felt that the window of opportunity was small and that both the reality and perception of quality supports and services in the community would continue to decline without a national grassroots campaign — now.
A Self-Advocate Perspective

Our Vision of Quality

We would like to extend our thanks to the following people for sharing their views and stories with us. It is their voices you hear.

Adam Denenberg
Anne Fracht
Natalie Frustaglia
George Garcia
Debra Graziano
Resa Hayes
Brian Keavey
Nora Kowalski
Steven Liscio
Linda McMillian
Joe Meadours
Teresa Moore
Delpha Palmer
Mia Peterson
Debbie Robinson
Craig Smith
Mike Thompson
Elouise Woods
In September 2000, the National Center on Outcomes Resources (NCOR), a division of The Council on Quality and Leadership, conducted a focus group with self-advocates to discover their opinions regarding the quality of services they receive. We captured their stories and ideas on videotape and shared that video with a panel of self-advocates at the Wingspread Conference. We then asked the panel to express their reactions to the comments they heard and to elaborate with their own experiences and feelings.

The purpose of this conference was to bring together people who influence the direction of services. Leaders in the field of disabilities — the policy makers, the executive directors, the state leaders — are struggling to redefine quality. Together with self-advocates, they want nothing more than to redesign systems and services to increase the quality of life that people with disabilities experience. But, this panel of self-advocates was concerned with more than policy or systems redesign. They weren’t discussing their jobs; they were sharing their lives.

In both groups, as they talked about their visions of quality and those issues most important to them, the following themes emerged: Respect, Supports/Services, Staff, Self Determination, Leadership, Employment, and Empowerment.
Session 1 — Our Vision of Quality

**Respect**

“My idea of quality service is really being respectful and dignified in one’s approach in dealing with people and also honoring individual choices, creating opportunities for people so that they reach their fullest potential.”

“Respect is valuing the individual and putting people first.”

“Attitudes are more important than all the money we could spend on programs.”

“I wish my privacy was respected. If there’s a problem, they should come to me and not go to other staff to discuss the situation. The entire agency finds out if you have a problem.”

**Supports/Services**

“Supports should work for the people — not just the agency.”

“You might think of (your work with me) as a paycheck; but to me it’s a lot more.”

“To me, health care people don’t really seem to care; they see me as a job and not a person.”

“They should ask us what kind of care we want.”

**Staff**

“Quality services mean having a good relationship with the person giving the service.”

“I feel special because the lady that works with me goes the extra mile for me.”

“It’s very important to pay our staff a decent wage. Some of the staff don’t think it’s fair that the consumers are making more money than them.”

**Self Determination**

“If you don’t talk about it (self determination) because it’s a sacred term, then it’s not going to become what we want it to become.”

“It’s going to become a word like choice, or empowerment,... and in the end, it’s not at all what the concept was intended to be.”

“Self determination is so important to get out there and give it to the people.”

“We don’t like slots. We have a new system in town called a self determination system meaning the individuals — let me say that again — the individuals are in the middle. They have choices for where they want to live, where they want to work. They tell the providers. They tell whoever asks them. It’s their lives. Nobody else can talk it down.”
**Leadership**

“I want to build a system that responds to each person’s needs, and treats each person with respect. Not one that requires spokespeople to tell me what all people need.”

“When we talk about leadership, we're for everybody, and hopefully in the future these environments will be more accessible for more people to participate.”

“Given the opportunity, every individual has a desire to learn.”

“We (self-advocates) are probably your front line out there in the community, making those connections with the self-advocates and the families, and we really want to support you.”

“We're always excited to have opportunities, so build us in to those opportunities.”

**Employment**

“Are workshops the answer to employing people with disabilities? No.”

“It’s been my experience that a lot of people won’t hire someone with a disability.”

“The quality of the jobs we are offered is not good.”

“Jobs paying fifty cents an hour are not the jobs for us. Work on our capabilities and put us in some type of training.”

**Empowerment**

“It’s your life, not someone else’s.”

“Empowerment is a choice... it is the individual voice.”

“Make our voices heard.”

“Always be a part of the whole solution.”

“Power to the people.”

“Dreams don’t die — people just stop dreaming.”

“Dream it — do it.”
Session 1 — Our Vision of Quality

“There’s a couple of words that we need to always carry with us — that we honor and respect each other. And that we don’t compare people with disabilities to other people with disabilities and try to figure out how to categorize people. Then you’re honoring them as individuals, and you respect their individuality, and you respect their wishes for their own future and the way their whole life would look for them.

“I honor that some money needs to exchange hands for the services that are provided. I need to understand what those are. I need to know what your business is like for you to make everything work for you from the staff people to the administration to the people that provide the funding from the federal government. I need to honor and respect that they’re going to try to help me the best they can.

“The old systems were a start. But now we need to see people as individuals, and we didn’t always do that, did we? And so when we talk about honoring and respecting each other throughout these days together, I’d like for us to try to listen to each other respectfully and to honor where we’re coming from. But realize that the self-advocates are a very valuable part of your teams, and we’re there to support you to do your jobs well and to do the things that you entered this business to do, which is to help the lives of people with disabilities to be whole and fulfilled, and hopefully in some way happy and successful, with the risk and the support there. I know that you have fears for me. And I want to hear what they are, and I want to support you to overcome them. And show you how you can support me better. And each individual person that you work with.”
A Federal Perspective

In Search of a Framework for Integrity and Quality in Home and Community-Based Services

Presenter

THOMAS E. HAMILTON

Reaction Panel

CElia FEINSTEIN
CHARLIE Lakin
LORRAINE SHEEHAN
I. Introduction

Rather than offering a “federal” perspective, this paper might best be considered a “sideways” look at human services from someone who has managed to work at state, local, and federal levels without ever being able to answer the important questions about quality in human services. Hence, we might best think of these preliminary remarks as more of a provocation for discussing quality, intended to stir the debate rather than resolve it. The many unasked-for opinions are my own, not necessarily those of the Health Care Finance Administration.

II. The Issue of Perspective

“The view depends on where one sits.” This common sense observation suggests that federal, state, provider, and consumer perspectives on quality will inherently and always be different.

Certainly each actor in the health and long-term care system has a different role to play. But is it necessary for very different notions of quality to prevail and compete? In the remarks which follow, one may find the argument that they not only do not need to be different, they must not be different.

This paper represents an amalgam of disparate thoughts recruited in the service of a customer-based, systems approach to quality.
By “customer-based” I mean that the customer is positioned (not “empowered”) to judge what constitutes “quality.” By “systems approach” I mean a method that accounts for the connections and relationships between all elements of a service system and seeks to ensure that they are aligned in support of a common purpose. Until such alignment occurs, quality will be an occasional and unreliable visitor. Dedicated providers, families, and others will often create quality in the face of a hostile environment. But the cost of fighting against the odds is high, the chances of success are uneven, and quality is likely to erode over time.

A condition in which all aspects of a system are aligned and unbroken has another name. Integrity.

When we say, for example, that our home and community-based waivers represent an alternative to institutional care for people who have an uncommon amount of trouble in their lives, do we not assume certain obligations to design a system adequate to the purpose? When we say that our system is intended to enable people to live in the community with dignity and independence, does that not mean that the system offers a sufficient array of consumer-responsive supports to achieve the result? If we design a system that does not support the stated purpose, do we still have a condition of integrity? Have we not designed quality out of the system rather than into the system? Once quality is designed out of the system, will any quantity of inspections and reviews put quality back in?

The parade of subsequent remarks are intended to establish the context of a changing environment for community-based long-term care, the urgency of both action and thought to address issues of quality, and the desirability of collaborative acts to build more capable and thoughtful systems.

III. Context: Challenge of Capacity

Services to support elderly and people with a disability have changed considerably in the past 20 years. Home and community-based services have expanded while reliance on institutions has attenuated. Yet a growing population of people who require long-term care, combined with clearer expectations on the part of such individuals that they
wish to continue participating in their communities, will pose significant challenges in the future. By way of specific context, we might consider the following:

**MAJORITY OF MEDICAID:** Services on behalf of people who are elderly or who have a disability represent the majority of Medicaid expenditures.

**DEMOGRAPHICS:** Higher survival rates of people with disabilities, combined with the aging of America, suggest significant challenges for the nation’s long-term care system.

For example, the population aged 65+ is expected to double between 2000 (35 million) and 2030 (70 million).

**HCBS GROWING:** Due to a bias in favor of institutional care, home and community-based services (HCBS) represented only a small portion of Medicaid spending for long-term care in the past.

The situation is changing, however. HCBS programs have gone from 10% of Medicaid long-term care spending in 1988 to 28% in 1999.

Future increases in the number of people needing assistance will magnify the challenges, since HCB services are generally preferred by such individuals and are, on average, somewhat less expensive than institutional care. These facts suggest that a doubling of the long-term care population will much more than double the demand for community-based care, since people will choose community services at higher rates than in the past. Higher education, more choice experience, and other factors indicate that future generations will have higher expectations for quality as well as location of services.

**STATE INFRASTRUCTURE:** States’ staffing and management infrastructure are quite limited in their ability to address these challenges. The development of home and community-based services coincided with the general downsizing of government, and few states have found effective ways of substituting a private sector management capability. This tends to mean that the most obvious staffing demands are satisfied first,
and anything that can be deferred into the future is deferred. Development of effective quality assurance systems tends to be an issue that is frequently subject to deferral.

**HCFA Infrastructure:** The Health Care Financing Administration (HCFA) has faced the same staffing and infrastructure challenges as states. The agency devotes 8 full time equivalents (FTE) to new HCBS waivers and waiver policy issues for the 56 states and territories. Another 6 FTE are devoted to policy for $70 billion in Medicaid State Plan services, such as home health, therapies, personal assistance services, durable medical equipment, nursing home payment policy, etc. It is questionable whether such limited capability will be able to manage the increased demands for both accountability and effective planning.

HCFA has also been subjected to the same pressures as states to satisfy immediate demands and defer issues that can be deferred. Consequently, there has been less investment in the development of quality assurance systems than would otherwise be desired. By way of example, HCFA spends approximately $400 million in direct monitoring and quality assurance activities for nursing facility and ICF/MR services. For HCBS services, direct HCFA spending is roughly estimated at $1 million.

**IV. Context: Challenges to Our Thinking**

**A. Various Approaches to the What, How and Who of Quality**

It has been fashionable to invoke Donabedian’s three domains of quality:

- Structure
- Process
- Outcomes

Disappointment with the structure and process approach to quality has given rise to more emphasis on outcomes.

Outcomes, of course, are difficult to measure. The most measurable outcomes tend to be the most trivial. Those that are not trivial tend to be very expensive to measure and to monitor. There is also a limit as to how many outcomes and measures an organization can maintain in its focus at any one time. This limit means that the organization
constantly shifts focus according to whatever measure(s) seem to be most in vogue at
the time, usually in response to its funders.

What we look at is important. Even more important is who looks at it. At the heart of
these debates is the often-implicit question: who will be the arbiter of quality? Who will
decide what structures and processes and outcomes are important? Who will decide if a
particular measure is satisfactory? And who will do what with the results?

Human services in the 20th century United States have tended to answer that the
professional provider and regulator are the arbiters of quality. Since the late 1970s there
has been a movement away from empowered professionals in favor of families and
individuals with disabilities. This is perhaps clearest in the fields of physical disabilities
(e.g., the independent living movement) and developmental disabilities (e.g., normaliza-
tion, person-centered planning, and the more recent personal outcome measurements
efforts).

Federal policies have tolerated these developments, then accommodated them to some
extent, and more recently encouraged them in limited ways (e.g., the cash and counsel
demonstrations, the self determination projects). Yet it would be fair to say that a person-
centered approach to quality has not taken root as the central organizing principle of
federal quality efforts.

B. Federal Quality Efforts

Federal quality efforts are concentrated on standard-setting and monitoring. For
institutional services, federal standards for both structure and process abound in regu-
lation and manual. The predominant, direct federal monetary investment in quality of
institutional services takes the form of survey and certification. Early estimates indicate
that about $400 million is spent each year in monitoring nursing homes and ICFs-MR
around the country. The facilities are surveyed for conformance with published standards.
Serious or repeated violations may give rise to a 21-day advance notice of funding
termination. If serious problems are not corrected then the facility is de-certified and no
longer eligible for Medicare or Medicaid funding. Since Medicaid and Medicare
generally represent the majority of funding, such de-certification usually means closure
of the facility.
In the s.1915(c) home and community-based service (HCBS) waiver programs, states must assure that “necessary safeguards have been taken to protect the health and welfare of the recipients of the services.” Such safeguards must include “adequate standards for all types of providers that provide services under the waiver.”

HCBS waivers are approved for an initial three-year period, with subsequent renewals for five-year periods. Federal protocols call for at least one review of waiver quality before the end of each approval period. If HCFA finds that the assurances are not being met, the agency may withhold approval of a renewal request or may terminate the waiver. Estimates suggest that HCFA itself spends approximately $1 million of its administrative budget on quality assurance activities for the HCBS waivers.

We can imagine some assumptions that could give rise to, or sustain, such an approach to quality:

- Conformance with minimum standards is the best way to ensure quality. It is not necessary to be concerned with providers above the minimum.
- After-the-fact inspection is the best way to assure conformance with minimum standards.
- Enforcement must be total. The price of total enforcement (e.g., facility or waiver termination) is less than the price of continued operation or any alternative remedy.
- There will always be an oversupply of providers, so that closing some providers will not leave program participants bereft of life-critical support.
- Improvement of operations is a provider’s responsibility.

Most people know that the above assumptions are invalid. Yet we do not have a better system in place.

Monitoring is also very expensive. One state estimated that it had about one state staff person for every three hundred nursing facility residents. Despite the extensive monitoring efforts, serious quality problems continue to occur with regularity. The Pulitzer-Prize winning set of articles by Katie Boo in the Washington Post in 1999, for example, indicated significant and life-threatening problems in administration of the Washington D.C. ICF/MR system — despite the monitoring processes in place.
Another remarkable feature of the federal system is the paucity of attention to (a) fixing problems (especially any joint notion of fixing problems) and (b) fixing the processes that give rise to the problems in the first place.

To the extent that the purpose of a monitoring system is to (a) have the findings used and (b) eventuate in positive changes to the system, it is remarkable that there is so little investment in the long-term care system to the improvement (versus detection) part of the equation.

