Data Quarterly

Defining What Really Matters:
A Report on the Delphi Survey on Person-Centered Services

CQL identified preliminary information gathering objectives for the *What Really Matters* Initiative across service settings for people with mental illness, people who are elderly, and people with intellectual and developmental disabilities.

Primary Goals for the Initiative:

- **To seek advice on the trends, issues, concerns, needs and goals of a wide range of people receiving human services – as well as those of organizations/service providers, public officials, advocates, and workers**
- **To obtain input about, and reaction to, these questions:**
  - **What is the current thinking about person-centered services and supports?**
  - **How are priorities for person-centered services defined across service sectors?**
  - **Where are the commonalities across different groups? Where are the differences?**
  - **What should quality measurement in person-centered services focus on?**
- **To convert this input into insight and action that will ultimately improve the lives of all stakeholders**

This report summarizes the findings from one aspect of CQL's data gathering – the Delphi Survey – conducted in the Fall of 2009.

What Really Matters Initiative

In the early 1990s, CQL | The Council on Quality and Leadership published the *Personal Outcome Measures®*. For the last 20 years CQL has collected data and explored variables that promote personal quality of life. In 2000, CQL introduced a dialogue on social capital and disability. CQL redefined quality within the context of community, arguing that people find meaningful life opportunities and alternatives outside of organizational services and programs. The role of organizations is to connect people with resources and social networks in their communities.

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Unfortunately, data and experience indicate that organizations are having difficulty making this connection to the importance of community and personal quality of life. In response, CQL launched a new initiative to focus system, organizational, and individual attention on "What Really Matters" to people. Our strategy is guided by the observation of artist Georgia O'Keeffe – "*Only by selection, by elimination, by emphasis do we get at the real meaning of things.*" CQL's new initiative assists organizations and communities to strip away unnecessary distractions and focus on the real meaning of things – personal choice and person-centered services.

The *What Really Matters* initiative identifies person-centered services with the greatest impact on people's quality of life. We measure the effectiveness of person-centered services through the right blend of measures, indicators, and questions such as the *Personal Outcome Measures®*. CQL guides organizations and communities in the development of person-centered services. This new prioritization allows us the opportunity to collaborate with colleagues and organizations, communities, and systems across the fields of physical disability, aging, mental health, and intellectual and developmental disabilities.

Delphi Survey Methodology

The Delphi method is an exercise in group communication among a group of geographically dispersed experts. A Delphi survey comprises a series of questionnaires sent to a pre-selected group of experts. These questionnaires are designed to elicit and develop individual responses to the problems posed and to enable the experts to refine their views as the group's work progresses in accordance with the assigned task. The Delphi method is designed to identify areas of agreement and concensus. The process deliberately pushes participants toward areas of common understanding. The group interaction in Delphi is anonymous, in the sense that comments, forecasts, and the like are not identified as to their originator but are presented to the group in such a way as to suppress any identification.

CQL developed the Delphi survey questionnaire items based on a report prepared by the Human Services Research Institute (HSRI) in the late summer of 2009. Staff from HSRI conducted a literature review and individual and focus group interviews to identify significant variables that influenced person-centered services.

The Delphi survey was administered in the Fall of 2009. Forty (40) people participated in the Delphi survey Round 1. Thirty seven participants (37) submitted valid responses.

The participants identified themselves with the following sectors:
- Intellectual and Developmental Disabilities (IDD)   19
- Mental Health (MH)   12
- Aging   5
- Other (public policy, disability, etc)   4

The participants identified themselves with the following roles:
- Advocate   10
- Provider   9
- Public Official   4
- Consumer   3
- Researcher   1
- Other (multiple roles—foundation, association, consultant, advocate)   13

In addition, six participants resided/worked in Europe, Australia, or New Zealand. Approximately 12 participants experience disability/aging, either individually or as a family member.

CQL staff conducted two rounds of the Delphi survey. Following the first round, we developed a set of questions for the second round. We shared the results of the first round of the survey with all respondents when we sent them the second survey. We analyzed the first round of all 37 respondents. We then analyzed the results by sector – mental health (MH), intellectual and developmental disabilities (IDD), and aging.

