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Long-term Services and Supports Assessing the Quality of Life of the LTSS Consumer

A Research Report



Prepared by Spark Policy Institute on behalf of the Long-term Services and Supports Consumer
Quality Research Council
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LONG TERM SUPPORT SERVICES: ASSESSING THE QUALITY OF LIFE OF THE LTSS CONSUMER

Table of Contents

OVERVIEW	1
LTSS Consumer Quality Research Council	1
The LTSS Consumer Quality Research Project	1
Next Steps and Recommendations	2
LTSS Consumer Quality Advisory Committee Website	2
Library of LTSS QOL Questions	2
Consumer Engagement in LTSS QOL Research	2
Quality Recommendations to the CLAG	3
Project Committees.....	5
LTSS Consumer Quality Advisory Committee.....	5
LTSS Technical Work Group	7
Project Contributors	8
Organization of this Report	9
LTSS CONSUMER QUALITY RESEARCH	10
The Need for LTSS Consumer Quality Research in Colorado	10
LTSS “Triple Aim” Principles Guiding the Research Council	10
National LTSS Service Quality Challenges	12
National LTSS Quality Survey Efforts.....	13
Federal Commission on Long-Term Care	13
Promising National Quality Measurement Tools.....	14
Colorado LTSS Service Quality Challenges	15
The Use of Quality Measurement in Colorado	16
Instruments Being Pilot Tested in Colorado.....	18
Other LTSS Quality of Life Instruments to be Evaluated in Colorado	19
IDENTIFICATION AND REVIEW OF LTSS QUALITY MEASUREMENT TOOLS.....	21
LTSS Expert Consultant.....	22
Conceptual Framework for Quality and Outcome Measurement in LTSS.....	22
Selection of Validated Survey Instruments	24
National Core Indicators Survey Instruments	27

CROSSWALK RESULTS: QOL DOMAINS BY SELECTED INSTRUMENTS29

- 1. Domain: Paid and Unpaid LTSS Providers.....29
- 2. Domain: Supportive Environment.....35
- 3. Domain: Services and Supports Received.....42
- 4. Domain: Consumer Outcomes49

Final Remarks62

REFERENCES63

APPENDIX A: FEDERAL COMMISSION ON LONG-TERM CARE PANEL HEARINGS.....65

APPENDIX B: FINAL REPORT PRESENTATION FROM THE COMMISSION ON LONG-TERM CARE –
RECOMMENDATIONS.....67

OVERVIEW

LTSS CONSUMER QUALITY RESEARCH COUNCIL

The idea for a Long Term Support Services (LTSS) Consumer Quality *Research Council* (CQRC) emerged from the Care Coordination Subcommittee (CCS) of the Community Living Advisory Group (CLAG), established by a July 2012 Executive Order signed by Governor Hickenlooper. The CLAG was directed to review and recommend changes to the LTSS system to address the needs of aging Coloradans and persons with disabilities. In August 2013, CLAG members endorsed CCS's proposal to pursue grant funding to form a "LTSS Consumer Quality Advisory Committee (CQAC)." The Governor's Advisory Council on Disabilities also provided unanimous support for the formation of the CQAC and sought grant funding for an initial six month LTSS metric review as further outlined in this report.

The purpose of the CQRC would be to provide LTSS consumers, family members, advocates and LTSS providers with an *organized voice* in statewide efforts to improve healthcare and long-term care delivery, particularly as reform efforts focus on improving quality and reducing costs, rather than rewarding the volume of care provided. The CQRC would be a permanent standing council to cooperate with, and provide a complementary role to, the Department of Healthcare Policy and Financing's (HCPF) quantitative research efforts.

The CQRC also would partner with the larger community to engage consumers in measuring and improving the consumer experience, quality of life, and services from a qualitative perspective. Non-traditional and targeted research strategies would be pursued, including culturally sensitive and consumer-directed research methods often not feasible with large-scale, standardized consumer research.

The purpose of the CQRC would be to provide consumers with a voice in statewide efforts to improve healthcare and LTSS delivery systems.

THE LTSS CONSUMER QUALITY RESEARCH PROJECT

As a first step toward a potential CQRC, The Colorado Health Foundation (TCHF) provided a six-month grant to fund the *LTSS Consumer Quality Research Project*. The purpose of the project was to research metrics for measuring individual level quality of life and experience of care outcomes and to develop consensus recommendations to CLAG for follow-up actions by HCPF and others.

The research project was co-chaired by two Care Coordination Subcommittee members, Jose Torres-Vega (also a member of the CLAG) and Gary Montrose, and consisted of two committees:

- The LTSS Consumer Quality Advisory Committee (Advisory Committee); and
- The LTSS Technical Work Group (Work Group)

The project had three objectives:

1. To identify, compare and recommend LTSS survey tools and research methods (existing and emerging) for evaluating Quality of Life (QOL) of people with disabilities and their experiences of care and care coordination activities.
2. To determine how different qualitative methods might be used as a means of engaging people with disabilities in quality research and program improvement.
3. To identify opportunities to test the feasibility of standardized and non-standardized LTSS research methods among Regional Care Coordination Collaboratives (RCCOs), medical practices and LTSS providers.

NEXT STEPS AND RECOMMENDATIONS

LTSS Consumer Quality Advisory Committee Website

To support the project, a website was created to house information about upcoming meetings, meeting materials, meeting minutes and supporting documents. It houses the Library of LTSS QOL questions. The website will continue to be a virtual space for supporting the LTSS Consumer Quality efforts and can be accessed here:

<http://ltssconsumerqualityadvisorycommittee.wordpress.com>

Library of LTSS QOL Questions

A “LTSS QOL Library of Questions” has been created as a result of the crosswalk conducted in this research project. The Library is searchable by the QOL domains and sub-domains, providing an easy way to identify questions that can capture issues of specific interest. The library should be considered a “living” collection to be updated as new instruments are developed or identified. It can be found at the above web address.

Consumer Engagement in LTSS QOL Research

It is critical to support processes to engage LTSS consumers in the development and implementation of data collection efforts. Participatory Action Research (PAR) is based on the principle that those affected by policies and services are critical to successful development and implementation of a system that truly meets the needs of the affected

population. Consumer engagement in the development of new data collection efforts will ensure the right issues are being probed, the questions are relevant and understandable and the data collected will be meaningful to improving the quality of life of the LTSS population.

The Advisory Committee discussed the need to have more information from consumers; family members and advocates about whether they trust their answers on surveys or during interviews will be kept confidential. The Advisory Committee believes at least some interviewees fear retribution or removal of services if they answer honestly about negative experiences and outcomes. A “Peer-to-Peer” interview approach may be able to lessen the fears and result in more complete and accurate information about the LTSS consumer’s QOL and experience of care. Exploration of this data collection approach would be the subject of future advisory committee research and development.

QUALITY RECOMMENDATIONS TO THE CLAG

The CLAG received and acted upon the consensus recommendations from the Advisory Committee. The following three recommendations were approved (by at least 70 percent) of the CLAG membership at its July 28th 2014 meeting in Denver:

Recommendation 1:

Update “HCPF Quality Strategy-2007,” with LTSS Consumer/Stakeholder Input

Formalize LTSS Consumer/Provider Quality Engagement with HCPF: Extend life of Consumer Quality Advisory Committee or similarly configured replacement group; supporting CLAG; HCPF’s Quality and Health Improvement Unit (QHI), including updating of HCPF’s 2007 Quality Strategy, which includes an LTSS consumer focus..