With regard to home and community-based services (HCBS), there has been a low level of federal presence to date for both detection and improvement. There are strong indications that this will change, at least for the detection aspect. First, a number of recent findings by both HCFA and others have indicated serious quality problems in some states. Second, as HCBS programs approach a third of total Medicaid long-term care spending, we might expect that the imbalance in HCFA attention between institutional and community reviews will change. Basic questions for the future might include:

- Should HCFA spend a proportionately equivalent amount of money on community quality assurance as it does on institutional quality assurance (e.g., $400 million x 28% = $112 million/year)? Should states? Is there an alternative that might be less expensive?
- What framework for quality ought to structure quality for home and community-based services? Who should judge quality?
- What needs to happen when quality is not present? What approaches might yield the highest probability that system improvement will occur? What might be done in the design of a quality assurance system to move attention from admiring problems to improving the systems that give rise to the problems in the first place?

If we wish to develop a more effective and less costly approach to quality in home and community-based services, it is worth looking to see where there are alternative models that are working.

Ironically, during the very period in which HCBS waivers were first being developed, there was a revolution in quality occurring in the United States in the private sector. The revolution was stimulated by success of the Japanese in improving quality to such an extent that Americans increasingly preferred their products, especially in the auto
industry. Among the Americans who had assisted the Japanese to achieve such results were W. Edwards Deming and Robert Juran. In the 1980s these leaders returned to the United States and their schedules were booked solid by America’s businesses eager to apply their lessons. Why have their approaches not been applied to any appreciable degree in health and long-term care, especially in the public sector? This phenomenon is all the more surprising given Deming’s antipathy to the principal technique used by HCFA for quality assurance — post-hoc inspection.

C. A RUTHLESSLY ABRIDGED OUTLINE OF DEMING’S TOTAL QUALITY MANAGEMENT

W. Edwards Deming used two notions to move away from an approach to quality built around professional opinion. First, he defined quality as meeting or exceeding customer expectations. This definition automatically positions the customer as the arbiter of quality. It also allows for a dynamic concept of quality. Since customer views of quality change over time, a process that keeps in constant and effective touch with customers will be able to adapt and improve quality faster than the competition. Further, it respects the transformative nature of quality. For example, an individual receiving quality education will develop a different view of quality and seek something different in the future.

Second, Deming emphasized what later became called “data-based decision making.” So, for example, if professional opinion indicated that back surgery was most often the desired remedy for back pain, but data indicated that 50% of people with surgery got better and 50% without surgery got better, the way was open to other remedies. Data-based decision making also has potential to be more democratic: more people can participate if given access to data, whereas professional opinion can be rendered only by those who are credentialed.

Deming found that widespread and continuing improvements generally resulted only when his quality improvement designs were combined with a management philosophy and a systems orientation. One phrase to indicate the combination of all of these elements became “total quality management.” The 14 points that comprised the core of Deming’s management philosophy are now legendary. Among them is the exhortation to “eliminate the need for inspection on a mass basis by building quality into the product in the first place... Inspection is too late. The quality, good or bad, is already in the product...”
D. Why Services Are Different; Why the Public Sector is Different

There are key differences between the manufacturing environment within which Deming did his early work and a service economy. For example, services are consumed at the point of production. There is nothing to look at later, no product to examine and perceive the defects in front of objective third parties at a later time.

There are even more differences when offering services in a public program. Consider, for example, that in the private sector the customer supplies both information (e.g., satisfaction) and resources (e.g., money). Once the product is delivered the relationship is largely two-way.

However, in a public program the immediate customer is generally not the main party supplying the resources in exchange for the transaction. There is at least one other major customer group: the taxpaying public. Further, the taxpaying public has many representatives, not all of whom consistently agree or enjoy one another’s company. The legislature and governor, for example, may send different messages regarding what is quality, different messages regarding “customer expectations.”

Finally, the environment is further complicated by the fact that for many human services the “product” is a co-production between the human service agency and the individual/family and others involved. The relationship looks like the illustration below:

Programs that ignore different expectations coming from different customers are destined for difficulty. This was the case with the AFDC program. The better the system became at dispensing one product (cash assistance) the less it was esteemed by the taxpaying public. Resources diminished and overall quality declined over time until the expectations were aligned with a product that could be valued by both customers (temporary cash and job assistance, long-term health and day care coverage, etc.).

“Meeting customer expectations” has problems as a touchstone for quality in the public sector when there is an oversupply of customers. If there
are too many customers and prices cannot be raised, then it matters less to the producer if some customers go away dissatisfied. To some extent, one may argue that public programs face a constant oversupply of user-customers, particularly from the view of the taxpaying public customer. Fewer users would be just fine from this point of view, and a diminishment of quality that discourages potential users of the system might then be viewed as the desired recipe. Unless the public perceives the product as valuable to them (now or in the possible future) then poor quality might actually be encouraged by the very customers that supply the necessary resources.

These meanderings suggest a continuing need to (a) pay attention to both major types of customers, and (b) find products that respond to the desires of both, and (c) maintain effective information exchange in all directions — that is, finding out what each customer group wants, and then making sure that there is understandable feedback regarding what the program has done to address those desires.

E. WHAT DOES THIS MEAN FOR PERSONAL OUTCOME MEASURES?

One of the promising developments of the past few years has been advances in research and model construction that, like the work of W. Edwards Deming, use a more person-centered approach to quality. “The Council on Quality and Leadership in Supports for People with Disabilities,” for example, re-defines quality as “responsiveness to personal outcomes rather than compliance with organizational process... Linking quality to people’s preferred outcomes transfers power from the professional and the bureaucracy to the people they serve.”

This leaves the pesky problem of multiple customers, however. It begs the question of how the expectations of taxpaying publics will be consistently consulted and accommodated. In particular, how will express conflicts in prioritized expectations be reconciled? For example, an individual may have a much higher tolerance for risk-taking than the public. When freedom is valued most highly by one customer and safety most highly by the other customer, some form of reconciliation must occur.

Personal outcome measures face the same challenges that Deming faced with his statistical process controls and later quality improvement techniques: the measurement systems,
the personal focus, and other features will not likely survive unless nested within a supportive management philosophy and systems design that make effective and continuous use of the results. This also means aligning different customer groups. It means aligning all parts of the system (and all levels, state, federal, local) along the sight lines of a common vision and operating plan.

Espousing personal outcomes as the focal point of quality is not likely to be sustained unless system managers operate within a context that motivates them to do so, and unless the taxpaying public views such an approach as the most desirable.

Personal Outcomes Measurement itself also faces the challenge of adopting an effective systems orientation. Consider, for example, the state HCBS waiver that offered personal assistance services as the only service available. Further, the personal assistance was available in unlimited quantities so long as it did not cost more than $6 per day. A person-centered approach operating in such a context is likely to be thwarted by the design limitations of the program. Every time an individual identifies something that could be satisfied only by going outside this limited menu, the answer is that the outcome desired cannot be met because it would require exceeding the authorized list. What is the imperative for the state to redesign its program?

V. A Possible Framework for Integrity and Quality

The preceding discussion suggests a certain framework, a certain blueprint for action:
A. Adopt a Dual Customer-Based, Systems Approach to Quality
B. Build Quality into the Design of the System at the Front End
C. Invest in Improvement
D. Improve Processes Based on Customer Outcomes — Fix the Processes That Give Rise to the Problems
E. Orient all Detection Systems Toward Fixing These Processes
F. View Quality as a Responsibility Shared at All Levels
These apparently simple changes of perspective could yield a fundamentally different approach to quality, especially if adopted as the basis for federal activities. If a federal approach to quality is inconsistent with a personal outcomes approach used at the local level, can a person-centered approach survive the test of time and trouble?

For example:

A systems approach to quality would mean many things, including:

- A front-end design focus — based on customer feedback, starting with the question of whether the system is designed to accommodate quality
- Structuring the system to acknowledge and (preferably) reward quality, while protecting against harm
- Beginning with HCFA “creating the market,” that is, so arranging incentives such that a value neutral individual would do the right thing
- Communicating clear expectations at all levels
- Based on customer expectations
- In every component of the system
- Under an overall framework for quality
- With adequate infrastructure (e.g., staffing, information systems, feedback loops)

It also means that information is collected and used:

- In real time, continuously (e.g., via trained and knowledgeable consumers, advocates and personal agents, community relationships, case management systems, major unusual incident reporting and investigation, etc.)
- With post hoc periodic monitoring (especially to see if real-time system is working)
- With tested, adequate tools for gathering information, taking measurements, especially in relation to the people enrolled in the program
- Comprehensive – e.g., garners feedback information from:
  - Consumers, directly
  - Consumer contacts, relationships
  - Providers
  - System sources (e.g., administrative data)
Reported directly to decision makers with *authority to act*

With immediate action capability, such as:
- Immediate jeopardy response
- Problem resolution for individuals
- Enforcement and follow-up
- System improvements needed immediately

Finally, the above framework would re-orient federal activities so they are focused on the ultimate purpose of quality assurance: improvement of the system and protection of individuals. Investing in improvement and supporting state efforts to do so would redress the current imbalance in which much more attention is devoted to detecting problems than fixing them.
I’d like to add a few brief comments in response to Thomas Hamilton’s paper. What struck me was the emphasis at HCFA on the institutional side in terms of surveys and certifications and the changes that have occurred across the country.

Upon reading Nancy Thaler and Bob Getting’s paper, some of their data amazed me. For example, since 1966 in Pennsylvania, when the Mental Health/Mental Retardation Act was passed, the population of people in publicly-funded Intermediate Care Facilities for People with Mental Retardation (ICFs/MR) decreased dramatically, from 13,000 to 1,900 individuals. However, the institutional population in the private ICF/MR program during the same period of time has only decreased by 200. In other words, in 34 years, we went from 1,500 to 1,300; I would bet that the reduction of 200 people has occurred largely through death. As Thomas Hamilton states in his paper, we should have some discussion in terms of what we are doing to celebrate 141 institutional closures over the past 34 years. In addition, it is time to look at the sacred cow called the private ICF/MR. As the data show, reductions in the population of those facilities are moving at a snail’s pace relative to the publicly-funded ICF/MR program.

The next area of discussion is related to Thomas Hamilton’s comments about basic questions for the future. Should we spend an equal amount of money in the community as we do on the institutional side? There is no reason for us to believe that the quality of people’s lives has improved as a result of survey and certification processes. Therefore, I think we need to really look at what we will do on the community side. The question then becomes,
“What is the role of the federal government in the community?” Many think that the role of the federal government should be to develop a set of requirements, give those requirements to the states, and measure against whether the requirements have been met. How states meet the requirements should be left to the states. For example, HCFA may choose to require that states have an outcome-oriented quality assurance system. However, the type of system the state adopts should be left to the discretion of the states, as long as it meets the criteria set forth by HCFA. HCFA then becomes the oversight body, as opposed to the licensing/surveying entity.

An example of this type of arrangement may be found in Pennsylvania, as they move toward state-county agreements. Instead of just having an allocation process to the counties, there will now be agreements. Certain things have to be in place as well as possessing specific qualities. Counties must have an independent monitoring project, where data are collected by people with disabilities, family members, and interested others. How independent monitoring is accomplished and by whom is left to the counties; the requirement is made by the state.

That is where my thinking is as we move toward thinking about what the federal role should be in the community.
Reaction to Thomas Hamilton’s Presentation on Home and Community-Based Services

Session 2
Charlie Lakin

Mr. Hamilton’s paper is remarkable in its thoughtful and thorough analysis of the many challenges that the current service system faces in achieving the contemporary goals held for it within the social, financial and policy contexts in which it operates.

The paper is so full and concisely written that a ‘brief response’ to just a few of its observations and implications could easily exceed in length to Mr. Hamilton’s complete paper. I will, therefore, focus on only a few of his observations and associated implications.

One of Mr. Hamilton’s observations/implications is that while we have probably been overly inclusive of who is viewed as a justifiable ‘stakeholder’ in our system of services by including service providers, non-elected officials, and other secondary beneficiaries, we are often shortsighted in not including as primary stakeholders the taxpayers who ultimately have purchased the services people receive. A second observation/implication with specific regard to Medicaid Home and Community-Based Services is that while we were debating whether Medicaid HCBS was a program or a funding stream, HCBS became THE PROGRAM for people with developmental disabilities, or if you prefer, the funding stream grew into a raging river of revenues. This HCBS program (or funding stream) will not be ignored with respect to its achievements and/or failures because it cannot be ignored; it’s just much too big and growing too steadily to be treated as though it were still some sort of experimental ‘alternative.’

HCBS is a $9 billion program that needs to have solid expectations of performance of states in financing their services through the HCBS program. A third observation/implication is that while we may all seek to move from inputs and processes to ‘outcomes’ in the definition and assessment of our long-term care
products, we still lack agreement about what our product is and how quality in its delivery is defined, much less how quality can and will be assessed and ‘assured.’

It is, as Mr. Hamilton notes, extremely important and timely (perhaps even a bit late) to be taking seriously on a national level the issues of ‘quality assurance’ in Home and Community-Based Services. The ‘low level of federal presence’ of which he speaks is no longer tenable because of the scandals he mentions and because of HCFA’s own findings in visiting state programs. The naive era in which community was assumed to be good for people because it wasn’t an institution, or that ideals well articulated and/or passionately held become reality, should be put to rest. As Mr. Hamilton seems to suggest, there should be greater balance in resources, expectations, and commitment to defining and monitoring quality between community (or HCBS) and institutional (or ICF/MR) services.

But none of this should be done without full attention to what has been learned along the way in providing services to people with developmental disabilities and in trying to assure some measure of their quality. We have experimented with models of the state, acting as the good parent, trying to step in to meet the needs, protect the interests, and promote the well-being of persons viewed as dependent. This experience for people with developmental disabilities came at substantial cost to individual rights and desired ways of living. Today the “progressive” faith that government can define what will be good for people and then cause that good to occur is rare. It’s not that government cannot identify real social problems; government is able to find poor conditions in service settings and even sometimes people being neglected or exploited. It’s just that its governmental solutions to these problems once identified have been in themselves undesirable and inadequate.

There is a simple legacy of our experience with government imposed systems of identifying and solving problems in the lives of people with developmental disabilities. It is an understanding that: 1) whatever formal systems may impose, real reforms produce perceptible improvements in the real lives of people; 2) there is no one perfect definition of what will meet the needs of all people even when they share identifiable distinctions (e.g., being impoverished or homeless, having a developmental disability); and 3) the use of discretionary authority by the government on behalf of
another person without that person’s involvement will often be insensitive or abusive, or at least be perceived to be so.

Today, as Mr. Hamilton observes, standards and the associated documentation required to demonstrate compliance with a universal definition of quality are increasingly viewed as unnecessarily burdensome and even counterproductive, particularly as the primary locus of supportive services has moved from institutional to community settings. Among the by-products observed from traditional “compliance with standards” approaches have been: 1) a frustrating and counterproductive appetite for paperwork; 2) the development of adversarial relationships between service providers and government; 3) inhibition of innovation and rational risk-taking in favor of rule following; 4) loss of self determination for the people being protected; 5) lack of involvement by government agencies in promoting “well-being” by means other than rules; and 6) promotion of an idea that protecting people well and supporting them well is the same thing.