Summary of Findings

We are able to note prioritization of items by the various sector representatives. However, the small sample size and sample selection criteria preclude any analysis beyond descriptive statistics and rank order of items. A review the results of both Round 1 and Round 2 of the Delphi Survey results and a look at Round 1 responses by sector, allow several observations.

The Delphi survey did reveal a remarkable consensus and agreement on the factors influencing person-centered services. Respondents only rarely rated items as "not important" or "somewhat unimportant." Major differences appeared within the relative rating of Strongly Agree/Very Important/Definitely Will (+2) vs. Agree/Important/Will (+1).
- Respondents acknowledged the importance of supports in terms of flexibility of supports, level of support, quality of supports, and availability of supports in a crisis.
- Respondents did not prioritize either support/service brokers or fiscal intermediaries as a priority *requirement* for person-centered services.

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- Respondents did not rate individual control particularly high. Control over individual budgets and individual authority to direct services did not emerge as priorities.
- Public transparency was not a priority.
- While a stable and reliable workforce was considered important, there was no corresponding priority placed on fair and affordable provider rates or effective pay for providers.
- Respondents showed less enthusiasm for theoretical constructs such as the use of informal community resources or collaborative provision of community supports.

- Peer support and natural support were a priority for IDD and MH sectors, but not for the aging sector.
- The aging sector placed less importance on community membership and collaborative support delivery.
- The aging sector was more inclined to emphasize provider rates, a stable work force, and quality assurance than the IDD or MH sectors.

Delphi Survey Round 2:
Results of Rank Ordering (27 responses)

	TOP 3 ITEMS	AVERAGE RANKING
		1= Most Important 7= Least Important
QUESTION 1		
#1 Rank	Peer support and/or natural support (such as family or close friends)	3.04
#2 Rank	Accessibility to supports	3.19
#3 Rank	Personal control over the individualized budget	3.30
QUESTION 2		
#1 Rank	Person centered planning	2.44
#2 Rank	Fair assessment of needs	3.07
#3 Rank	Information and training for individuals/participants	3.44
QUESTION 3		
#1 Rank	Planning is person-centered	2.11
#2 Rank	Individuals feel welcome and heard	3.44
#3 Rank	Supports are flexible to meet changing needs	3.63

	BOTTOM ITEM	AVERAGE RANKING
		1= Most Important 7= Least Important
QUESTION 1	Fiscal intermediary	6.15
QUESTION 2	Quality assurance	5.81
QUESTION 3	Supports are available in a crisis	5.19

QUESTION 4	Organization and/or systems transformation resulting in self-directed services and supports will require the following changes:	

	TOP 3 ITEMS	AVERAGE RANKING
		1= Most Important 7= Least Important
#1 Rank	Internal cultural change (attitude and behavioral change by employees)	2.74
#2 Rank	Access and availability of community based services to maintain and promote independence	2.93
#3 Rank	Support from advocates, self-advocates, peer supporters, mentors and champions	3.59

	BOTTOM ITEM	
#7 Rank	Public transparency	6.04

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Conclusions and Next Steps

The information gathering from CQL individual and focus group meetings, independent national experts, the Delphi Survey, and the CQL pilot tests have resulted in the development of a set of key elements and success factors in person-centered services. The use of independent consultants, focus group meetings of representatives from multiple service sectors and perspectives, and the Delphi Panel provide a preliminary measure of face and content validity for our emerging set of key elements and success factors in person-centered services.

We recognize difference between and among the different sectors of aging, mental health, and intellectual and developmental disabilities. CQL is developing a set of generic core factors that can guide person-centered services across these different sectors. At the same time, CQL is using each of these generic core factors as a beginning foundation for the refinement of more detailed and specific factors for applications in the sectors of aging, mental health, and intellectual and developmental disabilities.

CQL will incorporate these person-centered services factors in its ongoing quality improvement, organization development, and accreditation programs. We will gather data during our work on organizational priorities, continuous improvement practices, successful implementation, and finally the impact of these person-centered service factors on personal quality of life as measured with the Personal Outcome Measures®.

For a copy of the full report on the Delphi Survey, including all survey questions, visit   **www.thecouncil.org/delphisurvey.aspx**

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