Membership: Seniors and people with disabilities, acute, BH, LTSS providers, paid & unpaid supports, care givers, family members of children/youth, etc.

Focus: Consumer quality of care and quality of life, cultural inclusion, etc.

Scope: Including “pre-Medicaid” populations/issues.

Principles: Promoting consumer-directed principles such as individual choice, consumer direction & self-determination.

- Pursuit of real time data collection and reporting; staying on the forefront of data collection methods and research opportunities for LTSS populations.

Timing: Upon formation of one or more standing committees no later than January 30, 2015 with LTSS SME/staff expertise/members to compliment HCPF staff expertise.

Recommendation 2:

Consumer-Agency Alignment: LTSS Joint Standing Quality Committee(s) with HCPF

Establish one or more standing committee(s): HCPF-LTSS Consumer Joint Quality Committees under HCPF's Quality and Health Improvement Unit.

Membership: Seniors, persons with disabilities, LTSS providers, acute care, Behavioral Health, RCCOs, attendants, children, advocates, citizens, etc. – *with / without technical expertise*

Timing: by January 30, 2015, with staff and non-staff co-chairs and by-laws

Objective/Scope:

- **To align:** scope and timing with HCPF and non-HCPF Home and Community-based Services (HCBS) (standardized and non-standardized) quality surveys, metrics, methods, projects, demonstrations, etc.
- **To Review:** HCBS/LTSS quality measures and methods prior to future adoption or implementation by HCPF or other state agencies (e.g. Full Benefit Medicare-Medicaid Enrollees State Metric Set; Colorado Choice Transitions; Testing Experience and Functional Tools Grant (HCBS Experience of Care Survey)), etc.

Approach: Similar in form & function to the PIAC/ACC's Performance Improvement Committee(s) and Quarterly Quality Summit, for Acute Care, BH, etc.

Reassess: the feasibility/workability of this collaborative approach after 12, 24 months.

Recommendation 3:

Pursue LTSS Survey R&D, Feasibility Testing: TA as Needed

Work with state partners, market entities, others; for shared learning

- 1) **Maintain/grow Survey Library:** of LTSS Question/Methods consisting of existing and novel LTSS consumer survey questions and data collection strategies, with emphasis on disability cultural competency.
- 2) **Address Participation Disparities:** Address LTSS participation disparities by, for example, *'adding a single questions* to standardized state/national surveys in order to secure consume permission *to replicate state sampling methods, and survey with additional questions sets.*
- 3) **Test Non-Standardized Questions:** Explore the process of offering different questions (domains such as employment, transportation, etc.) of interests to different aged and disability communities, different region needs (e. g. rural conditions), etc.

- 4) **Test Non-Standardized Methods:** Explore different survey methodologies, such as *Peer-to-Peer* vs. professional interviewing (e.g. Participant Action Research) methods.
- 5) **Explore Social Media Opportunities:** Explore use of new media technologies for capturing *individual stories* using social media, video formats, etc.
- 6) **Modernize/more real-time:** Less invasive media strategies for faster consumer feedback.
- 7) **Monitor LTSS Consumer “Survey Fatigue:”** monitor all known LTSS consumer surveys and coordinate to extent possible in order to minimize family and participant survey fatigue due to “excessive” numbers of surveys.

PROJECT COMMITTEES

LTSS Consumer Quality Advisory Committee

The LTSS Advisory Committee provided guidance on the project including process and feedback on content identified by the Technical Work Group. The Advisory Committee was responsible for proposing/developing a set of consensus findings and recommendations that included LTSS quality research criteria, research priorities and recommended tools.

The Advisory Committee included LTSS consumers with cognitive and physical disabilities and/or their family members of all ages, LTSS providers, RCCOs, Single Entry Point Agencies (SEPs), Community Care Boards (CCBs), community-based mental health centers (MHCs), and local and state seniors service providers and stakeholders.

Table 1. LTSS Consumer Quality Advisory Committee Members/Participants

Name	Organization
Co-Chairs	
Jose Torres-Vega	Co-Chair - CLAG Member; Advocate - Colorado Cross-Disability Coalition
Gary Montrose	Co-Chair - CLASP Colorado Long-Term Assistance Service Providers (IHSS Trade Group), and The Independence Center – Colorado Springs
Spark Support Team	
Natalie Portman-Marsh	Spark Policy Institute – Facilitation/Project Management
Lyn Kathlene PhD	Spark Policy Institute - Research Director
Daniela Hernandez MSS	Spark Policy Institute - Project Coordinator

Name	Organization
CQAC Members/Participants*	
Ed Arnold	Parent-2-Parent
Jeanie Benfield	LTSS Consumer in RCCO-4 Pueblo
David Bolin	Accent on Independence
Betty Boyd	Chair - CLAG, Former State Senator
Dustin Dodson	Grand River Hospital District
Jose Esquibel	CDHS/Office of Children, Youth and Families
Julie Farrar	Colorado Developmental Disabilities Council
Regina Fetterolf	Colorado Community Health Alliance
Patrick Fox MD	Office of Behavioral Health, CDHS
Gerrie Frohne	Parent-2-Parent
Brenda Heimbach LPC, NCC	Rocky Mountain Options for LTC
Ellen Jensby JD	Public Policy Specialist
Drew Kasper	RCCOs 2,3, 5; Colorado Access
Stephen Kaye PhD	Institute for Health & Aging, Community Living Policy Center, UCSF
Lisa Keenan	Co-chair, Care Coordination Subcommittee; Value Options
Gurudev Khalsa	Spring Institute – Facilitator for Care Coordination Subcommittee
Mary Kay Kisseberth	Retired Administrator, CMS-Denver Regional Office
Chandra Matthews	Access Long Term Support Solutions (SEP), Colorado Access
Richard Mauro	Denver Regional Council of Governments
Carol Meredith	The ARC-Arapahoe/Douglas
Lois Munson	Senior Counseling Group, LLC
Sam Murillo	Family Voices Colorado
Allan Olipane MBA	Community Care Central Colorado
Julie Reiskin LCSW	Colorado-Cross Disability Coalition
Shari Repinski	Rocky Mountain Human Services
Sarah Roberts, MHA	LTSS Operations Division Director, HCPF
Linda Shaflen	ARC Adams Co.
Cassidy Smith	Senor Policy Officer, Advocacy for a Healthy Colorado, The Colorado Health Foundation
Heidi Walling	Quality and Health Improvement Unit, LTSS Specialist, HCPF
Jo Washburn	Personal Care Attendant - Pueblo

Name	Organization
Tim Wheat	Community Organizer, Center for People with Disabilities
John Zabawa	Seniors' Resource Center
Ryan Zeiger	Personal Assistance Services of Colorado (PASCO)
* Joined or participated in at least one meeting in person, by phone, webinar. Many attended all meetings.	

LTSS TECHNICAL WORK GROUP

The LTSS Technical Work Group (“Technical Work Group”) was responsible for reviewing technical and non-technical issues, consumer engagement strategies, current practices in data collection, and reporting in a way that is credible, meaningful, accessible and useful. Materials from the Technical Workgroup were shared with the LTSS Advisory Committee to provide consumer and stakeholder input.

The Technical Work Group was composed of quality/research professionals and local and national subject matter experts (SMEs).