The challenge of quality assurance is to contribute to people’s lives as they like to be able to live them while reducing harmful by-products of systems of quality assurance that seem innately driven to put ‘patches’ on every identifiable problem within contemporary service systems. The challenge of such change is magnified by systems that are dynamic, flawed, and buffeted by practical forces, that include:

1) **There is a vast and rapidly growing number of settings in which community services are provided.** Home and community care systems have become extremely dispersed and, as a result, they challenge government quality assurance monitoring efforts. As an example, in 1977, there were 11,025 separate households in which persons with developmental disabilities received out-of-family residential services. Twenty-two years later, in 1999, that number had grown 10-fold to more than 113,000 separate out-of-home settings (Prouty & Lakin, 2000), not to mention the hundreds of thousands of additional persons served in their family homes. This growth has continued without commensurate growth in the number of people available to monitor the quality of services received in these dispersed settings. Similar trends, albeit often less dramatic, are seen among other “disability groups.”
2) **There is doubtful reliability and validity in traditional quality assurance approaches.** Current quality assurance approaches are not producing the acceptable results. Most are inadequate in terms of efficacy, reliability, and validity. Virtually all of the federal court rulings and settlements related to the quality of institutional care in the past 20 years have involved facilities that had been certified as in compliance with ICF/MR standards. The highly publicized Washington Post series on the scandalous conditions of community ICFs/MR in Washington, DC raised similar doubts about validity of ICF/MR standards applied in the community. It is well-known and has been shown in limited research that different monitors who survey the same settings cite different deficiencies (Reid, Parsons & Green, 1991). A recent set of studies that focused on the backbone of service design and quality assurance, the Individual Program Plan (or Plan of Care), showed no association between what is written in people’s plans and their relative roles of engagement in or their accomplishment of (re)habilitative outcomes in real life (Stancliffe, Hayden & Lakin, 1999, 2000). In short, there is little reason to have faith in greater quantities of traditional quality assurance.

3) **Most quality assurance has little ability to contribute to improvement of most service providing agencies.** A 1990 report of the U.S. General Accounting Office, focusing on quality assurance in health care, contained an observation that is highly relevant to services for persons with disabilities:

> Quality assurance systems typically concentrate on quality assessment and the identification of the relatively small number of providers whose care is obviously unacceptable. They do comparatively little in attempting to directly improve the overall levels of quality provided by the majority of health professionals (p. 8).

Effective quality assurance should contribute to more than the identification of the worst agencies, those unable to meet the minimum levels expected by current regulatory practices. Effective quality assurance systems focus on the variables and resources that can improve quality in all agencies. Standard-based quality assurance has limited capacity to be effective in such a role.
4) **The ability to define, measure, and improve service quality in terms of outcomes important to service recipient is increasingly viewed as foundational to quality, but is still seldom the primary basis of quality assurance.** There is a growing commitment to developing a service system for persons with disabilities that focuses on the outcomes that people want in their lives. Efforts to integrate concepts and practices of person-centered planning, consumer-controlled housing, consumer-directed supports, individually managed budgets and so forth all reflect the goals of helping people achieve individually desired outcomes. The standards of the major accreditation organizations have established expectations that measurement of individually valued outcomes should be integrated into the management practices of agencies seeking accreditation. Outcome systems are, however, very complex and require sophistication in effective implementation. It is much easier to assure that a person has a bedroom of specified square footage, that there is documentation that staff have the sufficient hours of training in specific topical areas, or that service recipients have been assessed and individual programs plans have been developed and implemented, than it is to determine whether people are respected, increase their social networks, or become more satisfied with their lives. Despite the complexity, the growing consensus appears to be that there is too little benefit in quality definitions, assessments, and monitoring practices that attend to individually-based outcomes to not invest in a future of quality assurance based on such outcomes. But outcome-based quality assurance, with the assumption of potential for sanctions, public disclosure of performance, and associated economic implications remains threatening and still infrequently implemented as a substantial component of an “official” approach to quality assurance.

As Mr. Hamilton suggests, we must break out of the mold of trying to ‘inspect our way to quality.’ The quality we are looking for is not formulaic, but complex and multi-faceted. It requires seriousness about the disparity in the resources and effort committed to quality assessment, improvement, and information dissemination across the different states and the inadequacy of such resources and effort in the
vast majority of states. It is not necessary to change the proposition that the federal government’s role with HCBS is that of approving appropriate quality assurance programs and assuring that they are implemented as approved. It is, however, necessary that there be federal commitment to a) approve only those programs which honor people’s right to have quality defined with personally meaningful attention to their lifestyle, safety, and health needs; b) know whether and require that states actually provide the quality assurance programs that they request and receive federal approval to provide; and c) provide or sponsor the direct or indirect assistance that states need to develop and maintain meaningful quality assurance programs.

The definition of ‘meaningful quality assurance program’ is obviously complex and even contentious. But hopefully few would argue that ‘meaningful quality assurance’ is commonplace. Its elements present enormous challenges to systems that have been built on inspection models. Its necessary functions are extremely difficult to fulfill with front-line personnel who are career inspectors, who operate with relatively low status, respect, pay, practical experience, and passion for improving the everyday lives of people with disabilities. Its achievement requires resources, investments, and commitments that exceed those found in traditionally defined ‘quality assurance programs.’

During the past year I have had the opportunity to visit a few states in which quality assurance is viewed as a serious, integrated component of the overall home and community service delivery system. Those visits made it clear to me how very different, than typical, quality assurance must be if it is to be as effective as it could and should be. As I read Mr. Hamilton’s comments about the status, importance, and challenges of quality assurance, I reflected on the states that I had visited in which quality assurance was a serious activity, viewed as worthy of passion and commitment and expected to be responsible for contributing to the improvement of service quality. I have seen 10 characteristics that such programs appear to hold in common as achievements and/or visible public aspirations.
Common Features of Quality Assurance Systems That Contribute Positively to Quality

1) Everybody in government roles is in the quality business. There is a low division of labor when it comes to monitoring/working on quality and no one is in a role too high to be excluded from direct involvement and specification of specific roles and responsibilities in the effective implementation of the quality assurance/improvement system.

2) Everybody in government roles sees and knows the product in action. Authorities are in touch and know the strengths and limitations of the system in achieving quality outcomes.

3) There is a clear definition of quality and a structure to its assessment that is based on a foundation of values derived from aspirations of real people.

4) People involved in quality assessment have organizational positions/responsibilities, recognized expertise and commitments to quality that extend beyond the monitoring of quality. These quality assessment and improvement professionals are available (and useful) to work on matters related to quality irrespective of whether they are “detected” in formal monitoring activities.

5) Service providers know the quality assurance personnel in useful roles that extend beyond their formal quality assurance roles.

6) People involved in the quality review process are respected because the process is respected.

7) Service providers feel challenged by the quality review process and find validity in its observations and recommendations.

8) Observations/recommendations of the quality assurance program are integrated into program reform decisions from the service site and agency levels to the state level.

9) There is a periodic independent consumer satisfaction and service assessment conducted by an agency other than the state to measure the performance of the system in satisfying consumers and attending to organizational goals (e.g., “Do you like where/with whom you live? Did you choose where/with whom you live?”). Service recipients’ responses to such assessments have formal attention from
and influence on persons of policy decisions affecting service delivery at the individual, service site, agency, and regional/state levels.

10) Outcomes of quality assessments are publicly reported because they are considered 1) to be about topics of public importance; 2) to be valid and reliable information; 3) to be useful to consumers making service decisions; and 4) to contribute to accountability of service providers and the “system” as a whole.

As Mr. Hamilton observes a society that provides and pays for services for persons with disabilities has a right and a responsibility to articulate purposes for those services and expect indications that those purposes are being realized. The single most commonly articulated purpose of social services today is to enhance people’s quality of life. The concept of quality of life is largely personal, but most definitions articulated by persons with disabilities include components like physical presence in the community; health, safety, and comfort; personal growth and development; social and familial relationships; participation in valued roles of the society; and independence, individuality, and choice. Definitions and assessments of quality in services that seek to attend to such components of quality of life must do so in ways that are attentive to individual differences, appreciative of the sensitivity of the information being gathered and accommodative of the differing capacities of service recipients to understand and respond to the topics of the assessment.

We need federal participation in developing, testing and implementing effective means to accomplishing the appropriate ends of quality assessment and improvement programs. But while we concentrate on designing better approaches to quality assurance, we need to make sure that information about options and choices among them is the cornerstone to long-term care that respects people’s capacity and need to define and select those things that contribute to their own sense of quality in their daily lives.
References


The Issue of Perspective

I agree with Mr. Hamilton that federal, state, provider and consumer perspectives of quality vary greatly. I agree that it would be very helpful if all parties could agree to a broad concept of what defines quality. The development of a system that is integrated in its approach to quality would greatly enhance the delivery of supports and services.

Capacity

HCBS are growing according to Mr. Hamilton, but the institutional bias is still too strong. While HCBS spending has risen to 28%, the question to be answered is what percentage of total beneficiaries are funded by this 28%?

If the demand for HCBS will double, doesn’t “customer demand” suggest that the bias be directed to desired services? Without removing the institutional bias, there never will be enough funding for wanted services or a quality system.

Outcomes

The Council on Quality and Leadership is to be congratulated on developing a meaningful list of Outcomes. Measurement is very difficult. It is trendy for providers to conduct “surveys” of their consumers to allegedly measure quality. These surveys are suspect since they are either sent home in written form or conducted by on-site staff.

An independent evaluation of outcomes is necessary to truly measure customer satisfaction. Projects such as “Ask Me” in Maryland have been very effective. The surveyors are trained peers who visit with consumers with a set of professionally developed questions. This method has been deemed statistically validated by Dr. Gordon Bonheim of Towson University, Maryland, and Dr. Robert Schalock formerly of Hastings College.
The results of the Ask Me survey differ from the in-house surveys. I agree with Mr. Hamilton that a clear method of evaluating outcomes is essential!

Monitoring by HCFA

It is true that “reviewing mistakes” is not the best system. However, monitoring of the egregious abuse and neglect that occurs in some community programs might have protected people from harm and death.

Deming’s Total Quality Management

Deming’s definition of quality can be applied to human services, i.e., “meeting or exceeding customer expectations.” Planning and control of supports and services and then a review to be sure these wishes are being met are clearly the optimum of quality.

The second part of Deming’s definition also fits, “data-based decision making.” There is ample research in the field identifying best practices that enhance the inclusion and self-sufficiency of those served. Planning should be made within the “data-based decision making,” i.e., best practices.

Public Sector

HCFA, the states, and the Advocacy Community need to form a partnership that will convince policy makers and taxpayers of the advantages of quality supports in the community. The Advocacy Community needs to aggressively take the lead in this matter with HCFA and the states providing the implementation and data to back up the practice.
Session 3

A State Perspective

Balancing Individual Choice and Control with Personal Health and Safety

Presenters

Robert Gettings
Nancy R. Thaler

Reaction Panel

Valerie J. Bradley
Dennis Harkins
Glenn A. Stanton
I. Introduction

The past two decades have been marked by major improvements in the quality and accessibility of public services for individuals with developmental disabilities nationwide. The aggregate census of large state-operated institutions for persons with mental retardation declined by almost two-thirds between 1980 and 1999, while 141 state-run facilities were closed during this same time span.¹

Fueled by improved access to Medicaid funding, states have aggressively expanded home and community-based services and vastly improved the quality of care furnished to their remaining institutional populations. Family assistance, supported living and supported employment programs all have been initiated and rapidly expanded as public officials searched for new, more effective approaches to meeting the needs of persons with disabilities, while at the same time making better use of scarce public dollars.

Yet, despite the noteworthy accomplishments of past years, it has become increasingly clear that state/local developmental disabilities service systems will have to undergo fundamental structural reforms if they are to meet the challenges that lie ahead. Waiting lists for specialized community services have grown longer and longer in many states,

not withstanding an unprecedented growth in federal-state expenditures. Access to high quality services and supports vary markedly from one community to another, and the opportunity to choose freely between qualified providers of services too often is the exception rather than the rule. Existing funding streams are fragmented and organized along categorical lines. As a result, frequently it is difficult to use available resources in a flexible manner so that services and supports can be tailored to the needs and desires of each individual and family. Moreover, present service systems are far too reliant on prescriptive, highly regulated program models that gauge performance through detailed, process-oriented standards, rather than in terms of outcomes valued by consumers and families.

Trapped between rising consumer expectations and finite budgets, more and more states have concluded that the only reasonable approach to navigating this policy tight wire is to institute basic structural changes in the way their developmental disabilities service systems operate. The common goal of these change strategies is to create service delivery systems that are far more responsive to consumer needs and aspirations, while at the same time ensuring the quality and integrity of publicly-financed services. The central dilemma states face in achieving this goal is succinctly summarized in a recent report which Colorado DD officials submitted to the Joint Budget Committee of the State Legislature.

Developmental Disabilities Services... is in a position similar to a homeowner facing major remodeling and renovation needs that exceed the resources available to pay for them. The 36 year old community services system, like a similarly aged home, is experiencing some wear and tear both in its foundation and structure. Its foundation are the employees who provide services to those in the “home.” This foundation is cracked because the community service system can’t keep and attract sufficient staff with the wages it can afford to pay. At the same time, there are increasing needs for expansion to

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2 Total public spending for mental retardation services in the United States more than doubled (115%) during the ten year period between 1988 and 1998 ($11.9 billion in 1988 vs. $25.6 billion in 1999), according to Braddock, et.al. (D. Braddock, R. Hemp, S. Parish, and M.C. Rizzolo, *The State of the States in Developmental Disabilities: 2000 Summary Study*. Chicago: University of Illinois at Chicago, Department of Disability and Human Development, April 2000).

our home to make room for the many new people wanting to move in. This is all occurring at a time when financing is severely limited. Similar to the homeowner, we would love to address all of our capacity problems right away. Knowing that this is not possible, our task is to identify and prioritize our needs and to address them to the extent our banker is willing and able to finance them. We are very aware that the Department (of Human Services) has numerous other homes, beyond developmental disabilities, needing attention as well.⁴

The purpose of this paper is to: (a) pinpoint the principle factors motivating states to realign the policies, procedures and practices governing the operation of public developmental disabilities service systems along person/family-centered lines; (b) describe the implications and challenges of building quality management structures that are capable of supporting a person/family-centered service system; and (c) illustrate how one state — Pennsylvania — is striving to balance individual health and safety with personal choice and control as it transforms its existing mental retardation service system into a statewide network of person-centered supports.

