



# **Reinventing Quality:** *Person-Centered Supports* *They're for Everyone!*

---

## **ADD Project of National Significance:**

*Reinventing Quality: Fostering Promising Practices in Person-Centered  
Community Services and Quality Assurance for Persons with Developmental Disabilities*

### **Final Report**

**Grant Number:** 90DN0062

**ADD Project Officer:** Joan Rucker

**Primary Grant Recipient:** National Association of State Directors of  
Developmental Disabilities Services (NASDDDS)

**NASDDDS Staff Responsible:** Charles Moseley, Project Director

**Subcontractors:** Human Service Research Institute (HSRI);  
Institute on Community Integration/University of  
Minnesota

**Reporting Period:** September 1999 to September 2003

**Reinventing Quality:**  
***Person Centered Supports, They're for Everyone***  
**Final Progress Report**  
September, 1999 to September, 2003

**Introduction**

In 1999, NASDDDS, in collaboration with the Human Services Research Institute (HSRI) and the University of Minnesota Institute on Community Integration (ICI/UMN) awarded the Reinventing Quality grant by the Administration on Developmental Disabilities (ADD). The three-year \$750,000 grant project for developing quality practices was comprised of interrelated activities directed at effecting the adoption of person-centered principles and practices in public systems of services. The Project brought together consumers, families, government officials, service providers, and advocates to identify and evaluate information necessary to accelerate the adoption of person-centered principles and practices in public systems.

In 1999 the project organizers observed that, although person-centered services and quality assurance practices had gained broad acceptance, clear consensus was lacking regarding the essential elements that define public service systems grounded in person-centered principles. The lack of a clear implementation strategy proved an impediment to restructuring public systems based on person-centered community services. The project organizers set out to support efforts of stakeholders of all types and to disseminate information regarding best practices. Project Reinventing Quality was designed to provide the mechanisms and process for developing a clear vision and national strategy for designing public service systems based on person-centered principles that include accountability and quality assurance requirements.

Over the past four years, the Reinventing Quality project has helped to establish collaborative networks and interactive partnerships between consumers and their families and government, service provider systems and ADD networks. The project brought together a comprehensive stakeholder group (consumers, families, advocates, service providers and government officials) to identify and share information necessary to craft service systems based on contemporary best practices and innovations in supporting people with developmental disabilities and families. Project Reinventing Quality has provided many opportunities for interactive exchange and dissemination of information through a variety of media and activities.

The project has accomplished these goals through five distinct, yet interconnected, efforts:

1. Creating a state-of –the-art “Quality Mall” website, which provides an interactive forum for stakeholder communication and acts as a single source for dissemination of relevant information about person-centered services and quality promotion practices.

2. Organizing a Participant Advisory Committee (PAC) to ensure that individuals with developmental disabilities and their families are at the center of defining the project's directions and end products.
3. Organizing a Consensus Conference bringing together all stakeholders from all levels of government, service agencies, advocates, and others, for the purpose of identifying the essential features of public systems that employ person-centered principles.
4. Hosting the "Reinventing Quality" conferences, which enabled all stakeholders to share strategies and experiences in creating outcome oriented supports and quality assurance activities.
5. Conducting a series of state case studies to document efforts in selected states to improve and evaluate quality, and provide information on key elements and "best practices" of effectively working quality assurance programs.

### **Quality Mall.org**

The Quality Mall web site is the visible central focus of the project and serves as the nexus of the information network. The web site is designed to provide an internet-based point of access for individuals, families, professionals, advocates, government officials, and other stakeholders who are seeking information on the best practices in person-centered supports and quality assurance/enhancement. The site is operated, maintained, and managed by the Institute for Community Integration at the University of Minnesota personnel in consultation with the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute.

The Quality Mall became operational in September 2000 and has been "open" ever since. Twenty "stores," each of which houses several "departments" devoted to distinct topics, contain specific information on positive and best practices in person-centered supports as well as on cutting edge methods of providing quality assurance/enhancement. In total, there are 74 Quality Mall departments. Each department contains positive, best practice "products" with concise, user-friendly descriptions. A more detailed description is available to answer typical questions and enable Mall visitors to better access the information provided. A "direction-finder" function appears with each product to direct the visitor to more detailed descriptions of the practices or issues, to contact someone familiar with the particular subject, to order a publication or to directly access materials via links to other related sites.

**Site Usage:** Regarding site usage, the number of visitors to the Quality Mall has increased dramatically over the past 3 years. Project Team members, especially in 2002 and 2003, have engaged in a number of marketing strategies to increase awareness of, and traffic to, the mall. Site usage in 2003 reaches around 6,000 to 7,000 distinct visits per month, as compared to 2,000 to 3,000 in 2002. This extraordinary rise in usage, coupled with anecdotal evidence gathered by project members, suggests that the Quality Mall has achieved one of its key goals—to become a leading source of relevant

information about person-centered services and quality promotion practices for the entire developmental disability community.