Table 2. LTSS Technical Work Group

Name	Organization
Mona Allen	Quality Improvement, RCCO-4 Integrated Community Health Partners
Carrie Bindle, MPH	Director of Quality, Colorado Access
Jose Esquibel	CDHS/Office of Children, Youth and Families
David Gans, MSHA, FACMPE	Senior Fellow, Medical Group Management Association/ACMPE
Sarah Hoover M. Ed	JFK Partners, University of Colorado School of Medicine
Lyn Kathlene PhD	Project Research Director - Spark Policy Institute
Gary Montrose	CLASP Colorado Long-Term Assistance Service Providers (IHSS Trade Group)
Natalie Portman-Marsh LCSW	Facilitation, Project Management - Spark Policy Institute
Cordelia Robinson PhD, RN	JFK Partners, University of Colorado School of Medicine
Heidi Walling	LTSS, HCPF
Patricia Yeager PhD	The Independence Center-Colorado Springs

Project Contributors

In addition to the Advisory Committee, there were other people who followed the work of the project, attended meetings, and provided feedback through emails and phone calls with the Advisory Committee co-chairs. This group of people is listed in Table 3 below.

Table 3. Contributors, People Engaged in the LTSS Consumer Quality Project

Name	Organization
John Barry	Colorado Department of Health Care Policy and Financing
Sheryl Bellinger	Co-chair – Full Benefit Medicare Medicaid Eligibles Subcommittee; Professional Home Health Care, Inc.
Emily Blanford	Deputy Director, Division of Developmental Disabilities, HCPF/Administers NCI Survey-DD and AD
Todd Coffee	Aging and Adult Services, Colorado Department of Human Services
Patricia Cook RN, BSN	Coalition for MSP/LIS Consumer Outreach Initiative
Tim Cortez	HCPF
Cassidy Dellemonache	The Arc Colorado
Camille Harding LPC	Colorado Department of Health Care Policy and Financing
Evie Hudak	Hudak Consulting, LLC; Former State Senator
Christina Johnson	Seniors, Atlantis
Adrienne Jones	CDHHS
Heather Kijenka	Director of Quality Assurance and Human Resources/Laradon
John Mahalik PhD, MPA	CDHHS
Amy Rager	Laradon
Barb Ramsey	HCPF/DHS – Director, Division of Developmental Disabilities
Pamela Russell	TEFT Grant/CORHIO (Colorado Regional Health Information Organization)
Samantha Saxe	HCPF
Sara Schmitt	Colorado Health Institute
Jolene Singer RN	Mountain Family Health Centers
Tasia Sinn	LTSS Specialist, Colorado Health Institute
Gabrielle Steckman	Public Consulting Group
Whitney Zanutelli	HCPF

ORGANIZATION OF THIS REPORT

The following section begins with an overview of why QOL and experience of care research is now of growing interest and needed both nationally and in Colorado. Two conceptual models are introduced: (1) the “Triple Aim,” which provides the organizing policy principles identified by the HCPF and the CLAG; and (2) the “Conceptual Framework for Quality and Outcome Measurement in Long-Term Services and Supports,” (“Conceptual Framework”) which identifies domains and subdomains of LTSS systems, where QOL issues arise. Various instruments are summarized, including those in development nationally and those the state of Colorado (1) currently implements, (2) is in the process of testing, and (3) will be using in the near future.

The next section covers the results of the research conducted through a crosswalk of the questions in five key LTSS instruments relevant to the QOL domains and subdomains of the Conceptual Framework. This section also reports on the CQAC’s identification of specific types of experiences, challenges and issues that arise within each subdomain of the Conceptual Framework. A companion document, the “LTSS QOL Question Library,” is a standalone searchable version of this section.

The last section of the report includes key findings and next steps, as well as the consensus recommendations that came from this project and were adopted by the CLAG.

LTSS CONSUMER QUALITY RESEARCH

THE NEED FOR LTSS CONSUMER QUALITY RESEARCH IN COLORADO

As states, including Colorado, transition to Medicaid Managed Care Organizations (MCOs) to help manage the increased need for and cost of LTSS services, there is a danger that MCOs, many of which lack experience providing for the LTSS community, will lack the time, resources and interest to carefully track consumer concerns and outcomes. A shift from state-managed fee-for-service (FFS) care to MCOs may also result in less transparency to consumers and state policy makers. Yet, all stakeholders, including the MCOs, would benefit from systematic, reliable data on LTSS experience of care and QOL as key outcome metrics.

Additionally, there is increasing recognition that vulnerable populations such as the elderly, can be abused by caregivers (paid and unpaid) in community-based settings, group homes and by those trusted to look after the well-being and financial affairs of the person. As of July 1, 2014, Colorado law mandates reporting of suspected elder abuse. The list of mandatory reporters ranges from a long list of specific medical personnel to long-term facility personnel, mental health providers, social workers, caregivers, clergy, financial institutions and law enforcement (Colorado Coalition for Elder Rights and Adult Protection, 2014).

Policy makers, consumers, providers and others consider it critical for states to measure and track quality of life issues in the LTSS population with at least the same vigor as applied to acute care service delivery. Unfortunately, there is little consistency on metrics and methods for measuring the experience of consumers and those providing personal care services within and across most state LTSS programs. This gap in performance measurement is beginning to change with growing adoption of consumer quality metric programs such as the Core Indicators Project (for Developmental Disability and Adult Populations) and other quality measurement efforts (see below), which have been introduced in recent years or are being pilot tested in a number of states.

LTSS “TRIPLE AIM” PRINCIPLES GUIDING THE RESEARCH COUNCIL

In 2013, prior to the beginning of this project, the Care Coordination Subcommittee of the CLAG developed and voted to adopt a set of organizing principles for this quality project.

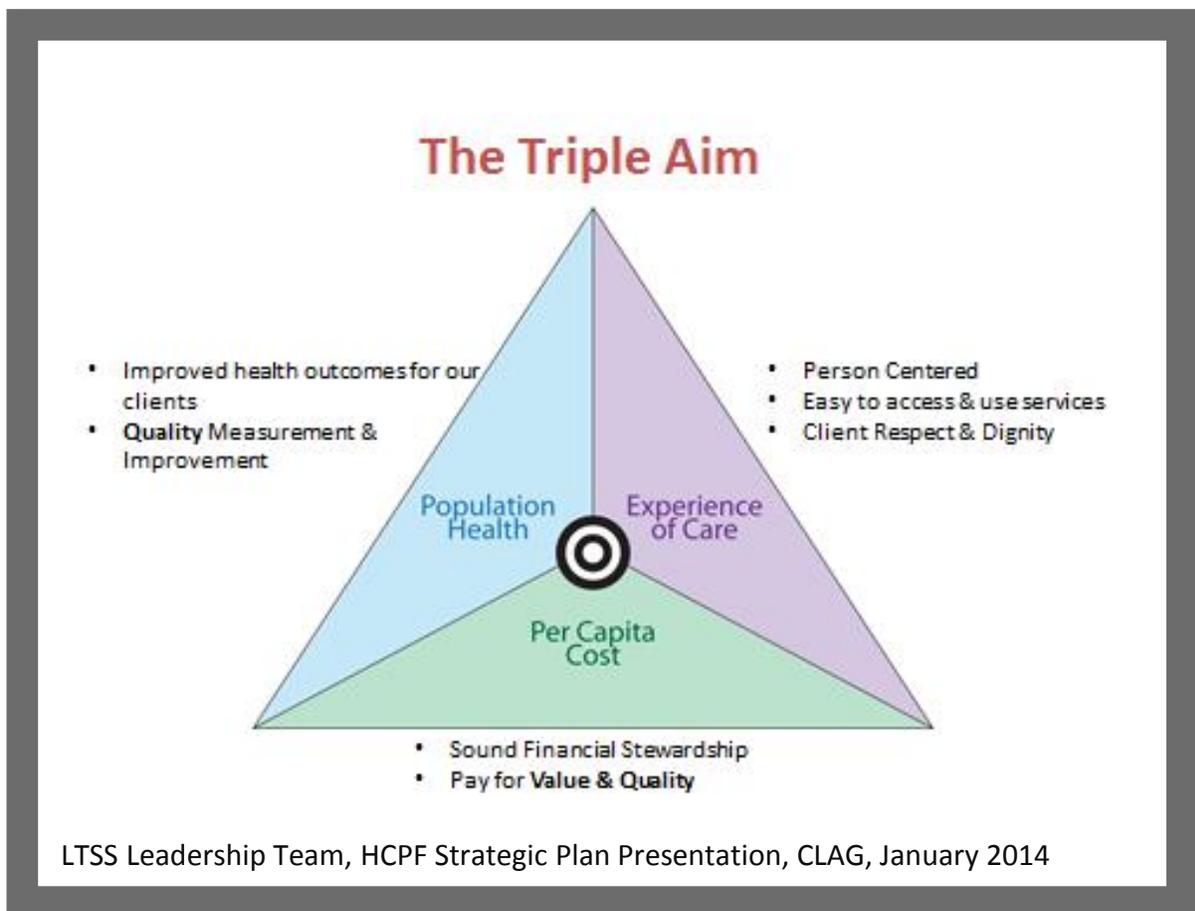
These included:

1. **Independence:** Free from undue influence from providers, agencies, etc.
2. **Populations:** Focus on community dwelling seniors and people with disabilities of all ages, including those living in assisted living facilities.

3. **Maximizing:** Respecting consumer choice and the dignity of risk, considering social determinants of health and addressing the “human side” of health care reform.
4. **Identify quality research gaps and priorities:** How care coordination systems work together in fee-for-service (FFS) and emerging managed care models.
5. **Collaboration:** with HCPF, CDHS, CDPHE, ADRCs/AAAs, LTSS providers, etc.
6. **Being Open:** to productive, creative thinking and spirited debate.
7. **‘LTSS Triple Aim’:** Evaluating quality of life and consumer experience/activation; quality/health and value/fiscal responsibility from a non-medical, consumer perspective.

The Triple Aim encapsulates the joint interests of the state, managed care providers and the LTSS consumer. Figure 1 below identifies how the inclusion of the consumer perspective can and should enhance the outcomes of each segment of the LTSS system.

Figure 1. The LTSS Triple Aim model*



The *voice of the consumer* is important for the measurement and reporting of QOL outcomes for the LTSS population in eight specific and tangible ways:

1. Gaining a better understanding of LTSS systemic program challenges, by telling people's stories and describing what works and doesn't work in LTSS programs from those receiving and providing services.
2. Identifying issues with services delivery from independent and reliable consumer/family perspectives and direct experience, *without fear of agency or provider retribution*, within this highly vulnerable population (whether such fear is warranted or not).
3. Identifying problems before they become serious issues of harm, negligence or abuse.
4. Identifying exemplary service delivery practices for acknowledgment and replication.
5. Identifying regional and rural issues, and generating statewide/national comparisons when possible.
6. Contributing to Pay-for-Performance discussion with the state (for ACC/Medicaid Reform Shared Savings programs).
7. Capturing consumer/family experiences in a deeper, more meaningful way than standardized, large-scale surveys administered on a national or statewide basis.
8. Partnering with agencies in consumer-informed quality deliberations, providing technical support and a recognized platform for capturing the voice of the consumer.

NATIONAL LTSS SERVICE QUALITY CHALLENGES

Twelve million Americans are assisted through a web of LTSS (Commission on Long-Term Care, 2013b), approximately 11 million of whom are community residents and about half of whom are non-elderly. Community-based LTSS are essential to the well-being of many elderly and non-elderly individuals who have limitations to performing daily activities (Kay, Harrington & La Plante 2010). Currently, the United States is facing a significant demographic change as the baby boomer population ages and puts pressure on an already-strained fiscal system (Kay, Harrington & La Plante 2010). In short, the current organization and financing of LTSS is untenable as the baby boomer generation continues to age and live longer, with a range of disabilities.

These studies point to great demographic and structural challenges ahead in the funding and delivery of long term services and supports nationally and in Colorado:

- Only 12% of community residents receive paid help; the rest receive unpaid help.

- Family caregivers provide most of the care now, but it can be overwhelming and the availability of families to provide this care will decline in the future.
- Paid LTSS are expensive and can be financially catastrophic for a family. Americans reaching retirement are not adequately prepared to cover LTSS costs.
- The direct care workforce has training and retention issues that could affect the quality and availability of experienced workers in the future.
- Paid LTSS are highly fragmented and difficult to access. The system lacks focus and coordination to ensure the best outcomes, and the process can be expensive and inefficient (Commission on Long-Term Care, 2013b).

NATIONAL LTSS QUALITY SURVEY EFFORTS

Federal Commission on Long-Term Care

The Federal Commission on Long-Term Care was created by the American Taxpayer Relief Act. The Commission was tasked with advising Congress on how long-term care can be better provided and financed for the nation's older adults and people with disabilities, now and in the future. Their charge, by statute, was to develop a "plan for the establishment, implementation, and financing of a comprehensive, coordinated, and high-quality system that ensures the availability of long-term services and supports for individuals in need" (Commission on Long-Term Care, 2013a). The Commission held four public hearings on seven topical issues, each of which included a panel of expert witnesses (see Appendix A), and solicited comments from the public. The topics addressed were:

1. Diversity of LTSS Demand: Subpopulations and Their LTSS Needs
2. Strengthening Medicaid LTSS
3. Strengthening Medicare for LTSS
4. Strengthening Private Long-Term Care Insurance
5. Interaction of Insurance, Private Resources, and Medicaid
6. Service Delivery and Provider Innovation and Issues
7. Workforce Innovation and Issues

The final report was released on September 18, 2013. One of the recommendations the Commission addressed was service delivery quality. Specifically, the Commission recommended "accelerated development of LTSS quality measures for home and community-based services and to make them available to consumers" (Commission on Long-Term Care, 2013b, p.13) (see Appendix B for all recommendations).

Promising National Quality Measurement Tools

Home- and Community-Based Services (HCBS) Experience Survey

The Centers for Medicare & Medicaid Services (CMS) supported Truven Health Analytics and its subcontractor AIR to develop and pilot the HCBS Survey. The goal of the HCBS Survey is to measure the experiences of services and care by individuals, across disabilities, who received HCBS (another and broad term for LTSS). The HCBS Survey is still in the pilot design and testing phase. Pilot testing will be conducted in Colorado in 2014.