II. Transitioning to Person-Centered Support Systems

Community MR/DD services, historically, have been built around a limited number of pre-packaged, congregate programming models (group homes, sheltered workshops, day habilitation centers, etc.). The basic approach to serving persons with lifelong disabilities has been rooted in the belief that, through the systematic application of a regimen of care, treatment, and developmental training furnished in a specially designed setting, the vast majority of individuals with developmental disabilities can acquire the adaptive skills necessary to live productive lives in the community. This “community readiness” approach to programming is based on the assumption that a person can be “slotted” into a daytime and/or residential service model appropriate to his or her particular developmental needs as new resources become available; and then, as each individual acquires enhanced adaptive skills, he or she can move to less restrictive service alternatives and greater independence and social integration.

⁴ For a number of years, Colorado state government has operated under a constitutional provision which limits overall growth in expenditures to roughly 6 percent annually. Equivalent constitutional or statutory limitation on expenditures or revenues also exist in a number of other states.
In recent years, a new approach to assisting persons with disabilities live full and productive lives in the community has emerged and gradually gained acceptance in the field of developmental disabilities. Assigned various labels, this new approach rejects many of the central premises of the existing community readiness model (i.e., maintaining a service continuum; the predominant emphasis on acquiring community coping skills; the provision of services in segregated, congregate settings, etc.), arguing that this theoretical model has failed to produce the promised results. The cornerstones of the new approach can be summarized as follows:

- A strong commitment to individually tailoring supports to the needs and aspirations of each person, rather than “slotting” individuals into a limited range of prefabricated, one-size-fits-all program models;
- Placing primary emphasis on helping each individual to live a meaningful, productive life in the community, rather than “treating” his or her disability;
- Giving the person with the disability and his or her loved ones a decisive voice in formulating individual support goals and determining how public dollars can best be deployed to achieve these goals;
- Fostering the development and use of informal support networks as well as establishing strong ties to the local community; and
- Limiting paid supports to those aspects of an individual’s service plan which: (a) are deemed essential to the achievement of his or her life goals, and (b) cannot be accomplished by the individual’s informal support network.

Today, examples of local support agencies which adhere to the above operating concepts can be found in virtually every state in the union. Yet, the vast majority of consumers still receive their services through community facilities and programs based on traditional congregate service models.

State officials face enormous challenges as they attempt to guide the transition toward person-centered support systems. Among the major obstacles are:

- Tens of billions of dollars – plus unfathomable psychic investments – are tied to the operation of existing community service systems. The process of disinvesting in the current system and replacing it with flexible networks of individual, person and family-controlled supports inevitably will be a long and, at times, agonizing journey, given the (a) centrifugal economic forces to maintain an existing system that
benefits powerful interests within the developmental disabilities “industry” and (b) the fears and uncertainties generated by the change process, especially for consumers and family members who, understandably, want assurances that the restructured system will lead to improvements in services and supports for people with developmental disabilities and their families.

- **Creating an Infrastructure Capable of Supporting Flexible Networks of Individually Tailored Supports.** States and localities which have begun the transition process have quickly discovered that the present state/local service delivery infrastructure needs to be re-conceptualized and re-tooled, from top to bottom, in order to manage a service system built around the principles articulated above. When decision making responsibility is shifted to the individual and his or her circle of support, old managerial approaches — from individual program planning, budgeting and payment methods, to quality oversight processes and management information needs — must be restructured to meet new demands. In service systems that have been in operation for many decades and, consequently, have developed deeply entrenched operating routines, such fundamental structural and (at least equally important) attitudinal changes represent a monumental undertaking.

- **Reconciling a State’s Systemic Reform Objectives with Existing Federal/State Laws and Regulations Governing the Funding of Long-Term Services to Persons with Developmental Disabilities.** Given the states’ increasing reliance on Medicaid funding, the “fit” between state restructuring goals and often antiquated federal Title XIX policies has emerged as a significant barrier to carrying out the changes necessary to institute person/family-driven systems of supports. Particularly problematic are: (a) the dual funding of specialized DD services (ICF/MR vs. HCB waiver funding) mandated under existing federal Title XIX law and the resulting limitations it imposes on the capacity of states to manage system-wide dollars in a holistic manner and (b) the lack of clarity regarding the latitude states may exercise in incorporating

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5 While the reliance of states on Medicaid dollars varies to some degree, on average around three-quarters of the funds expended by state MR/DD agencies now are derived from federal-state Medicaid payments.

6 It is worth noting that, while the total number of recipients of ICF/MR services have declined in recent years while the enrollment in MR/DD waiver program has continued to climb, 53 percent of the Medicaid dollars expended by the states ($9.6 billion) were claimed on behalf of ICF/MR residents (“Facts and Figures: Medicaid Long-Term Services for Persons with Developmental Disabilities,” NASDDDS, May 2000). At the time, over twice as many individuals were being served through HCB waiver programs (261,930) than ICFs/MR (117,895).
self-determined/self-managed service practices into the organization and management of their HCB waiver programs.

Reconciling the inherent tensions in managing a service system in accordance with person-centered, self-determined principles. These tensions include: (a) balancing individual/family choice with the health and safety of vulnerable individuals; (b) promptly furnishing services to all qualified Medicaid beneficiaries while remaining within the constraints imposed by fixed budgets; (c) maintaining public commitments to existing service system participants, regardless of the setting in which services are being furnished, while creating the additional capacity necessary to address unmet demands; (d) permitting consumers/families to exercise real control while assuring accountability for public expenditures; (e) integrating paid and natural supports in a comprehensive, personally-tailored service plan; (f) building a competent, stable workforce while controlling the growth in personnel costs, system-wide; (g) developing and utilizing valid personal and systemic outcome data to monitor and improve service system performance; and (h) balancing the obligation to monitor and enforce quality standards with efforts to promote continuous quality improvement.

Overcoming negative public stereotypes regarding persons with physical and cognitive disabilities. With the passage of the Americans with Disabilities Act and various other disability rights statutes over the past three decades, significant strides have been made in addressing this problem. But if the central goal of the current reform effort is to be achieved — i.e., helping people with disabilities to become valued participants in their local communities, rather than the targets of scorn and pity — the focus on changing public attitudes will need to be continued and intensified in coming years.

If state officials were able to isolate these various challenges and address them sequentially, the task might not be nearly as imposing as it is. But, the reality is that the various components of the change process are inexorably intertwined and, as a result, must be addressed simultaneously. Thus, in order to make person-centered, consumer-directed supports mainstream practice within its MR/DD service system, a state must orchestrate an incredibly diverse array of changes in funding, contracting and payment policies, quality management practices, organizational structures and cultures, management information systems and business practices, case management/service coordination sys-
tems and many other related areas. These changes, of course, have to occur at all levels of the service delivery system — within the state agency, local management entities (county/regional/area-wide authorities), service provider agencies, as well as among consumers and families — and be sequenced accordingly. Moreover, throughout the transition process, continued attention must be focused on individuals receiving services in traditional programs and settings in order to avoid a deterioration in the quality of services furnished to such persons. Overseeing a system in transition inevitably means operating with one foot in the new world and one foot in the old world, continuously attempting to strike a balance between the demands of both components of the service system.

III. Building a New Quality Management System

As pointed out earlier in this paper, one of the major challenges a state must grapple with in transitioning to a person/family-centered support system is the development of a quality management program that complements its overall system change agenda. Historically, state quality assurance programs have been built around facility/program licensing/certification requirements that rely largely on input and process measures to assess the appropriateness and quality of the services being rendered. On-site licensure/certification reviews typically have been conducted periodically (usually annually) to determine the program/facility’s compliance with state standards. The primary emphasis has been on policing provider performance, rather than to actively promote quality improvements. Until recently, relatively little attention has been directed toward assessing the quality of life experienced by individual program/facility participants, and then usually on an antidotal basis only.

Traditional approaches to assessing the quality and appropriateness of community MR/DD services are largely antithetical to many of the underlying concepts of individually tailored, consumer-directed supports. States, therefore, need to design and implement quality management programs that:

- **Include the capability to assess systematically personal outcomes and use the resulting information to improve the services and supports made available at an individual level as well as on a system-wide basis.** The process of designing and validating outcome measures, along with methods of systematically gathering, analyz-
ing and using the results, can pose serious, time-consuming methodological, logistical and practical problems. But, heeding the voice of the beneficiary of services is central to the concept of person-centered supports and, consequently, the capacity to assess personal outcomes needs to be a prominent part of a state’s quality management strategy.

- **Remove unnecessary requirements that have the effect of stifling innovation and preventing flexible responses to legitimate support needs.** Too often, state licensing, certification and other regulatory policies have tended to micro-manage the service delivery process, leaving little room for tailoring supports to the individual’s needs. As states transition toward individual support networks, it will be important to review all existing state and local authority rules and policies in an effort to strip out provisions that tend to impede flexibility without affording consumers or the public any demonstrable benefits.

- **Restructure traditional case management roles so that consumers, in concert with their circles of support, receive the assistance they need to develop person-centered plans and effectively manage the services and supports specified in such plans.** Most MR/DD service systems, historically, have expected the case manager/service coordinator to function both as an advocate for the individuals on his or her caseload as well as a gatekeeper for the system. As states put into place the infrastructure necessary to under gird individual networks of supports, these functions will need to be realigned to ensure that individuals and families receive un-conflicted assistance in constructing and overseeing the implementation of effective individual support plans.

- **Furnish service system managers at all levels – state, county/regional and provider agency – with prompt feedback on the results of quality reviews as well as other, critical performance information.** A service system in which consumers and their circles of support are encouraged to create personal support networks must, of necessity, be highly decentralized. Rule-bound, top-down managerial approaches simply will not work in this type of administrative environment. Instead, managers much have continual access to information on the service system’s performance. It, therefore, is important that quality management data be viewed as a central and integral part of a restructured management information system.
Include regular, structured on-site (field) reviews conducted by appropriately constituted teams consisting of qualified personnel not affiliated with any provider agency. The findings of these independent quality review teams should supplement the information provided by state licensing/certification reviews as well as the regular feedback received from case managers/service coordinators. Again, as the consumer, with the assistance of his or her circle of support, assumes primary responsibility for designing and overseeing the implementation of an individual support plan, the importance of having independent sources of feedback becomes a more vital component of a system for ensuring public accountability and protecting the health and welfare of vulnerable individuals.

Include explicit strategies for improving the quality and accessibility of publicly-funded services and supports. Quality management must be more than simply a way of policing compliance with minimum standards or operating requirements. It also must encompass a commitment to continually press for improvements in the service delivery process as well as the outcomes achieved by consumers. This suggests that the quality management system must be closely linked to the state’s training and technical assistance program objectives, so that as quality issues surface they can be promptly and pro-actively addressed, both within particular service agencies as well as on a system-wide basis.

Again, it is important to recognize that the task of restructuring a state’s approach to quality management is part of a larger system change agenda that a state must pursue if it is to successfully complete the transition to a service system that resolutely adheres to individual support principles. Thus, for example, installing improved systems for reporting, investigating and following up on serious incidents is an important step in building an effective quality management program; but, it also is a task that has significant implications for designing an integrated information system that furnishes program managers at all levels with the timely feedback they need to carry out their responsibilities competently and effectively. Similarly, the development of accurate and reliable methods of projecting resource needs and constructing individualized budgets is an important system reform task in its own right; but, it also has extraordinary implications for assuring the overall quality and accessibility of the supports provided to individuals, system-wide.
IV. Pennsylvania: A Service System in Transition

As is the case in many other states, Pennsylvania’s mental retardation program has evolved over the past 30 years from a predominately facility-based system, comprised mainly of large, public and private residential facilities, to an increasingly flexible and dynamic network of community services and supports tailored to the needs of persons living in the community. In 1966, when the Mental Health and Mental Retardation Act was initially enacted, over 13,000 individuals resided in state-operated residential centers and another 1,500 persons were living in large, privately-run, state-subsidized facilities. Today, less than 1,900 individuals reside in state-operated centers and under 1,300 in large, private facilities. In contrast, the Office of Mental Retardation currently furnishes services to over 74,000 children and adults living in the community, including 13,500 individuals who reside in small (15-bed or less) community residences (over 90% of whom live in settings with 3 beds or less).

In accordance with the provisions of the 1966 Act as amended, the community mental retardation system is managed through a network of 46 county MH/MR programs. The Office of Mental Retardation (OMR), a unit of the state Department of Public Welfare, establishes statewide policies and oversees the operation of the community MR system. OMR also is responsible for managing six state MR centers, plus one MR unit in a state psychiatric facility, as well as funding institutional care in privately-operated residential facilities.

While by any reasonable measure the changes in the Commonwealth’s mental retardation system had been dramatic, OMR officials, in collaboration with a broad spectrum of stakeholders, concluded in the mid-1990s that further, fundamental reforms would have to be pursued in order to make the service system more responsive to the needs of Pennsylvanians with mental retardation and related disabilities. Over the next two years, this decision led to the development of the Multi-Year Plan for Pennsylvania’s Mental Retardation System. The Multi-Year Plan, a collaborative effort of OMR’s Planning Advisory Committee (which is comprised of individuals, families, providers and advocates), lays out a broad blueprint for restructuring the state’s MR service system. In addition to establishing specific five-year goals (e.g., reducing the state

7 A Multi-Year Plan or Pennsylvania’s Mental Retardation System, presented to the Pennsylvania Department of Public Welfare by the Planning Advisory Committee to the Office of Mental Retardation, July 1997.
center population by 50% and transferring the funding of two-thirds of private ICF/MR beds to the state’s HCB waiver program), the multi-year plan resolutely embraces the goal of creating a future MR service system that is consumer-driven, value-based, outcome-oriented and cost efficient. These guiding principles were a logical extension of the 1991 publication of “Everyday Lives,” which established a consensus regarding the basic values that would guide the system for the next decade.

The Multi-Year Plan centers around achieving two primary goals: 1) reforming the existing service system; and 2) meeting the backlog of unmet needs represented by lengthy service waiting lists. Following the adoption of the plan, it soon became apparent that OMR would need to develop a more explicit waiting list reduction strategy, so the state Planning Advisory Committee was asked, once again, to work with Agency officials in developing *A Long Term Plan to Address the Waiting List for Mental Retardation Services*. The final waiting list plan, released in October 1999, adopts the fundamental premises of OMR’s Multi-Year Plan to guide the required service expansion (i.e., person-centered approaches; consumer choice and control over resources; personally defined outcomes; financial accountability; and health and safety safeguards).