**Product Development:** The number of products available at QualityMall.org has increased steadily since the site's inception. The number of products published to QualityMall.org now stands at 780. At the end of 2002, project staff revamped and streamlined the formerly bulky product nomination process, which has resulted in an increase in product nominations. In addition, a great deal of new media continues to be added to the Quality Cinema, as well as to the departments in the form of "Voice of Experience" clips, short interviews with experienced professionals discussing key issues relevant to service quality. To more effectively maintain up to date information on current or emerging events without overreaching the resources of the project, the current events department has been redesigned to contain links to important recent news items on other websites rather than relying on the more cumbersome process of importing the article to the Quality Mall or writing an original news report. The more streamlined format increases the responsiveness of the project and helps to contain costs.

The staff of the project have continuously refined the design of the website ever since its launch. A Webmaster was hired during the summer of 2001 to develop a new "look," chosen by a majority of stakeholders for its ease of use and accessibility for individuals with disabilities. As a result, the Quality Mall now stands as an easily navigable, one-stop center for the dissemination of relevant information about person-centered services and quality promotion practices. The Quality Mall has, in fact, become so valuable to policy makers, researchers, and advocates that the project team has determined that it will remain operational beyond the end of the grant period, and are currently seeking funding opportunities to sustain it.

### **Participant Advisory Committee**

Throughout its four years of activity, the project has received guidance and advice from a Participant Advisory Committee (PAC) composed of four individuals with developmental disabilities and four individuals who have a family member with a developmental disability. The PAC is composed of: (a) individuals with disabilities: Liz Obermayer (Maryland); Chester Finn (New York); Joe Meadours (Illinois); and Gail Bottoms (Georgia); and, (b) family members: Jackie Golden (Maryland), Sue Fox (New Hampshire), Sherri Huwe (Washington State), and Monica Herring (Maryland).

The PAC reviewed all aspects of the project and provided advice and counsel to the Project Team. The PAC was instrumental in guiding the focus and shaping the results of the consensus conference. The PAC also participated in the framing of the theme for each Reinventing Quality Conference, providing key suggestions for improvement that, among other things, allowed the conference series to maintain its strong focus on including self-advocates, both as presenters and as attendees.

### **Consensus Conference**

During year one of the project, the project team and PAC convened a three day “Consensus Conference” aimed at achieving agreement among the major stakeholders in the developmental disabilities community concerning the essential “principles” and related “markers” (or indicators) of a person-centered public system of consumer-directed, outcome oriented community supports and related quality assurance/improvement methods.

Person-centered services and individually tailored quality management practices have gained broad acceptance in the developmental disabilities field in recent years. Yet, the RQ project team concluded that a clear consensus had not yet emerged regarding the essential elements that define a public service system grounded in the principles of person-centered supports. The “Consensus Conference” was organized in order to help fill this void.

To ensure that all major stakeholder groups were represented at the conference, the RQ project team and steering committee agreed to the following categories of attendees: (a) ten self-advocates; (b) ten family members; (c) four direct service workers; (d) four representatives of service provider agencies; (e) six “funders” of service (local, state, and federal officials); (f) four regulators of services (representatives of licensing/certification agency and accrediting bodies); (g) eight advocates/professionals in the MR/DD field; and (h) four services coordinators/case managers.

A set of nine principles to guide the operation of a system of quality, person-centered supports was drafted and distributed to the consensus conference participants in advance of the April 13-15, 2000 meeting. Based on the feedback received, the project staff revised the original principles and used them as a framework for organizing the conference. Participants also received background materials that explained the aims and organization of the conference.

The bulk of the April 2000 meeting was spent on the development of “markers” or indicators of the presence or absence of the essential principles, elements and features of person-centered public systems of consumer-directed, outcome oriented community supports. Following the conference, the NASDDDS project staff disseminated a meeting summary to the conference to participants. Feedback was gathered over the summer months and assimilated into an initial, draft “Consensus Statement.” In August 2000, the draft statement was distributed to participants for final comment and, in October, the final version was posted at the Quality Mall.

The Consensus Statement proved invaluable as a guide for the remaining activities of the Reinventing Quality project, guiding the contents of the Quality Mall Web site, aiding in the design of case studies of the service system in four states that have been identified as best practice models of person-centered services; and informing the programs of the Reinventing Quality conferences.