There are nine domains of questions (CMS, 2013) in the HCBS Survey:

1. Services and Supports from Personal Assistant and Behavioral Staff
2. Services and Supports from Homemakers
3. Your Case Manager
4. Choosing Your Services
5. Transportation
6. Personal Safety
7. Community Inclusion and Empowerment
8. Supplemental Employment Module
9. You

interRAI Assessment System

The interRAI Assessment System consists of a suite of 15 comprehensive instruments targeted to specific populations who are elderly, frail or disabled. Each instrument has been extensively researched and tested to establish the reliability and validity of items, outcome measures and assessment protocols and quality indicators. The 15 interRAI instruments are:

1. interRAI Home Care (HC)
2. interRAI Community Health Assessment (CHA)
3. interRAI Wellness (WELL)
4. interRAI Assisted Living (AL)
5. interRAI Long-Term Care Facilities (LTCF)
6. interRAI Post-Acute Care (PAC)
7. interRAI Acute Care (AC)
8. interRAI Palliative Care (PC)
9. interRAI Mental Health (MH)
10. interRAI Community Mental Health (CMH)

11. interRAI Intellectual Disability (ID)
12. interRAI Mental Health for Correctional Facilities (CF)
13. interRAI Contact Assessment (CA)
14. interRAI Emergency Screener for Psychiatry (ESP)
15. interRAI Self-Report Quality of Life (QOL)

Each of the 15 instruments consists of a user's manual, multiple data collection instruments, standardized scoring schema, and other specific support materials and software systems. The interRAI suite is a set of comprehensive, integrated consumer assessment tools, designed primarily to assess consumer program qualifications (eligibility) and personal assistance needs, but which may be used in whole or in part as quality measurement instruments as well.

Colorado LTSS Service Quality Challenges

There are serious concerns that the fiscal pressures of providing LTSS services to a large and growing population of elderly and non-elderly individuals with disabilities will strain the state's already limited resources. Between 2010 and 2013, the number of Colorado's households with persons aged 65 and over increased by 123 percent!

A recent study of Colorado caregivers LTSS family members who were Medicaid and Medicare eligible found the logistics of navigating the system – searching for a quality care provider, securing transportation, and making calls to organize payment systems – was difficult and frustrating due to the complicated and inefficient way care is coordinated and delivered.

Recently, Colorado took a first step to address some of these concerns by passing a bill that provides additional long-term options that are projected to save the state money. The intent of the bill is to help more Coloradans stay in their home longer (Jones 2014), which, in turn, will save money as community-based care is less costly than institutionalization (Kaye, Harrington and La Plante 2010). Further, home-based care is also better for the well-being of individuals not requiring 24/7 acute or chronic medical care and observational services (Kaye, et al., 2010).

The system is not just financially strained; it is also difficult for consumers and families to navigate. A recent study of Colorado caregivers of LTSS family members who were Medicaid and Medicare eligible found the logistics of navigating the system – searching for a quality care provider, providing transportation, and making calls to organize payment systems – was difficult and frustrating due to the complicated and inefficient way services are coordinated and delivered (Corona Insights, 2010).

The Use of Quality Measurement in Colorado

Because the LTSS consumer receives services through a variety of different agencies and agency divisions within Colorado state government, there are no generally accepted, central data collection programs for assessing the adequacy or quality of LTSS services received, the full range of consumer needs or their overall QOL. Moreover, consumer/family members and provider community input into the selection, use, evaluation and reporting of results has been limited.

Four data collection instruments currently used in Colorado to assess QOL for the LTSS population are listed below.

1. Mental Health Statistics Improvement Program/Youth Services Survey for Families/Youth Services Survey (MHSIP/YSS-F/YSS).

This instrument is housed in the Department of Human Services: Office of Behavioral Health, Data and Evaluation unit. This tool uses primarily quantitative methodology.

- It includes over 45 close-ended questions. More than half of the questions are specifically directed at five domains regarding behavioral health treatment:
 - Access to services and general satisfaction
 - Participation in treatment planning
 - Quality of treatment (cultural sensitivity for youth clients)
 - Perceived outcome
 - Social connectedness and functions
- It includes two open-ended questions regarding behavioral health services received at state-funded community mental health centers (CMHCs).
- It also collects demographic information.

The data is collected via a convenience sample, where paper surveys are given to current clients of community mental health clinics; during a regular, non-intake appointment.

2. Money Follows the Person (MPF) Quality of Life Survey

The MFP is implemented by Colorado Department of Health Care Policy and Financing (HCPF). This survey evaluates a person's transition from institutions to the community. To date, 45 states, including Colorado have received MPF demonstration grants. The survey is required for people enrolled in the MPF program. It collects primarily quantitative data with the purpose of understanding trends across the state. The data is organized into the following main domains:

1. Living situation
2. Choice and control

3. Access to personal care
4. Respect and dignity
5. Community integration and inclusion
6. Satisfaction
7. Health status

The MPF is conducted through in-person interviews in a consumer's home or their institutional place of residency (e.g., an intermediate care facility or nursing home). The survey is administered by phone in cases where an in-person interview is not possible. Data is collected three times for each client enrolled in the MFP program.

3. Client Satisfaction Survey (CSS) Waiver

The survey was created and mandated solely by the state of Colorado and implemented by the HCPF's Program and Performance Improvement Unit. The primary method of data collection is quantitative, with a final comment section that collects open-ended qualitative data. It contains the following five domains, evaluating:

1. Their case manager
2. Level of involvement and choice in service and providers
3. Availability of information and resources
4. Knowledge on how to file complaints
5. Quality of care received from caregivers

The CSS is an online survey sent from HCPF to Single Entry Point (SEP) agencies. Each SEP prints and mails paper copies to a sample of their clients. The surveys are returned to HCPF and the results are entered into an online survey platform. Historically, this survey has had a low response rate and, due to its format, there is no ability to follow up with specific clients. Because this is a state-created instrument, there is more opportunity to redesign it or add questions. The state is open to changing it.

4. Consumer Assessment of Healthcare Providers and Systems (CAHPS) or "Adult Quality Survey" (administered in 2014 by The Colorado Health Institute for HCPF)

The HCPF's Quality and Health Unit sponsors the administration of this quality of service instrument. It is used to assess adult and child Medicaid (fee-for-service and managed-care) and Child Health Plan Plus (CHP+) recipients with a large statewide sample using primarily qualitative data collection methods (telephone and in-person interviews where possible). The survey is used to compare consumer satisfaction with acute care and behavioral health providers, with samples sizes in 2014 large enough to be statistically significant across all seven RCCOs.

It includes the following four domains:

1. Rating of all health care
2. Rating of personal doctor;
3. Rating of specialist seeing most often
4. Coordination of care

Self-reported data from a random sample of consumers is collected by phone or mail and implemented by the Health Service Advisory Group, an external quality review organization.

There are no procedures for working with people with cognitive or physical disabilities (specifically, the survey specifically excludes seniors and people with disabilities who cannot navigate the survey process as currently administered). Further, there is no current or future process identified to engage consumers and the affected LTSS provider community in the survey planning process, data collection and analysis reporting.

Instruments Being Pilot Tested in Colorado

Colorado is currently pilot testing three new data collection instruments, which are listed below.

1. ECHO+, a modified version of the Experience of Care and Health Outcome Survey (ECHO)

The ECHO survey has two versions:

- The Managed Care Organizations (MCO) version for adults and children; and
- The Managed Behavioral Health Care Organization (MBHO) for adults and children.

An additional list of questions can be added to either survey to allow users to modify the survey to meet their needs. The ECHO survey and its associated instructions are currently being updated.

2. National Core Indicators - Developmental Disabilities and Adult Consumer Survey (NCI-DD)

This survey is currently being implemented by HCPF - Division for Intellectual Disabilities (DIDD). (See description of the instrument in section "Identification of Quality Measurement Tools"). The pilot testing period is 2014-2015.

3. Home and Community-Based Experiences Survey (HCBS) for Seniors and Adults.

HCPF's Quality and Health Improvement Unit is planning to use this instrument as part of the Testing Experience and Functional Tools (TEFT) grant in Community-Based LTSS. This instrument includes the following eight domains:

- Services and supports from personal assistant and behavioral staff;
- Services and supports from homemakers;
- Case management;
- Choice;
- Transportation;
- Personal safety;
- Community inclusion and empowerment; and
- Employment.