Earlier this year, Governor Tom Ridge embraced the objectives of OMR’s waiting list reduction plan and committed state government to go beyond recommendations in the plan to expand services over a five-year period in order to achieve a capacity in residential services of 185 individuals per 100,000 in the general population. OMR’s FY 2000-01 budget, which was approved in final form by the General Assembly in June 2000, includes $51 million new dollars to extend community services to 861 additional individuals, as the first step toward reducing the waiting list for residential services, with an additional 906 individuals to be removed from the residential waiting list during each of the ensuing years. In addition, the budget includes funds to: (a) expand support services to over 2,000 people living with their families; (b) place an additional 221 state center residents in the community, thus continuing OMR efforts to downsize the census of the six state centers; and (c) support various infrastructure improvements aimed at improving the system’s capability to manage services on a person-centered, consumer-driven basis.
Thus, Pennsylvania has embarked on a course of expanding access to public-funded mental retardation services while simultaneously restructuring the service delivery process to achieve the broad system change goals outlined in the Agency’s Multi-Year Plan. This is a highly complex undertaking that involves a carefully orchestrated series of changes in policies, procedures and practices at various levels of the service delivery system.

Recognizing that the state’s existing management information system will have to be retooled to meet the demands of providing consumers with more control over their individual budgets and monitoring for quality, last year OMR retained Deloitte Consulting LLP, a large, nationwide consulting firm, to assist Agency officials in designing a new information system. It soon became apparent that revising OMR’s management information system was just one component of a whole array of changes in policies, procedures and practices that would have to be undertaken if system reform efforts were to move forward. With the help of the consultants, a series of task forces and work groups, comprised of Agency officials and stakeholder representatives, were established to hammer out a comprehensive system restructuring strategy. This strategy, called the “Transformation Process,” is being implemented in four distinct, sequential phases: (a) the creation of the vision and a master plan for the strategic use of technology (Phase I); (b) a detailed design phase that involves the development of new and standardized business processes — e.g., consumer enrollment, individual planning and budgeting, payments for services, and service monitoring (Phase II); (c) a “construction” phase in which the core components of the MR information management system are to be developed, along with a prototype OMR web page (Phase III); and (d) an implementation phase in which the new business processes and core management information system are put into place. The entire transformation process began in September 1999 and is expected to be fully realized by June 2003.

In addition to enabling consumers to direct their own services, the Transformation Process also will result in the development of a Quality Management (QM) program. The QM program is designed to focus greater attention on health and safety, consumer outcomes, and resource utilization as control is shifted to individuals and families. The program consists of new organizational units within state and county governments and quality assurance and improvement processes to be carried out by each governing entity.
Among the steps that have been taken to date are:

- **An OMR Bureau of Quality Management and Policy** has been created within the state office to oversee the design and implementation of the restructured Quality Management Program; and **Quality Management Field Staff** have been hired and assigned to OMR’s four regional offices. In addition, **Quality Improvement Teams** are being established in each of the six state mental retardation centers. The purpose of these teams, which are expected to be operational in all state-operated facilities by December 2000, is to assure the health and safety, enhance the quality, and improve the accountability of the services rendered to facility residents.

- A **State Toll-Free Hot Line** has been set up to receive inquiries and complaints. The information received from all callers is being treated as confidential communications.

- **County Independent Monitoring Teams** (IMTs), made up of individuals with disabilities, family members, and other interested citizens, have been formed to conduct reviews that focus on the life quality of beneficiaries of OMR-funded community services. The mission of the IMTs, which function under contracts with county MH/MR programs, is to: (a) identify outcomes achieved by persons receiving state-funded supports; (b) measure achievements; (c) recommend improvements; and (d) continually promote the value of *Everyday Lives*. Thirty-five county MH/MR programs had contracts with IMTs as of April 2000, and OMR anticipates that the remaining 11 county programs will have similar contractual arrangements by November of this year.

- **Pennsylvania** is among the 15 states participating in NASDDDS’ **Core Indicators Project**, a collaborative, inter-state effort to collect and analyze valid and reliable information on the outcomes and performance of state MR/DD service systems. County IMTs have combined the Core Indicator survey with the standard monitoring survey to reduce the number of interviews consumers and families will have to participate in. Unlike the other participating states, Pennsylvania has elected to gather data on a large enough sample of system participants to draw valid intra-state (county to county), as well as inter-state (state to state) comparisons. OMR’s aim is to give system administrators and the interested public access to objective data comparing county to county performance along a number of key dimensions (e.g., consumer and family satisfaction and outcomes; health and safety; etc.).
**COUNTY HEALTH CARE COORDINATION UNITS** (HCCUs) are being established across the state to monitor the health status of individuals receiving community MR services. Staffed by a team of qualified health professionals, the HCCUs are responsible for building capacity and competency to meet the physical and behavioral health care needs of people with developmental disabilities living in Pennsylvania. The primary activities of HCCUs include: (a) the assessment of individual health and systems of health care; (b) providing clinical health care expertise to counties as well as residential and day service providers; (c) health-related training; (d) linking community health care expertise with county MR programs as well as residential and day service providers; (e) integrating community health care expertise with state/regional quality improvements structures and processes; and (f) health advocacy. As of June 2000, four HCCUs were in operation in various parts of the state. By the end of the year, OMR hopes to have a complete, statewide network of HCCUs in place, linked contractually to all 46 county MH/MR programs.

**HCCUs will conduct HEALTH RISK ASSESSMENTS** to screen for physical and behavioral health risk factors and provide health care services targeted to identified needs among persons with mental retardation who live in the community. A health risk assessment (HRA) is a standardized instrument designed to pinpoint physical and behavioral health risk factors among the population being served through county MR programs.

Other activities to improve monitoring activities are:

- **OMR has developed a proposal to divide the existing RESPONSIBILITIES OF COUNTY CASE MANAGERS** as part of its proposed system Transformation Process. Subject to stakeholder feedback, the current plan is to split case management functions between county administrative staff and a newly created network of support coordinators. The support coordinators would be responsible for: (a) advocating on behalf of the individual and family; (b) assisting the individual and his or her circle of support to identify needs and select service providers; and (c) monitor the quality of the services and supports delivered to the individual/family. Meanwhile, the county administrative staff would: (a) authorize the use of public funds in accordance with the provisions of approved person-centered plans; (b) approve individual plans of care in final form; and (c) monitor the performance of community provider agencies/practitioners.
A revamped system for managing unusual incidents is being instituted. To date, OMR has prepared a draft redesign of the standards and procedures to be used in reporting, investigating and managing unusual incidents. By the end of the year, OMR plans to promulgate final policies and procedures as well as train county staff on procedures for investigating serious incidents such as abuse, neglect, and deaths.

Consumer and family choice will increase with the implementation of a County Invitation to Qualify, which will open contract enrollment annually to all qualified providers that wish to participate in the program. To assist consumers and families, a Provider Resource Directory will be included on OMR’s website, along with provider performance reports.

Since January, OMR has been in the process of designing a Quality Management Database as part of the overall process of upgrading and realigning the system’s management information capabilities. By early 2001, OMR plans to have the basic elements of this database in place. It will include all data from IMT reviews, Core Indicator data, health risk assessment information, waiver monitoring reviews, and incident reports. Over the succeeding two years (2001-03), the core information system requirements will be extended to all 46 county MH/MR programs.

Public reporting is an important part of any quality improvement program. OMR has created a website to provide the public with progress reports on the Transformation Process and intends to publish regular reports on the performance of individual providers as well as the service system as a whole. These reports will be based on valid and reliable information.

All of the above initiatives are being developed as part of a comprehensive Quality Management Program and implemented in tandem, rather than on a piecemeal basis. The aim is to create a quality management system in which component activities are engineered to interact with one another and, in the process, produce an accurate, well-rounded picture of service system performance. The subsidy aim is to build a system with feedback loops that lead to prompt corrective actions as actual and potential trouble spots are identified.
The most eloquently designed quality management system, however, is doomed to fail unless it is linked to efforts to improve essential components of the service delivery infrastructure. This truism is nowhere more apparent than in the maintenance of a competent, well-qualified workforce — the heart and soul of any community services system. In this area, the Commonwealth faces the same challenges as many other states. Unquestionably, the state’s booming economy and the additional tax revenues it has generated has permitted policymakers to address pro-actively a variety of issues that have festered for many years (e.g., the waiting list crisis). But, a full employment economy also has created stiff competition for the element most critical to providing high quality services and supports — well-qualified, dedicated front-line staff.

The Pennsylvania Office of Mental Retardation is attempting to address this problem by assigning workforce improvement and stabilization efforts a prominent place in the system Transformation Process. The Governor’s Five Year Plan to Address the Waiting List recognized that historical reimbursement levels would be inadequate to support new services. Consequently, the plan incorporates additional resources to assure stable, high quality services. The OMR Transformation Process has as one of its five elements, the design and operation of a competency based training program. The Department of Public Welfare, the state’s umbrella human services agency, has begun to work collaboratively with the county programs to develop alternative workforce stabilization strategies, such as the provision of technical assistance to help county MH/MR programs and community provider agencies address critical staff recruitment, retention, and turnover problems.

V. Conclusion

State policymakers and administrators face enormous challenges as they strive to build quality management systems capable of accommodating the demands imposed by 21st century service delivery systems. These challenges include reconciling the sometimes contradictory forces that shape current service delivery policy and practices. On the one hand, for example, a rapidly growing number of individuals and families want to exercise greater control over the manner in which public dollars are deployed to meet their
unique needs; yet, at the same time, federal, state, and local officials are demanding more rigorous safeguards to protect the health and safety of recipients of public funding. Efforts to assure service quality and protect beneficiaries should not trample on the rights of individuals and families to live lives of their own choosing. Yet, the taxpaying public and its elected and appointed representatives have every right to expect that the beneficiaries of government assistance are safe and secure and that public dollars are used in an accountable manner. An effective quality management system must be capable of balancing these competing interests.

When the number of individuals receiving publicly-funded community MR/DD services was smaller, individual monitoring by service coordinators, backed up by periodic state licensing reviews, may have been adequate to ensure the health and safety of program participants. But, with thousands and thousands of individuals (over 75,000 in Pennsylvania) now relying on supports furnished through an increasingly complex web of community provider agencies/practitioners, new more sophisticated tools must be developed to assure and improve the quality of such services. The need for such tools will be accentuated as states transform their existing community service systems into ever more diverse networks of person-centered supports. Among these tools are state-of-the-art, fully integrated data tracking systems which permit system managers at all levels to assess and analyze outcomes, identify shortcomings (both at an individual and system level) and institute corrective actions. The capability of analyzing serious incident patterns, for example, can assist county and state managers to identify and target technical assistance resources and training activities. Similarly, well-structured consumer/family satisfaction data can help guide decisions regarding needed modifications in policies, program designs, service practices, training, and technical support.

The aim of this paper has been to sketch out the major challenges that states face in developing comprehensive quality management programs which accommodate the historic changes that are occurring in service delivery policies and practices, and illustrate how stakeholders within one large state MR/DD system are attempting to address these
challenges. The major lessons that can be derived from this brief analysis are that: (a) modifications in a state’s existing quality management system need to be developed and implemented in tandem with other major service system reform initiatives; (b) a state’s quality management program must be capable of simultaneously assuring and improving the quality and appropriateness of the services and supports furnished to individuals with disabilities, systemwide; and (c) the use of modern communication technology to collect, analyze, and track performance across the service system must be viewed as an integral and essential part of a state’s quality management program, especially in states with very large community service caseloads. The task of building such a quality management system is complex and resource intensive; but the evidence suggests that, indeed, it is possible to protect the health and welfare of vulnerable individuals and assure public accountability within a service system that honors the principles of consumer choice and control.
To enhance the ability of states to ensure quality in a highly decentralized system of supports, states need to move from a “mom-and-pop” management approach to a more sophisticated and intentional approach.

To create and enhance individual supports will ironically require a significant level of bureaucratic complexity — both to dismantle conventional congregate services and to restructure based on a more person-centered model.

Briefly, I’d like to point out some things that really stood out for me in the paper and that I would strongly endorse. First is the rethinking of service coordination or case management. We have been trying to reinvent case management for the 30 years I have been in this field, and we still haven’t reached the ideal. To get closer to that ideal, we need to think about how to peel away all the administrative functions that have been layered on to the basic brokering function.

Further, in order to broaden the audience for quality information, we need to make our public systems more transparent through the broad dissemination of information. This data on quality belongs to all of us — particularly to the people and families who use services.

In thinking out priority areas in quality we oversee, we should stress health and wellness issues. Pennsylvania and Massachusetts are at least two of the states that are developing ways of surveying health status of individuals in communities. I am convinced that health issues represent a potentially serious challenge to a lot of states. Our data, certainly in the Core Indicators projects, suggest there are clear warning signs that, if not heeded, may put some individuals with developmental disabilities in serious jeopardy. Health monitoring should include a variety of issues including a strong mortality reporting system.
The staffing issue is absolutely critical for many individuals. For individuals living in small, supported settings, the person who provides the support is the system to the individual with a disability. So, unless we can insure that these supporters are competent and understand what quality means, we are in deep trouble.

There are some issues, although touched upon in the paper, that should also be emphasized. For example, though we all espouse a belief in person-centered approaches like person-centered planning and positive behavior approaches, in many states knowledge regarding these important components is a mile wide and an inch deep. The situation is made worse by staff turnover and the need to continually train and build competency in these areas.

There are some other challenges faced by states that, unlike Pennsylvania did not make some of the same decisions early on in the development of community services. Specifically, Pennsylvania decided not to expand the ICF/MR program in the community, and instead used the Medicaid Home and Community-Based Waiver to generate small community residences called CLAs. Many states were not as prescient. Some are still expanding ICFs. Unlike Pennsylvania, many states still don’t have sufficient authority over Medicaid policy. In fact, in some states the power of the Medicaid agency over DD policy is continuing to grow, threatening the person-centered character of emerging supports. Finally, Pennsylvania managed to separate DD from mental health several years ago which gave added energy and focus to the growing community system.

Finally, we need to continue to focus on the importance of collaboration and trust among the advocates, providers, and the managers in order to make quality attainable.
Thaler and Gettings point out that most of our current policies and practices (the “It”) are not consistent with contemporary values (the “We”) that are clarifying our vision of how we ought to support each person (the “I”) in our system. They note the challenges in reforming a $30 billion industry which is based upon a different era’s values and perceptions of people with the most significant disabilities. They then present Pennsylvania’s well-conceived, comprehensive approach to increasing quality while reforming its system.

It is important to note that Pennsylvania has been one of the places in North America in which the voice of the “I” has been best listened to over the past two decades. Listening to that voice has influenced the values represented by the “We” and the policies and practices of the “It.” That voice and those values are obviously present within the transitions occurring in Pennsylvania. Understandably, however,
the greatest emphasis in terms of time, money, and attention in Pennsylvania’s planning is within the administrative and service structure.