## **The Reinventing Quality Conferences**

As part of the Reinventing Quality Project, NASDDDS undertook to sponsor two national conferences bringing together consumers, advocates, and professionals to identify and explore issues involving quality service and care. This conference series was so successful that it spawned a third event, in 2003, and has generated enough momentum that conference organizers are already considering sites for both a 2004 and 2005 conference. The first conference, in 2001, focused on a critical question: "How do we assure and improve the quality of community services without compromising the principles of person-centered supports?" The conference offered workshops that fell into eight different categories, including: (a) forging stakeholder partnerships; (b) building quality driven community organizations; (c) promoting quality outcomes system wide; (d) involving self advocates and family; (e) managing risk; (f) maintaining health and emotional well being; (g) assuring safety and security; and (h) relating choice to service quality. The 2002 conference examined the relationship between a system's ability to effectively balance the need to respect personal freedom and autonomy while protecting the individual from harm, with the need to have a skilled, sensitive and responsive direct support staff, and offered workshops that focused on a number of topics crucial to quality, including: (a) balancing freedom and safety; (b) building a quality workforce of direct support professionals; (c) promoting quality outcomes system wide; (d) involving self advocates and family; (e) managing risk; (f) federal initiatives that impact quality; (g) forging stakeholder partnerships; and (h) building quality driven community organizations. In 2003, the conference theme explored methods of integrating the rapidly developing technology into DD service delivery; discuss approaches to collecting, managing, and using information effectively, and highlight how information can be made available and accessible to consumers and families to enable them to make their own decisions regarding service quality during periods of fiscal restraint, budget cuts and economic down-turns. Additionally, sessions identified specific initiatives that are effective at the local level to increase consumer and parent control.

The feedback received by the conference organizers for each conference were remarkably similar. The responses to each year's survey indicated a high degree of satisfaction with the content of the conference's sessions, the topics covered, and the format within which the material was presented. Evaluations completed by conference participants yielded overwhelmingly positive feedback with over 90% of those responding rating session presentations as either *helpful* (54%) or *very helpful* (41%) each year. Conference participants each year expressed a clear preference for sessions that offer practical, hands-on tools that can be readily used to improve the quality of personal supports, and each year conference organizers increased and improved these offerings.

The conferences, which yielded 350 attendees in 2001, and 250 each in 2002 and 2003 as state budget crises and general economic woes set in, have become a professional high point of the year for many service providers, policy makers, and advocates (including self-advocates) in the developmental disability community. Conference organizers each year were told that the Reinventing Quality Conferences were the "best conferences all year," and attendees urged that the series be continued. The project team has committed to organizing Reinventing Quality conferences in 2004 and 2005.

## **State Case Studies**

The Reinventing Quality project began with the proposition that effective practices are in fact present or “coming on line” in some form during the project period. Therefore, a main project goal was to investigate and validate particular practices or approaches to the broad adoption of person-centered principles and to determine whether they were seen as effective in the eyes of system stakeholders, including and especially people with developmental disabilities and their families. In order to determine how and whether these principles were present in the context of actual public DD service systems around the country, the Human Services Research Institute (HSRI) chose four states to exemplify how these principles have been woven into specific public systems. In order to narrow the field to the final four, hsri canvassed available statistics that ranked states based on performance in a variety of areas. HSRI used specific indicators falling within these broad areas: community inclusion and integration; deinstitutionalization; early intervention and education; integrated employment; fiscal effort; and system organization and efficiency.

Data on each of these indicators were arrayed for all states nationally and an aggregate score was developed. With the assistance of the Participant Advisory Committee, the project staff reviewed the top 10 ranked states and picked the final four states. The final selection took into account geographic distribution, rural/urban characteristics, population size, and the configuration of the state system (e.g., county-based, state regions, etc.). The states selected were: Wyoming, Wisconsin, Kansas, and Connecticut.

During Years 2 and 3 of the grant project, HSRI and NASDDDS staff conducted 3 day site visits to these four states to learn from stakeholders the key elements and strategies that were instrumental in bringing about broad scale system reconfiguration in the selected states. The aim was to gather and synthesize information concerning how the jurisdiction addresses each key element as well as probe concerning additional factors (e.g., leadership) that played a central role in the jurisdiction’s broad-scale adoption of person-centered principles to guide the provision of supports for people with developmental disabilities and their families. During the course of each site visit, the project staff interviewed scores of individuals in each state, including people with developmental disabilities, families, public officials, advocates, direct support professionals, service agency managers, and others. They generously shared their experiences in advocating for and implementing person-centered supports. To ensure that the state case studies yielded relevant insights, an inquiry guide was developed. Key questions were framed based on the markers described in the consensus statement "Person-Centered Supports - They're for Everyone!"

HSRI issued papers on each of the four site visits, as well as a final, “synthesis” paper. This paper provided a synopsis of what was learned on site, the lessons learned, and potential implications for other public systems in fostering person-centered supports for people with developmental disabilities. While each of the four states traveled a different path in embracing the principles of person-centered supports in the operation of their systems, their collective experiences and discoveries will provide valuable insights to reformers around the country.