The instrument will be tested nationally and in Colorado. Testing in Colorado is to start in 2014 and will be administered by an outside contractor (Truven). It will be tested with HCBS for Elderly, Blind and Disabled (HCBS-EBD). Seven hundred consumers will be randomly selected from each of the EBD and Supported Living Services (SLS) waiver populations, with the goal of 250 completed surveys from each population. Interpreters for the deaf and hard-of-hearing community will be employed to assist in the process.

Other LTSS Quality of Life Instruments to be Evaluated in Colorado

Colorado will be piloting two new data collection instruments in the near future.

1. National Core Indicators – Aging and Disabilities (NCI-AD)

The state of Colorado will be a test site for this new NCI survey. HCPF's DIDD is planning to pilot this instrument in 2015 (a full description of the instrument is available in the section "Identification of Quality Measurement Tools"). The two surveys will be administered in-person but, in subsequent years, they might be administered through the mail. HCPF believes at least 5 years of data collection is needed for the survey to be useful at determining program improvement trends or gaps that might affect major policy decisions. At the time of this process, there were no plans by HCPF to engage consumers in reviewing the administration or reporting of this survey.

2. Life Domains

The Waiver Simplification Subcommittee of the CLAG was charged with recommending an array long-term services and supports life domains. Each service is to be defined and

constructed so as to minimize restrictions on the lives of seniors and people with disabilities to live life fully and independently as possible, while supporting health and safety.

The Life Domains survey is organized into three domains of questions that include the following core life objectives:

1. Community Integration – “Individuals have the same opportunity to live in the community just like people without disabilities. They have choices for how they spend their time, with whom they spend their time and how they contribute to the community.”
2. Living Arrangements – “With access to the services and supports needed to live safely and comfortably, individuals have choices with whom they want to live and where they want to live.”
3. Health and Safety – “Individuals access the services and supports necessary to address their needs, to live successfully in the community and to mitigate any risks for institutionalization, avoidable acute conditions and incidents of abuse, neglect and exploitation” (CLAG, n.d).

IDENTIFICATION AND REVIEW OF LTSS QUALITY MEASUREMENT TOOLS

The Technical Work Group, co-chairs of the LTSS Consumer Quality Project, and a national expert on LTSS quality issues helped identify existing data collection instruments that could potentially capture quality of life (QOL) input currently not collected through existing surveys in Colorado.

During the course of this six-month research project, the state of Colorado's LTSS data collection efforts evolved rapidly, including the decision to join the NCI project and implement the NCI Developmental Disabilities Adult Consumer Survey (NCI-DD) in 2014, an interview-style survey conducted in person. Decisions about which measurement tools to review by the LTSS CQAG were made by the department prior to HCPF's announcement that they had entered into a contract to test the NCI-DD and NCI Aging and Disability Consumer Survey (NCI-AD) instruments in Colorado. Prior to the state's decisions to pilot the surveys, both the NCI-DD and NCI-AD were identified by the Work Group as instruments that should be reviewed for questions around individual QOL and experience of care (please see our companion "LTSS Quality Survey Library" and section that follows).

Important to the QOL research for the LTSS population is the need to capture the narrative "voice" of the consumer and family members, which can only be adequately accomplished through *qualitative* data collection. Qualitative data is time consuming to capture and analyze and therefore cannot be done with large samples of the LTSS population. However, because the state uses a variety of data collection instruments, there may be an opportunity to connect qualitative questions to existing NCI survey processes. The questions identified in this project may be a good starting point for LTSS QOL researchers to add uniquely framed qualitative measures that can supplement the state's existing data collection.

Participant Action Research (PAR) or Peer-to-Peer Interviewing

Of equal if not greater importance is the opportunity to use Participant Action Research (PAR) methods, which employ consumers known or trusted by other consumers to administer qualitative surveys. Through PAR methods coupled with peer-to-peer interviewing, it is possible to obtain more complete, locally- and individually-relevant and honest responses than through standardized tests administered by paid professionals who may be seen as threats to the level of services an individual is receiving or even threats to their personal safety.

Gathering accurate information requires the survey respondent or interviewee to feel free to answer honestly. When LTSS consumers fear retribution through a loss of services

or are currently in a situation where abuse is occurring, they may not reveal the true state of their experience of care. Using a peer-to-peer interviewing model can be an effective method to gather more accurate sensitive data, and to validate current data collection methods.

LTSS Expert Consultant

The project engaged Dr. Stephen Kaye to provide direction and feedback on the work of the Colorado LTSS CQAC. Dr. Kaye, is a professor at the Institute for Health and Aging at the Department of Social and Behavioral Sciences, University of California at San Francisco. Dr. Kay is a nationally-recognized authority in LTSS research across a range of technical policy issues including LTSS system design. His primary research interests focus on community-based LTSS needed by adults with physical disabilities, employment issues, use of information and assistive technology, and LTSS quality measurement and data collection. Dr. Kaye was also recently named Director and Principal Investigator of the Community Living Policy Center, a new national research center funded by the National Institute on Disability and Rehabilitation Research and CMS's new Administration for Community Living.

Dr. Kaye's role in the project was three-fold:

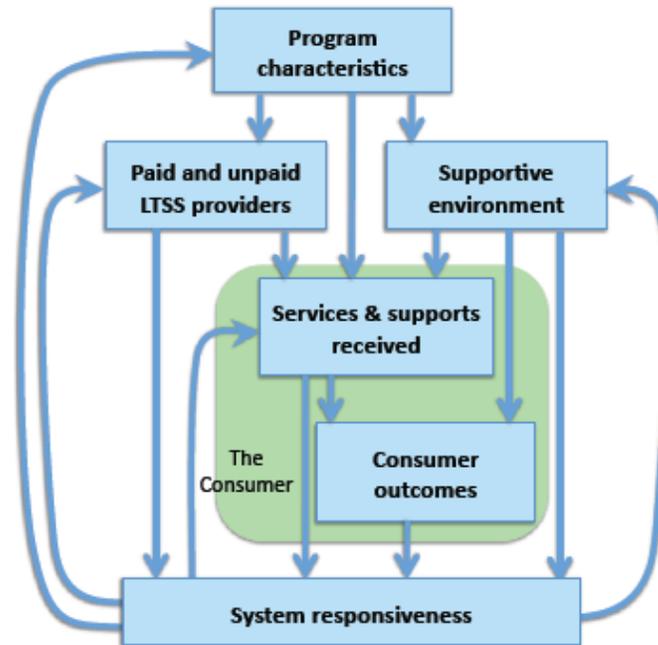
1. He was the keynote speaker at a joint Advisory Committee/Technical Work Group meeting in March 2014. His presentation addressed QOL issues in the LTSS community, the new national data collection efforts currently in development and his assessment of existing LTSS instruments.
2. After the presentation, Dr. Kaye lead a workshop with the Technical Work Group, discussing the issues Colorado is addressing and providing guidance on the instrument selection and construction process.

Dr. Kaye presented a conceptual framework for identifying quality and outcome measurements for the LTSS consumer. This framework served as the basis for identification of QOL issues from a consumer perspective, guiding the Committee's selection of instruments to review. Dr. Kaye's Framework also served as the organizing structure for the LTSS Question Library.