One reaction to that emphasis is to paraphrase Einstein and to suggest that complex problems cannot be solved primarily at the level at which they were created. The evolution of Pennsylvania’s comprehensive transition plan (as well as future efforts of other states) might be enhanced by a substantial increase in time, money, and attention focused on greater involvement of the people we serve and those who love and care about them in both planning for systems change and in day-to-day implementation of those plans. A resource that would help guide such involvement in relation to issues of quality is Assistance with Integrity: The Search for Accountability and the Lives of People with Developmental Disabilities written in 1993 by John O’Brien and Connie Lyle O’Brien of Responsive Systems Associates in Lithonia, Georgia.

States’ work in organizational reform and quality management would be further enhanced by going beyond the use of traditional business consultants, such as those used by Pennsylvania in its planning process, to learn from and with today’s most influential and highly-respected leaders in reform of business, government, religious, and non-profit organizations. Such individuals include Margaret Wheatley and Myron Kellner-Rogers at the Berkana Institute (www.berkana.org), Dee Hock at the Chaordic Alliance (www.chaordic.org), and Joseph Jaworski and Peter Senge at Generon Consulting (www.generonconsulting.com). These individuals and others with whom they work share a belief that the substantial reform needed in how we work together is based not upon the business values of speed and efficiency, but rather upon a deep understanding of the spiritual and purposeful nature of the universe, a focus on the power of love, and a recognition of the importance of sustaining and creating community.
It is with pleasure and respect that I offer the following reaction to my colleagues’ thoughtful paper. I concur with the principal factors for change identified, with the identified “tensions” that exist as systems move forward, and commend Pennsylvania for its efforts.

In Michigan we have made some of the systemic changes necessary to facilitate person-centered quality. For example, person-centered planning (PCP) has been required by state statute since 1996; we have a one-of-a-kind Medicaid 1915(b)/(c) managed care waiver which allows for highly flexible services and supports for persons with developmental disabilities; we have a Quality Management System that has been identified as “Best Practice” by the HCFA Regional Office during their monitoring visits; and we have fewer than 270 persons with developmental disabilities residing in state operated ICF/MR centers.

Yet even with these changes, we are also a state with two potential Olmstead-related complaints being considered; where PCP is not uniformly implemented throughout the community-based system; and where more than 10,000 adults with a developmental disability receive services in segregated day programs.

If we want to achieve those things identified in Nancy and Bob’s paper, that is to “...permit consumers/families to exercise real control while assuring accountability for public expenditures” and measure and improve quality through the assessment of “personal outcomes,” there are additional factors to consider.

When does the state’s expectation for specific outcomes or preventive action (e.g., health and safety) outweigh the individual’s sovereignty to make choices or purchase goods to achieve personal outcomes? One example, not specific to developmental
disabilities, is the use of helmets when riding motorcycles. Some states require this “merit purchase” in order to protect the health and safety of individuals and to protect the state against the higher public costs associated with accidents. These discussions about the state’s responsibility for health and safety are legitimate, but are determined locally. Therefore, consensus on how to proceed will likely vary by state.

Quality should be measured based upon the exchange that is occurring. Therefore, quality should be measured differently for the exchange between the state and its provider/managers and the exchange between the individual with disabilities and the provider of service. How does a state’s quality management system do this and meet the goal of allowing the individual to exert real control? On one level, quality must meet the assurances made by the state to the federal partner and therefore review quality in the aggregate. However, the state’s quality system can also aggregate individual consumer preferences which in turn signals the creation of “markets” where individuals can make purchases. Further, the aggregation of individual perceptions of quality can lead to the creation of information to assist individuals in making choices in the newly created markets and avoiding the potential opportunism of providers.

It is hard work to assure that persons with disabilities are afforded the capability to function, the freedom to choose, and the opportunity to achieve. It is our role to continue to identify the challenges, both social and economic, and pursue the struggle.
Session 4

A Provider Perspective

Creating the Conditions for Self Determination

Presenter

Arthur Dykstra

Reaction Panel

Kevin Casey
Susan Fox
George Jesien
I. Introduction

That we are in the midst of an evolution within the developmental disabilities service and support system seems apparent. This evolution reflects movement from an expert driven “trust me to know what’s best for you” approach, to one that recognizes the authority of the person in matters of decision making and personal control.

As suggested by this Wingspread Conference, the values and importance of such a direction are becoming more accepted and operational. The “how to get there” factors, however, are still unfolding.

As Elliot Jaques has observed, “the complexity of a problem does not lie in the complexity of the goal (self determination), but in the complexity of the pathway that has to be constructed and then traversed in order to get to the goal.”

The remainder of this paper seeks to outline some of the significant and complicated issues that are being confronted in attempting to unfold greater patterns of self determination. And, lastly, to identify some possible areas that might be explored in developing practices and pathways to a more effective public policy regarding persons with developmental disabilities.

ENLARGING THE CONTEXT A model to help visualize the change occurring might be drawn as a series of interlocking circles. First, a crescent moon of the smallest circle is being shed (a). Secondly, the next circle is larger because the potential of what is emerging and evolving is greater than has existed until now (b). Another circle grows out of the second (c), and so on. A third, critical aspect is the area of overlap between the circles. This intersect provides grounding spiritually and emotionally in the same way gravity serves us physically. Leadership in a New Era, edited by John Renesch.
One final introductory note, having had the opportunity in my career to administer supported employment programs, support coordination programs, a school, developmental training programs, and a variety of other services and supports, no responsibility is as scary and challenging as being responsible for the provision of residential supports and services. I still remember the words of the regional director who appointed me to the position of residential services director, “this job,” he said, “is about keeping people alive.”

This paper is being written from the perspective of an organization that provides residential supports and services to people with developmental disabilities across a wide spectrum of residential living alternatives.

II. Some Background Issues

Because of the limited length of this paper, the following issues will not be fully developed. Hopefully, however, enough discussion will occur to identify the significance of the observations.

A. The Use Of Public Monies

Balancing the concerns of health, safety, and welfare with the achievement of personal outcomes and self determination (hereafter referred to as the Balance) generally occurs through the use of public monies.

This fact in and of itself requires much thought, especially when considering individual budgeting. The stated ideal is that each person should develop his or her own budget. But how much money is available? What economic lifestyle will taxpayers support for people with disabilities?

This issue is extremely critical in considering the Balance; it is my thought that most individual budgets will not allow for enough monies for the person to purchase the necessary and significant health and safety supports.

Because public monies are the primary financing vehicle, it is reasonable to expect that public accountability for these monies is a necessary consideration. Many of the outcomes that a person with disabilities seeks are considered “soft and nice,” whereas such activities as monitoring, auditing, and environmental safety checks are seen as “hard and necessary.”
Recently, a number of United Way volunteers visited the home of four people whom our agency supports in the community. At the conclusion of the tour, two of the volunteers expressed their concern that the house was extravagant (it wasn’t) and wanted to know if taxpayers’ money was paying for the home.

The extent to which the general public is concerned with the manner in which dollars are expended is not to be underestimated.

B. BEING DISABLED

Humanness, the desirability of achieving personal outcomes and meaningfulness, is enormously important in moving towards a structure and system of self determination.

There remains, however, a need to be mindful of the reality of disability, to recognize the reality of intellectual impairments when they are present, and not to return to the old ways but to ensure the fact that we do not mislead the person with disabilities, nor the persons he or she interacts with, nor the general public.

In moving forward, we need to remember that some people will or do learn more slowly than others, some may not remember facts and experiences as long as others, and still others have very brief attention spans and need much repetition in becoming more personally masterful.

Obviously, one can make the above learning statements regarding any population group of our society, but it is essentially because of the presence of a disability that public monies become available to people with intellectual disabilities. It isn’t because they lack friends, don’t own their own home, or need help in planning their vocations.

Economic support for persons with developmental disabilities comes as the result of a public recognition of unusual vulnerability.

AN UNEASY FEELING:

I am beginning to develop an uneasy feeling with respect to the future for those who in the context of intelligence testing are characterized as being “mildly retarded.” If the message of certain self-advocacy groups and others is only heard as “we just want our
rights, we want jobs, we want to do our own budgeting,” and so on, it is conceivable to me that in an uncertain economic future, public policy could emerge that would substantially limit the financial revenues such individuals receive and follow the impetus of the welfare to work reform, meaning that able-bodied, mildly intellectually impaired individuals will be required to seek and find employment or lose many of their benefits.

III. An Assessment of Risk

It is well understood that persons with developmental disabilities are unique with respect to their needs and wants, as well as their strengths and weaknesses. From this understanding comes the realization that achieving the Balance is a greater challenge for some persons than others.

In the absence of empirical data, it is proposed that the Pareto Principle may be at work here. That is, 20 percent of the individuals being served and supported may account for 80 percent of the significant worry and challenges of risk management.

The principles of self determination, freedom, authority, support, and responsibility no doubt apply to individuals who are without language, perhaps bedfast, or without self-help skills. In all likelihood, however, these people will be living in settings of greater staff support and experience less environmental and personal risk than those who are a part of the less staff-intensive residential support environment.

As our organization moves to support more and more individuals in less formal living arrangements, often because of their stated request, the following situations and circumstances create the greatest challenge. These experiences are, in all probability, consistent with the experiences of other providers across the country.

SERVING PERSONS WITH THE DUAL DIAGNOSES OF MENTAL ILLNESS AND MENTAL RETARDATION Of concern here are such issues as the ebb and flow of psychotic conditions, a frequent refusal to take necessary medications, suicidal threats and attempts, and a tendency for some people to socially isolate themselves, including a refusal to allow visitors in their homes or apartments.
- **PERSONS WHO REFUSE TO FOLLOW HEALTHY LIFESTYLES**  Of concern here are individuals with major health problems who are unwilling to keep their medical appointments as recommended or directed. Still others refuse regular physical checkups even if their age or medical condition warrants the same.

Also included in the category of health risk are those individuals who are elderly, those who are subject to premature aging, falling, or specific respiratory problems, etc.

- **PERSONS WITH SIGNIFICANT DISABILITIES WHO ARE REARING CHILDREN**  Of concern here are psychologically complicated reactions to childbirth, marital difficulties, the health of the child, child-rearing skill development, and the management of competing responsibilities.

- **PROBLEMATIC FRIENDSHIPS**  It may not be as prevalent in rural environments as in urban neighborhoods, but the possibility of associating with persons seen as problematic in our society is already happening.

Joining or being exploited by community gangs in carrying out criminal activities is one possibility. Being taken advantage of financially or sexually are still other possible consequences. Being exposed to drugs, and all of the related behaviors, theft, shoplifting, disease, etc., is common.

- **UNSAFE SEXUAL PRACTICES**  In spite of sex education efforts and counseling, many persons with disabilities, just as in the general public, participate in unsafe sexual practices.

The concerns of the residential provider obviously become greater when such persons are known to be HIV positive, to have sexually transmitted diseases, or, for that matter, to have a criminal background.
**Patterns of Enhanced Risk** There are a number of other areas of concern that cause providers to confront the Balance.

- **Smoking** Persons who live in their own apartments or homes and engage in careless smoking behavior are frequently supported on an intermittent staff basis. Obviously, there are many opportunities for smoking to occur when there is no staff supervision available.

- **Anger Management** Many individuals who live in community settings have developed the skills and abilities to live quite independently — except for certain occasions when they may not be able to manage their feelings of anger. The consequences can be significant and include loss of residence, physical harm to themselves and others, and even arrest and incarceration.

- **Food Selection and Preparation** It is not infrequent that as certain individuals with disabilities experience failing health that medical professionals may, for example, recommend the use of pureed food preparation. It may even take the form of “doctor’s orders.” Some people with disabilities choose not to follow such food practices. Achieving the Balance in these situations is not always easy.

- **Other Situations** Of additional concern are such issues as the presence of self-injurious behavior, significant money management difficulties, gambling, and disorientation (particularly with persons traveling in unfamiliar areas).

The above mentioned situations are not only challenges to providers, but also to funding and regulatory bodies as well. The fear of most providers is that in supporting individuals to achieve greater patterns of self determination, some major untoward event will occur that, apart from being catastrophic to the person, will put the provider organization at risk.

At risk is being defined here as a loss of community support, financial resources, or reputation. Obviously, such consequences will come to affect the lives of all other persons who are being served and supported by the organization. As one particularly nervous provider expressed, “there is a clear conflict between the forces of personal and mass salvation.”
It is unlikely that one or two single decisions or insights will enable stakeholders to achieve or maintain the Balance. And as has been suggested, the Balance may in fact be different for different people. What is key in managing this dilemma is that we must know the people we are serving and supporting.

The following ideas are offered for consideration in attempting to create additional pathways towards the goal of creating a structure and system that maximizes self determination.

A. SERVICE AGREEMENTS  Achieving agreement between persons seeking services and supports and the provider of such should occur early in the relationship, and it should be done in writing. Developing such an agreement allows for open communication regarding risk and responsibility. It’s a mutually benefiting process and document. Such agreements provide an additional ongoing basis for dialogue concerning issues important to both parties.

B. A VULNERABILITY SCREEN  Basically, a vulnerability screen considers the presence of vulnerability and possible risk with respect to personal and environmental safety factors. It is not a readiness screen designed to hold people back from the community.

The screen would not just be one more check list, but it would be an instrument to provide support staff and those state and federal agencies involved in funding or monitoring to be aware of the need for the differential application of resources.

Greater attention might, therefore, be given to those who are more vulnerable rather than following the simplistic practice of “everybody gets everything.”

C. EMPOWERED HUMAN RIGHTS COMMITTEES  Most provider human rights committees are under utilized and under nourished. Such committees can be incredibly valuable in attempting to achieve the Balance, especially when the committee includes a number of people with disabilities. Challenges confronting the Balance could be worked through with staff of the provider organization and the person pursuing a course of action that caused concern to others. The well-known feasibility, benefit, and acceptability dimensions or stages of Interest-Based Bargaining could be utilized. Human rights com-
mittees should be challenged to do more than review behavior plans. Such committees provide support to both the person with disabilities and the provider agency.

**D. PURCHASERS, NOT CONSUMERS** More and more, people are expressing dissatisfaction with the term “consumer.” The problem being that the term consumer generally communicates a mental image of “using up” rather than one of “producing.” Unfortunately, the concept being expressed is most frequently in the context of tax dollars, not goods and market place services.

It is likely that if a reference designation is necessary, the term “purchaser of services and supports” would facilitate self determination and increase personal authority with respect to determining acceptable levels of risk.

As the general public comes to realize that persons with developmental disabilities are in fact purchasers and not just consumers, future acceptable standards for matters of health and safety will hopefully become more of a partnership effort.

**E. TECHNOLOGICAL RESOURCES** A great many options exist for expanding the use of computers, pagers, cell phones, and Web TV in ensuring that basic health and safety concerns are being addressed. In most circumstances, the person with disabilities would determine the scope, variety, and frequency. This gives even greater personal freedom. An approach of more intensive interaction might also be utilized if service agreements were not being followed and a clear pattern of harm or danger emerged.

**F. CO-EVALUATION EFFORTS** As suggested in *Evaluation with Power*, published by the Independent Sector (1999), future approaches to evaluation efforts, including matters of health, safety and welfare, and self determination, will likely occur through an approach known as co-evaluation. All stakeholders could be involved in this process.

“Co-evaluation is the means by which an organization continuously learns how to be more effective. It provides a means of organizational learning, a way for the organization to assess its progress and change in ways that lead to greater achievement of its mission in the context of its vision. A process and not an event, it is ongoing rather than episodic. As it becomes ingrained in day-to-day operations, the participants see results in terms of improvements in their own work and the teams’ achievement of
outcomes, as well as the organization’s functioning as a total system because of the interdependent nature of the process. Evaluation got its unfortunate image by being a report card, an after-the-fact rating that came too late to permit any improvement. Co-evaluation is a tool, always in use, always opening the door to the next beneficial step.”

Such efforts in the context of this discussion could easily incorporate relevant provider performance indicators being self reported to a central body, a state department, or private party, such as The Council on Quality and Leadership for example, thus allowing for benchmarking and performance improvement. These measures could be bolstered when necessary with technical assistance and consultation.

V. Summary

The challenges of balancing health, safety, and welfare concerns for persons with developmental disabilities with the achievement of personal outcomes and self determinations is real and of growing importance, especially in light of the fact that more and more individuals are living in the community with less and less 24-hour staff supervision.

This fact, coupled with the reality of insufficient economic resources, requires new or revised pathways of response and approach. What is suggested in this paper is that matters of personal and environmental risk be evaluated on the basis of crafting alternative strategies for each particular risk situation. Emerging from this consideration would be the development of suggested guidelines and Best Practices.

Lengthier or computer generated plans of correction and faster fire drills are not the answer.
Reaction to Art Dykstra’s Presentation on Creating the Conditions for Self Determination

Session 4
Kevin Casey

I. The real problem is self determination
   A. Real choice
   B. Real respect
   C. One more good idea perverted

II. The real problem is health and safety
   A. Person-centered training
   B. The monitoring and accountability mess
   C. Person-centered monitoring

III. The unreal excuses
   A. Staff salaries and turnover
   B. Darn those families
   C. Darn those consumers

IV. The real bottom line
   A. Provider accountability
   B. Rewards and consequences
   C. You can’t do business in my state

V. There is no conflict
   A. Self determination and health and safety can co-exist
   B. Stop making excuses
I react to Art’s paper on the issue of balancing the concerns of health, safety and welfare of persons with developmental disabilities with the achievement of personal outcomes and self-determination wearing two hats.

One hat is as a state administrator who is charged with managing millions of public dollars for the provision of supports and services to persons with developmental disabilities and monitoring the quality of those services. The other hat is as a mother of a daughter receiving support through this publicly-funded system.

On one hand, I worry daily that some catastrophic event will occur and the public will view the system as having acted irresponsibly in allowing persons the freedoms and choices that led to the event. On the other hand, I experience great frustration as my daughter is assessed and months pass by while a safety program is set up to allow her to take a walk and cross the street on her own, even though she has been allowed these freedoms at home her whole life.

I understand fully the risk management issues that the system must be concerned about. However, we cannot let these fears become an excuse for not affording persons basic dignity, respect, freedom, and responsibility. Similarly, we cannot let choice be the scapegoat when things go wrong. The system is responsible for providing for individuals’ basic health and safety. John O’Brien has stated, “Choice is not a reason for a person to live in an unsafe place. Choice is not a reason for a person to live in filth. Choice is not a reason for a person to smell bad. Choice is not a reason for a person to inflict self-harm.” It is never acceptable to allow someone to be exposed to abusive or neglectful situations and use “it was their choice” as the excuse. Here lies the real balance we must strike between allowing people freedom to choose while assuring...
their health and safety and we cannot let that balance tip too far in either direction.

I agree with Art that well-written, clear service agreements that spell out each party’s responsibility are important to both the provider and the individual. Equally important is educating families and individuals of the risks involved in certain choices and helping them to make informed choices. Decisions which are well documented in service agreements and made based on informed choices should help providers feel more confident in supporting a decision that they may not fully agree with.

I believe there is another very powerful and effective safeguard that exists for people with developmental disabilities and that is their connection to family, friends, and community. When a person is well connected to family and friends and well known in the community, effective formal and informal protections are in place. It is important to work to maintain and strengthen each person’s ties to their family, friends, and community.

Another critical safeguard is a well trained and adequately paid direct support workforce. Direct support professionals are the keystone of today’s service system and often have the closest relationship with the individual. Well trained staff, committed to providing high quality supports and services, are the front line defense to protecting each individual’s health, safety, and welfare. Training is critical and the skillset necessary for staff today is quite different. Staff must be skilled in facilitation, working with families and allowing people to experience their independence and free choice.

None of the areas listed by Art Dykstra or the additional areas I have noted above are easily achieved. But, in order to achieve the Balance that Art discusses in his paper, these are just a few of the challenges that must be addressed.
Reaction to Art Dykstra’s Presentation on Creating the Conditions for Self Determination

Session 4
George Jesien

Background

The purpose of this paper is to outline some of the significant and complicated issues to be confronted to create greater self-determination.

This paper uses the analogy of constructing a “pathway” to be traversed to getting to the goal. Also, it characterizes the role of providing residential supports and services “as scary” given the responsibility facing providers.

The paper describes two background issues — use of public monies including the perception of the public on how tax dollars are being spent and the need to be mindful of the reality of having a disability. It then proceeds to enumerate and describe a series of risk assessment challenges including dual diagnosis, lifestyles, problematic friendships, unsafe sexual practices, etc. Possible recommendations for dealing with these challenges are proposed, including service agreements, vulnerability screens, empowered human rights committees, use of tech resources, and co-evaluation efforts.

Reactions

Clearly there are many dangers and challenges that will have to be addressed as consumers and family members move toward a more consumer-oriented implementation of residential and support services. But at the risk of sounding naïve, do we focus from the start on the problems and challenges or do we deal with each challenge as the vision of what could be fleshed out? The dangers and risks are
real as are the concerns for health and safety, but can they overshadow and slow the process of making a system more flexible and responsive to individual needs? I believe they can.

Maximizing opportunities and minimizing risk will be a difficult challenge. What we focus on will help determine how far we can go in moving the change process. Historically, each time we have pushed the envelope for additional opportunity we have been surprised how the challenges have been met and the many feared dangers avoided or minimized. The “balance” and whether it slants toward safety or freedom will in great part be determined by where we focus our time, effort, and resources.
A Service Coordination and Point of Entry Perspective

Barriers to Self Determination — What’s Next?

Presenter

ALAN GREENE

Reaction Panel

STEVEN M. EIDELMAN
ELIZABETH PRIAULX
LINDA TIMMONS
I. Introduction

Twenty-five years ago many people in America were drawn to a cause. They set out to right a wrong — to free people who, because they were different, because they had a developmental disability, were locked up. These seekers of justice set out to create a set of services and supports in the community.

The Monadnock region of New Hampshire saw this begin in the mid 1970s. The pace picked up and by 1980, New Hampshire began investing many resources to bring people from its institution to the community. Through the 1980s we did a great job of creating homes and facilities in the community, but not of the community. About 1990 we became increasingly aware that we (the “professionals”) were making all the decisions. We knew who should live with whom; what jobs people would have the best success with; the best places for people to live; and which of us (staff) would be best able to support them (the people we support). Isn’t that circular? Don’t we have a better way to express ourselves?

II. The Problem — 1990

We created community programs, but we also managed to separate “us” from “them.” In our rush to develop a community experience we missed the point and found ourselves making too many of the decisions. We thought we knew best. We struggled for a few years over this difficulty. Freedom, choice, and control were too often not being
experienced by the people we had freed*. People with disabilities became subordinate to the needs of staff, programs, and agencies. Our promise had not been kept. In 1990 we were struggling with these concepts. Although in retrospect it may seem obvious, it wasn’t until about 1993 that our ideas began to gel. What emerged became termed Self Determination. I’m not sure where the phrase came from, but it helped us articulate our thoughts about freedom, choice, and control.

II. The Problem — 2000

Today we are being asked to discuss the impediments to self determination. We are being asked to examine this concept within the context of state and federal regulations and also health and safety. These questions come at a time when we at Monadnock Developmental Services find ourselves struggling over what, I believe, is the next evolutionary stage of our system. The Monadnock region of New Hampshire has embraced self determination as a right, not a program, for about five years. Self determination was quickly and easily exercised by some of the individuals that we support, but not all. For those that did, the simple declaration was sufficient for them to take control of their own lives. However, for too many of the people we support, it is not enough.

CONTAINMENT AND CONTROL VS. GROWTH AND LEARNING

The large life decisions are more likely and more easily put into the hands of the people we support and their friends and family. However, we too often fail with the small, daily decisions. People decide where to live, but not what’s for dinner. They decide where to work, but not how to spend their own money. This may sound counter-intuitive, but it’s easier to ensure people’s rights for the big things — there can be more eyes watching. The small things, the decisions made during the normal flow of life, are simply more difficult to ensure that the person with the disability is in control.

The apparatus of the service system, as well as society itself, often bars people with disabilities from truly being at the helm of their own lives, especially on a day-to-day basis. Our system proclaims we believe people with disabilities should be in charge of their own lives, but we have not yet removed all the barriers. There are too many

* Community services were not just created for people coming out of institutions. Many of the people who took advantage of them were living at home at the time. However, for simplicity, and to acknowledge the primary impetus for creating community services, we must recognize that the states and courts mandated community services as a response to the inhumane conditions of the institutions.
consequences in place. “If you don’t shower every day, you can’t participate in community activities, you can’t have a special food, you can’t do or have whatever we decide.” In other words, you are a child, and we get to make daily decisions. We will decide which behaviors get rewarded and which get punished (or at least not rewarded). For people with disabilities to truly be accepted by their community, we need to do more than simply recognize their civil rights — an essential, but insufficient, step.

The Self Determination movement understands that while containment and control stand in the way of freedom, simply telling people they are free is not always enough. Witness Russia. Their freedom has been very painful. Many Russians were more than ready to be free; for others the struggle has been very difficult. Similarly, many people who have a developmental disability are unable to overcome the many barriers to self determination on their own; we need to do more. We need to create opportunities for growth and learning. And we need to eliminate the barriers, barriers created by staff, programs, agencies, families, and society.

III. Our System – a Paradox

Impediments to Self Determination

It would be great to blame state and federal regulations for all problems within the developmental disabilities system. Unfortunately, though tempting, this would be wrong. Focusing on the rules and regulations that are barriers to freedom often masks the impediments to self determination that we can change. Health and safety are frequently invoked as a counterbalance to self determination. People in control often say “you can’t do that, it wouldn’t be safe,” or “let’s do this, it’s healthier.” The person in control is the arbiter of what is a “bad choice.” This is often a value judgment that has nothing to do with health or safety. I feel that invoking health and safely is often a façade for a whole host of other motivators.

Our society is built on a balance of the needs of the individual versus the needs of the group. Both the law and our culture have checks and balances built in to keep these two competing needs in equilibrium. Too often, unfortunately, if someone has a developmental disability, there is disequilibrium. The needs of others often overwhelm
the needs of the person with a disability. In addition, society’s institutions (schools, government, social service programs, organized religions, etc.) put a premium on compliance. The system of checks and balances only works when the individual can counterbalance his or her own needs with the needs of other individuals and the demand for compliance from societal institutions. I will explore a number of the impediments that people with a disability face.

STAFF

We hire staff to support people with disabilities. We train them to understand that people with disabilities have rights, they are in charge of their own lives, they can make choices, they have control, and they are free. Then we make sure the staff understand that they are responsible for the health and safety of the person they are supporting. This paradox creates a terrible double bind for staff.

It is possible for an extraordinary person to be able to handle the complex tasks of both self determination and health and safety. In reality, the people we hire to be direct care staff rarely have the required multiple skill sets necessary to carry this off. Therefore, we tend to err on the side of health and safety. I believe this skewing of who we hire has unintended consequences.

We hire staff to assure that the people they support are safe and cared for. Not surprisingly, we attract natural caretakers — people who “need to be needed.” In some (too many) instances, this can lead to a fostering of co-dependence. Some people in our society find it reinforcing when other people need them. It simply makes them feel good; they like it. They like making decisions for other people. This is not the ideal personality to guide or even allow a person with a disability to become more independent, more connected with a wide selection of community contacts, or be in charge of his or her own life.

The pay is typically very low. A full-time annual income of $20,000 is an upper limit (or simply unattainable) for direct care staff. Many people simply won’t work for so low an amount. The likelihood of staff having all the necessary skills is rare. I would suspect that people attracted to direct care are more likely to bring the caretaker skill set with them than others.
Anecdotally, I believe that many of the people we hire to do direct care have only limited self determination in their own lives. When true, such a person serves as a poor envoy to self determination.

Our language itself speaks volumes. While we, as a system, struggle the terms “Client” versus “Consumer” versus “Customer,” we seem to be quite comfortable with “Direct Care Staff.” We shouldn’t be surprised when they see themselves as caretakers.

**PROGRAMS**

Programs are typically run for multiple people with disabilities. When this happens, people who didn’t choose to live together are forced to compromise their desires for the good of the group. Rules get promulgated. Money gets co-mingled. When this happens, it becomes harder for a person to choose to receive supports differently.

These issues tend to be more operational and therefore more easily corrected. Although we haven’t finished the job, at Monadnock Developmental Services we have had good success addressing many of the operational issues.

**AGENCIES**

Agencies often limit choice under the guise of health and safety in order to reduce their liability. Agencies are concerned about lawsuits. Is a program’s reticence to let a person take risk more related to the inherent nature of the risk or the liability to the staff person, program, or agency? In my experience the behavior that is prohibited because it is too risky is often one that we, as individuals, are often willing to accept for ourselves or our loved ones. These would include unhealthy foods, cigarettes, alcohol, or coffee. It would also include “questionable” friends, living on one’s own, staying up late, engaging in sexual behavior and many, many more things. Quite simply, it includes all the things that make each of us not perfect. But, because an agency is involved, any “mistake” that’s tolerated can put the whole organization in jeopardy. The state, the press, or lawyers can have a field day — after the fact.

Of course, people rarely cite liability and risk as the reason for rules. Rather health and safety are claimed. Even worse, the more intolerant people are of risk in their own lives,
the more likely that they will be the ones to make the rules. Typically, discussions around safety lead to more restrictive rules, not more freedom.

Simply put, if a person with a disability wants to make some choice that someone (anyone, really) objects too, everyone else in the agency will be apt to take the more conservative option, the safer (for them) course. In other words, “I’m sorry, that just wouldn’t be a good idea, it’s not safe.” When the person with a disability takes a risk, the benefit to the agency staff pales in comparison with the risk that they themselves must take on. They might get written up. This could effect future promotions or pay raises. They could even lose their jobs. The agency could be sued or get bad publicity.