Conceptual Framework for Quality & Outcome Measurement in LTSS

Dr. Kaye's proposed LTSS Conceptual Framework was chosen from many possible models as the most appropriate for its relevance, simplicity and comprehensive view of both LTSS as a closed loop system and the consumer's experience of that system.

Figure 2. Stephen Kaye, PhD LTSS Conceptual Framework for Quality and Outcome Measurement in Long-Term Services and Supports



Four Core Domains Specific to Quality of Life Measurement

- 1. **Paid and Unpaid LTSS Providers**
- 2. **Supportive Environment**
- 3. **Services & Supports Received**
- 4. **Consumer Outcomes**

At the top of the diagram are *program characteristics* that flow into and affect the LTSS system. The core *resources* affecting consumer’s lives include: LTSS providers, their unique environment and the consumer’s experience of these life-sustaining resources. The bottom of the diagram represents LTSS system responsiveness, or the quality improvement process that is the feedback loop to improve LTSS programs.

The four “domains” in the middle of the diagram are the focus of the research for this project. These domains cover the types of QOL survey content discussed throughout the remainder of this paper and our companion LTSS Quality Library.

Early in the project, the Advisory Committee was introduced to the conceptual framework and engaged in brainstorming sessions about each subdomain to flesh out the LTSS consumers’ experiences, challenges and issues that fit within it. Advisory Committee input was then used to guide the selection of questions for each question “subdomain” (question set) described below.

Selection of Validated Survey Instruments

The first phase in developing the LTSS question library was a crosswalk between five of the most mature, validated and consumer-focused survey instruments known at the time of this research, organized along the lines of the core LTSS system domains of Kaye’s framework. Below are the instruments examined, their acronyms and a short description of each.

The National Core Indicators Program

The National Core Indicators (NCI) program is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Service Research Institute (HSRI). The project started in 1997 and sought to develop a set of indicators of system performance to evaluate and track the progress of change and improvement in systems of support for people with intellectual and developmental disabilities and their families. National Core Indicators has been collecting data for over a decade and is recognized as a source of information about individuals with developmental disabilities who are receiving services across a large sample of states. The current NCI database contains randomly-selected representative samples in 40 states.

The current set of indicators includes approximately 150 consumer, family, system and health and safety outcomes. Each performance indicator is associated with a source of data. Currently, the primary sources of NCI data are the Adult Consumer Surveys and the Family Surveys. Table 4 describes core indicators associated with these two surveys.

National Core Indicators Adult Consumer Survey (NCI-DD)

The NCI-DD is a nationally-recognized survey tool currently used in 40 states and Washington D.C.

Table 4: NCI Domains and Subdomains

Domains	Subdomains
Individual Outcomes	Work
	Community Inclusion
	Choice and Decision-Making
	Self Determination
	Relationships
Family Outcomes	Satisfaction
	Information and Planning
	Choice and control
	Access and Support Delivery
	Community Connections
	Family Involvement
	Satisfaction
Health, Welfare and Rights	Family Outcomes
	Safety
	Safety
	Health
	Medications
	Wellness
	Restraints
Respect/Rights	
Staff Stability and Competence	Staff Stability
	Staff Competence
System Performance	Service Coordination
	Access

Colorado elected to implement the NCI-DD in 2014. The survey instrument includes a set of interview questions and collects pre-defined demographic and other contextual information from consumers or representative of the person.

Background and pre-survey information is gathered by a case manager prior to the interview. A few questions such as “have you had a flu vaccination this year?” are asked when the interview is scheduled.

The interview is conducted face-to-face at the agency, at the person’s home or at an alternate place of the person’s choice. It is required that the first section of the interview be conducted with the client as these questions are subjective and can be answered only by the individual. It is preferred that the client answer the second section of the survey but, if the client is unable or would rather have someone else answer, the second section can be completed by a proxy.

Staff employed by the state of Colorado conducts the interviews. One full time agency employee and temporary staff hired for the project are provided with three days of NCI and HCPF’s Division of Developmental Disabilities training. The interviewer documents the client’s answers in the NCI data system using a laptop computer.

National Core Indicators – Adult Family Guardian Survey (NCI Family I/DD)

This survey is given to families/guardians who have an adult with an intellectual/developmental disability (I/DD) living in a residential placement center. The survey includes questions addressing how well services received are meeting the needs of the adult with I/DD and the needs of their family.¹

National Core Indicators – Aging and Disabilities Adult Consumer Survey (NCI-AD)

The NCI-AD is currently being piloted in three states. Colorado is seeking funding to pilot it in 2015. The survey instrument includes a set of interview questions and collects data in pre-defined data categories. The NCI-AD has more than twice the number of domains and significantly more questions than the NC-DD, especially around QOL issues.

There are 11 major sections in the NCI-AD instrument:

1. Service Satisfaction
2. Living Space
3. Safety/Security/Privacy
4. Community

¹ There are two additional family surveys: the Adult Family Survey for families who have an adult family member with a developmental disability who lives with them and a Child Family Survey for families who have a child with a developmental disability who lives with them. All three family surveys have very similar questions but there are some differences.

5. Everyday Living
6. Relationships
7. Healthcare
8. Planning for the Future
9. Independence/Functional Competence
10. Direct Care Workers
11. Healthcare Workers

The Council on Quality and Leadership (CQL)

The CQL started in the 1960s and has assumed the leadership role in developing and validating a lengthy, progressive set of measures of LTSS quality, as well as QOL and community life outcomes. In the early 1990s, CQL conducted a series of focus groups with people with disabilities and their families in which respondents defined what outcomes were most important to them. At this time, CQL started to shift its focus to work on “Personal Outcomes Measures”, which represented a departure from traditional quality systems. The Council changed the definition of quality from “compliance with program or process standards” to “responsiveness to individuals.” The shift to a focus on individual QOL included changes in the measures and process of gathering information. The foundation of their data-gathering process is conducting interviews with people with intellectual disabilities, mental illness or other conditions.

The Council offers an accreditation program that includes three parts: CQL Basic Assurances, Personal Outcome Measures (POMS) and Evidence-based Practices in Person Centered Excellence (onsite visit).

CQL Basic Assurances

As part of its accreditation program, the CQL Basic Assurances includes a set of non-negotiable requirements for all service and support providers. While the Basic Assurances contains requirements for certain systems and policies and procedures, the effectiveness of the system or policy is determined in practice, person by person. The CQL Basic Assurances includes a set of questions to be asked during an interview designed to get the information from the perspective of the person receiving the services. Most of the questions are open ended and each section contains a list of probes in case the interviewer considers that more information is necessary. The CQL Basic Assurances includes 10 factors:

1. Rights protection and promotion
2. Safe environments
3. Dignity and respect
4. Staff resources and supports

5. Natural support networks
6. Positive resources and supports
7. Protection from abuse, neglect, mistreatment and exploitation
8. Continuity and personal security
9. Best possible health
10. Basic assurances system

CQL Personal Outcome Measures (POMS)

The Personal Outcome Measures are key questions used to identify people's QOL outcomes, plan supports and gather information and data about individual outcomes. Professionals conduct Personal Outcome Measures via face-to-face interviews in order to examine the link between personally-defined quality of life and excellence in person-centered services, and to highlight the importance of data planning and making change. The questions are open-ended and each section includes a list of probes in case the interviewer thinks more information is needed. In addition to questions for the individual receiving services, each section contains a set of follow-up questions that those who "know the person best" can answer.

The Personal Outcome Measures are organized into three factors:

- *My Self*: Who I am as a result of my unique heredity, life experiences and decisions.
- *My World*: Where I work, live, socialize, belong or connect.
- *My Dreams*: How I want my life (self and world) to be.