“Quality assurance” inspections are more about paper compliance than quality. They are a manifestation of the state’s concern about risk. I’m not saying that we should ignore these issues. Rather, we need to open our eyes to how they affect our actions. We need to stop deceiving ourselves.

Families/Parents

Typically, as humans develop, there is a premium on safety for the younger child. Parents and society generally expect and accept that it is everyone’s responsibility to protect young children. If you see a toddler unattended in a car, you are expected to intervene. The checks and balances of our society anticipate that, as the child grows older, there begins a developmental process where the child exerts his or her independence. Freedom begins to replace imposed safety. Children become more responsible for their own safety as they grow up. Self determination emerges as the developmental process unfolds. Parents don’t so much give independence as the child takes it.

It is well understood that as the child enters the teen years, family harmony often suffers. However, if the child has a developmental disability, his or her natural proclivity to wrest freedom from unwilling parents may be insufficient to overcome the parents’ perception that their son or daughter can’t make safe decisions. As the parent of two teenagers, I know that my children make, in my opinion, bad and even dangerous decisions, but with each passing year, my influence declines. (The dance we do over who gets to decide results in my children having more control and my wife and I having less.) How many of us have had parents who would have been happy making decisions
for us well into our adulthood. For some, the parental desire for control never goes away, and if the person has a developmental disability, this desire too often becomes actualized and even legalized via guardianship.

Official guardianship creates an additional authority over another person. Greater even than the typical guardianship a parent has over a minor child. The official status of a guardian often has that person acting in ways a parent never would over a teenaged son or daughter.

SOCIETY

In many ways, society is simply ignorant about how to deal with people with a developmental disability. For most of the 20th Century, people with disabilities were locked up in institutions or hidden from the rest of society by families. There were many notable exceptions, however, the vast majority of people with disabilities simply were unseen. Most people in society just don’t have the skills, experience, or knowledge of how they should act. This is going away, but very slowly. It affects self determination because the person with the disability is too often just ignored — this rather limits one’s choices.

Conclusion

Health and safety are crucial for all people — with or without a disability. Unfortunately, they also make a great excuse for containing and controlling people with disabilities. They are used as justification for blocking self determination. Health and safety shouldn’t trump freedom. We need to do more to help people grow and learn to take charge of their own lives. We need to protect people — but we can’t eliminate failure. It’s difficult to learn without sometimes failing — this is how humans grow. It is possible to prepare for failure without saying “I told you so.” It is our job to employ natural consequences, not create artificial ones. If a person wants to try something that we “know” won’t work, our instinct may be to prevent this from happening in the first place. A better reaction is to do everything possible to help the person succeed, but if they fail, to be able to go back to the old way. Many young adults strike out on their own, only to fail, and then move back in with mom and dad. Can we do less for the people with disabilities that we support?
Moving people from institutions to community was, in most of the United States, a shift in real estate but not a shift in how people lived. In his very fine outline, Alan Greene does what many of us did, and continue to do, focus on what we moved from. In many respects, our movement is in a similar position to U.S. foreign policy after the Cold War. We have spent so much time rallying against something we dislike, that we have not always clearly articulated what we are for. In many ways, it is easier to be against something and “rally the troops,” than it is to be in favor of a positive movement and generate similar passion.

One point that needs to be made is that the “system” as we now know it was mostly created by “us.” We can no longer flail against the medical model, berate institutions and those who run them, lambaste those uncaring and insensitive bureaucrats (speaking as a recovering state DD Director) who have caused these situations. For the most part, those of us in leadership positions locally, statewide, and nationally have been a part of the movement that created the current system. To be introspective and self-critical is important, but after a period of self-flagellation (which is not productive), we must move forward to improve what can be improved and to change what cannot be improved.

In many ways, we have hurt people both emotionally and physically. In our zeal and passion to free people from institutions, we have created community settings that forgot the basics around safety, health, and protection. We have, in many places, exercised excess caution, and made it so that people have little or no freedom.
In others, we did not adequately prepare our staffs and people suffered as a result.

We have said that our services and supports will be cheaper, but most of the cost difference remains attributable to lower wages. We have seen the quality that people receive suffer directly as a result of those lower wages. We must stop this.

Alan Greene’s central point will be the most challenging for all of us... “We need to create opportunities for growth and learning. And we need to eliminate the barriers, barriers created by staff, programs, agencies, families, and society.” Pogo was right; we have met the enemy, and he is us.

Alan also forces us to examine that it is “us.” While improvements in state and federal regulations would certainly facilitate the changes we need to make, we can all point to examples where, with existing state and federal regulations, the goal of self determination has been met for people in communities. We cannot only blame the regulations.

Alan says, “We hire staff to support people with disabilities. We train them to understand that people with disabilities have rights, they are in charge of their own lives, they can make choices, they have control and they are free. Then we make sure the staff understands that they are responsible for the health and safety of the person they are supporting. This paradox creates a terrible double bind for staff.” I am not so certain this is a double bind.

What we do is open up our minds so much, that our brains fall out! If we are truly supportive of people we recognize that the people we support, just like the rest of humanity in 21st century America, is interdependent. All of us, every day, balance risks and rewards, opportunities and choices. It is not a linear decision we make in most cases, and it rarely is neat and clean. We want to support people with disabilities to the extent they need support in facing these decisions. Being safe and healthy does not mean doing nothing and eating only bean sprouts!

Society — We have done a poor job of helping explain to the society at large what people want, what they need, in general terms. Perhaps inclusion and self determination are counter-intuitive and will only be understood when all children are in neighborhood schools and we learn when we are young. But in the nation that invented marketing, perhaps there are also other ways.
My first reaction to this paper is that it is honest and unusually straightforward.

Alan Greene identifies five barriers that contribute to a shortage of consumer-directed community supports and services, including: 1) staff; 2) families; 3) agencies; 4) programs; and 5) society.

The paper does not include numerous cites to studies or data to support his conclusions, and the surprising thing is he did not need to. The barriers he identifies are easily recognizable to people familiar with the disability service system. These obvious barriers don’t have obvious solutions, and it is not the object of this paper to identify such solutions. However, the paper does lead its reader to the conclusion that many of the solutions for overcoming these barriers will need to involve systemic change in service delivery, as well as a higher level of involvement from people and agencies that is not traditionally a part of disability related service systems.

The portion of the paper identifying “society” as a barrier seemed to warrant more discussion. Of all the barriers identified, this was the least developed. Perhaps this is because it is the barrier over which we have the least power to change. Mr. Greene suggests that society is a barrier because “the person with the disability is too often just ignored, and this limits one’s choices.” I would suggest, further, that ignoring people with disabilities not only limits one’s choices, but also means a smaller public presence and political voice. Without a strong political voice or public presence, services and supports for people with disabilities are more likely to be underfunded. Also, people who provide these services may be ignored by society or have careers that carry less prestige.
Lack of funding and lack of prestige seem to directly impact the four other barriers identified in this paper.

Of the other four barriers, I particularly appreciated Mr. Greene’s description of why “staff” was a barrier to quality community supports. He observes that “agencies tend to hire people as direct care providers who have very little self determination in their own lives.” This is significant, since a provider who is used to a life of limited control over his or her own choices, will likely have a difficult time fostering self determination in others, or even understanding the concepts.

The staff barrier is shown to be much more complex than simply increasing wages can address. Providing supports to people with disabilities is not always attractive work, regardless of how much it pays. The work is often physically demanding, for example, help with lifting, toileting, and bathing. Often the work is emotionally draining or lonely, if for example communication is difficult.

Addressing the staff barrier will probably also require changing the public perception of what personal assistants provide — shifting from the picture many direct support providers are offered today, one of a purely medical nature, to a career image that emphasizes that personal assistants enable people with disability to contribute in all aspects of society.
I appreciate Alan Greene’s well-written comments as he represents the “service coordination, point of entry” perspective. As a senior staff member of a national not-for-profit organization, I seek to provide a reaction based upon my experiences in the provider world.

While service coordination and providers can often times find themselves at odds, it is critical to realize that it is the partnership between our organizations that most significantly impacts a person in “the system” and the family members involved. Many times, service coordination holds the purse strings and monitors “quality,” while the provider bears the responsibility of providing an array of services. We both have awesome responsibilities.

The problem, as seen in the year 2000, is well stated in Mr. Greene’s paper. There are many impediments to self determination, including the impact of regulations and a sometimes overbearing desire to focus on health and safety. We are at a critical developmental stage — person-centered services, individualized supports — in the realization that self determination is the right thing to do, but the roadmap to attaining this goal is very unclear. Rather than focus on past mistakes in designing the service delivery system, a broad base of stakeholders must partner to look toward the future and institute systems change.

The reality, as I see it, is as follows:

- We must shift to less staff-intensive models of service. Providers can’t recruit and retain qualified staff; thus, the quality of services and supports is low and continuity is not present in the lives of people. As stated by Mr. Greene, many staff have limited self determination in their own lives — how can they make this happen for others? Generally, little training is provided,
and staff are sent away with a lot of responsibility to work, often times alone, in “the community.”

- The regulatory pendulum continues to swing from one extreme to another. The most basic element of quality is health and safety — without that, what else exists? Regulators, funders, and agencies must advocate for a quality management methodology that focuses on personal outcomes — are the service providers meeting the goals of the person in service?

- As evidenced in today’s marketplace, we are faced with competing demands. People with disabilities and their families are challenged to find quality providers who will listen to them and provide the desired services and supports. Funders want the “best deal” for the least money so they can serve the most people. Not-for-profit providers have realized the need to operate as a business, not a charity, or they will cease to exist.

- Human service agencies (federal, state, public, private, etc.) are under more public scrutiny than ever before. Money has been wasted; mass media exposed horrors in institutions, community programs, and private homes. These are frightening times for providers: When will we be sued? Do you have a crisis communication plan? Know a good attorney? These threats are real and make providers pause to ask questions, determine potential liability, and sometimes say “no” to doing the things people want most. This is the tightrope we walk 24 hours a day, 7 days a week, 365 days a year.

Finally, I worry about the concept of “self determination” being watered down even before we know what it means, much less how to do it. Those of us involved in this conference and working in the field must be vigilant about upholding the virtues of the movement. The concepts presented in the self determination movement are not simply ways to reduce funding — they are important elements designed to support people in making decisions. We can work together towards the common goal of establishing a service delivery system that meets the ideals as set forth in the paper — “We need to do more to help people grow and learn to take charge of their own lives.”
As the Wingspread Conference came to a close, we reflected on the events and discussions of the past few days. With different views and perspectives, we were brought together by a common concern regarding the question of quality and services for people with disabilities. And we left with a feeling of collective responsibility, a shared vision, and support for a new entity — the Developmental Disabilities Quality Coalition (DDQC).

The DDQC was formed to prospectively address the public issues surrounding the quality and availability of community services for persons with developmental disabilities. The goal is to show a broad consensus in the field serving such persons and the mutual commitment to work together now and in the future to address the issues, challenges, and opportunities of the wonderful shift from congregate to community living for the people we serve. The group is committed to addressing the issues, challenges, and opportunities of community-based services and supports. The Coalition will also serve as the steering group to carry forward the priorities identified at Wingspread.
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AAMR promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual disabilities.
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American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP)
UAPs are located at major universities and teaching hospitals in all states, the District of Columbia, the U.S. Virgin Islands, Puerto Rico and territories. UAPs target and engage in activities to support the independence, productivity, integration, and inclusion into the community of individuals with developmental disabilities and their families.
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American Network of Community Options and Resources (ANCOR)
Since 1970, ANCOR has been the pre-eminent voice in Washington on behalf of private agencies that provide services and supports to people with disabilities and their families.
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The Arc of the United States
The Arc works to improve the lives of children and adults with mental retardation and their families, including securing expanded services and benefits as well as research and prevention programs for these citizens and their families.
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Consortium of Developmental Disabilities Councils (CDDC)
CDDC is a member-driven organization that is committed to representing the diverse interests of Developmental Disabilities Councils and the people with disabilities that Councils were created to serve.
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NADDC promotes national policy which enables individuals with developmental disabilities the opportunity to make choices regarding the quality of their lives and be included in the community.
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National Association of Protection and Advocacy Systems (NAPAS)
NAPAS is an association which represents federally mandated programs that protect the rights of persons with disabilities.
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National Association of State Directors of Developmental Disabilities Services, Inc. (NASDDDS)
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The Council on Quality and Leadership
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The Council on Quality and Leadership provides a continuum of services and resources that increase the effectiveness of individuals, organizations, and systems. The Council accomplishes this mission by working collaboratively with its customers and in partnership with public and private organizations to:

- Develop quality measures, performance indicators, and evaluation methods that are person-centered;
- Provide consultation, education, and other learning tools to build individual and organizational capacity;
- Conduct research and promote the availability of data for decision making and policy development; and
- Provide access to the latest information, developments, trends, and best practices to consumers, their families, support and service organizations, and public organizations.

The Wingspread Conference was organized by The Council’s National Center on Outcomes Resources (NCOR).

NCOR operates under a cooperative agreement between The Administration on Developmental Disabilities — United States Department of Health and Human Services and The Council on Quality and Leadership in Supports for People with Disabilities.

The Administration on Developmental Disabilities (ADD)
ADD serves as the key federal agency in the United States responsible for ensuring the implementation of the Developmental Disabilities Assistance and Bill of Rights Act and its regulations.

The mission of ADD is to assure that individuals with developmental disabilities and their families participate in the design of, and have access to, culturally competent services, supports, and other assistance and opportunities that promote independence, productivity, integration, and inclusion into the community. The mission is accomplished through:

- State Councils on Developmental Disabilities
- State Protection and Advocacy Agencies
- National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Services
- Projects of National Significance

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The views expressed herein, however, do not necessarily reflect the position of The Administration on Developmental Disabilities.
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Wingspread is the house that Frank Lloyd Wright built in the late 1930s for the H.F. Johnson family.

In 1959, the Johnson family moved into a smaller home next door. Years later, after extensive remodeling, the house was donated to The Johnson Foundation to serve as a conference facility.

“Wright believed that a heightened experience of nature led to a better understanding of one’s own, inner nature. He designed Wingspread to encourage the awareness and cultivation of both.” Wingspread is much more than a meeting center; it is a place of tranquility and peace where the spirit is set free and dreams begin.

We extend a heartfelt thank you to The Johnson Foundation for their generosity, graciousness, support, and encouragement to allow us to come together and create a shared vision to improve the quality of lives of people with disabilities.

Our mission is to help ideas to have consequences on behalf of the common good.

The Johnson Foundation