National Core Indicators Survey Instruments

The state of Colorado is currently using the National Core Indicators-Adult Consumer Survey DD (NCI-DD). The state will pilot the National Core Indicators Aging and Disability (NCI-AD) in 2015. The NCI-DD has the following four sections:

1. Pre-survey form:
2. Background Information form:
3. Section I: Direct Interview with Person Receiving Services and Supports
4. Section II: Interview with the Person Receiving Services or with Other Respondents.

The NCI-AD has the following three sections:

1. Pre-survey form:
2. Background Information form:
3. Consumer Survey

The summary and analysis of the crosswalk are provided in the next section, along with the identification of questions from other instruments that could be used to supplement the NCI instruments.

CROSSWALK RESULTS: QOL DOMAINS BY SELECTED INSTRUMENTS

The five instruments identified by the Technical Work Group were cross walked against Kaye's Conceptual Framework, domains and subdomains relevant to QOL issues determined to be of importance to the LTSS consumer by the Advisory Committee.

I. Domain: Paid and Unpaid LTSS Providers

Subdomain: Caregiver/Family Support

Most caregiving is performed by unpaid workers, most of whom are family members. Quality of life and experience of care is directly affected by the abilities of the caregiver and the degree to which the caregiver is able to attend to their own physical, mental and social needs.

Subdomain Description: Support for and status of families and family/friend caregivers, compensation of family members, and impact of caregiving on families.

Measures in the NCI Instruments: The NCI-DD does not ask any questions that pertain directly to family caregivers. While the pre-survey asks questions about where the person is living and who the person lives with, the NCI-DD survey does not contain any questions about how families care for persons with disabilities or what types of supports the family receives. The NCI-DD asks the following question in the background section:

- Does this person receive either ICF/ID (formerly ICF/MR) or HCBS Waiver funding?

Findings: The National Core Indicators Aging and Disability (NCI-AD) tool contains some questions that start to address the role of caregiver/family support.

- First, it asks the respondent a list of questions about what type of needs they have (e.g., self-care needs, everyday activities and help with finances). Within the types of needs, e.g., self-care, the survey provides a long list of options (bathing, dressing, going to the bathroom, eating, etc.).
- For each question, the survey asks who provides services and whether or not the individual is receiving adequate help for their needs.
- Additionally, all the questions about staff stability and staff competence consider that the person providing the support could be paid or unpaid staff/caregivers.

However, aside from the question mentioned above, neither the NCI-AD nor the NCI-DD contain questions about the supports families with family members with disabilities receive. The NCI has two other tools for families (of adults and children with disabilities) that include questions about the types of supports families receive. ***Both the DD and AD fall short in capturing QOL issues related to caregiver/family supports.***

Advisory Committee Input/Potential Supplemental Question

Table 1. Caregiver/Family Support Subdomain

AC Committee Input ²	Potential Questions
<p>Unpaid Caregivers</p> <ul style="list-style-type: none"> • Respite needed. • Natural supports may be disrespecting of families. • Do family caregivers have the capacity to meet the needs of their family member? • Elders as caregivers may be unable to meet the needs of their family member • Help caregivers self-assess their own abilities, level of exhaustion, supports they need. • Adequate supports for caregivers. • Relying on unpaid support can result in burnout. • Do not expect family members should provide LTSS, the only way they should do this is for pay. • Is there a need for family engagement support? • Treat LTSS caregivers with respect. 	<p>Suggested question from the NCI-Family I/DD survey</p> <ul style="list-style-type: none"> • Approximately, how much out of pocket money did you spend last year on this person's medical services, equipment, supplies, therapies, and other supports and services?
<p>Paid Caregivers</p> <ul style="list-style-type: none"> • Workforce retention. • Training on how to communicate with clients. • Consumer perspective not included in paid staff evaluations. • Training on behavioral management with clients. • Opportunities to support client beyond specific skill set of the LTSS provider job description. • Patient safety. 	<p>Suggested questions from the NCI-AD (see questions under Workforce Development and Worker Availability and Quality)</p>

² Some AC input is relevant to more than one subdomain and will be shown in more than one subdomain where applicable.

AC Committee Input ²	Potential Questions
<ul style="list-style-type: none"> • Adequate pay for caregivers. • Increase funding for reimbursements. • Treat LTSS staff with respect. 	

Subdomain: Workforce Development

Quality of life and experience of care is directly affected by paid workforce: low pay and lack of training can result in substandard care and even abuse.

Subdomain Description: Job characteristics such as wages and benefits, training/certification, injury rates and satisfaction.

Measures in the NCI Instruments: The NCI-DD asks the following question that would fit under this subdomain.

- Do you feel your support staff have the right training to meet your needs?

Remarks: The NCI-AD provides a few more questions that address this component of the workforce development subdomain. Other customer satisfaction surveys that were cross-walked for this project do not include questions that would add anything significant to the NCI-AD. However, tools that are used for facility certification processes contain some questions that could be adapted to strengthen the battery of questions for this subdomain.

Advisory Committee Input/Potential Supplemental Questions

Table 2. Workforce Development Subdomain

AC Committee Input	Potential Questions
<p>Unpaid Caregivers</p> <ul style="list-style-type: none"> • Training resources/services available, transport and skills. • Family caregiver: do they have the capacity to meet the needs of their LTSS? • Help caregivers self-assess their capacity, skills, etc. • Needs to be consumer-directed, person and family-centered. 	<p>Suggested questions from the NCI I/DD</p> <ul style="list-style-type: none"> • Do the support workers have the right training to meet your family member’s needs?

AC Committee Input	Potential Questions
<p>Paid Caregivers</p> <ul style="list-style-type: none"> • Training: <ul style="list-style-type: none"> ○ Communication with clients; ○ Working with medically fragile individuals; ○ Behavioral management training; and ○ Overall training. • Consumer perspective not included in paid staff evaluation. • Workforce sub group exploring a “certification”. • Broad career development so it isn’t seen as a job no one wants or one someone has to settle. • Consumer-driven training. • Provide support to avoid staff burnout. 	<p>Suggested questions from the POMS</p> <ul style="list-style-type: none"> • How do staff treat you? <p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • Do you feel that the people who are paid to help you treat you with respect? • Do you feel safe around the people who are paid to help you? • Overall, how satisfied are you with the people who are paid to help you? • Do you think that the people who are paid to help you (OR PAID RELATIVES/PAID FRIENDS, IF APPLICABLE) have had enough training to work with you? <p>Suggested questions from the NCI Family I/DD</p> <ul style="list-style-type: none"> • Do the support workers have the right training to meet your family member’s needs? <p>Suggested questions from CQL Basic Assurances</p> <ul style="list-style-type: none"> • Do direct support staff receive competency based training to recognize and respond to people experiencing medical emergencies. • Do all staff in direct contact with receiving support have a minimum of First Aid, CPR and general medication training including how to recognize harmful side effects.

Subdomain: Workers’ Availability and Quality

Subdomain Description: Worker shortages, workforce turnover, skill levels that match consumer needs.

Measures in the NCI Instruments: The NCI-DD asks the following questions that would fit under this category.

- If you call and leave a message, does your case manager/service coordinator take a long time to call you back, or does s/he call back right away?
- Do your staff come when they are supposed to?
- If you have problems with your staff, do you get the help you want to fix these problems?
- Did you choose or pick your case manager/service coordinator?
- Do you choose (or pick) your staff?

Remarks: The NCI-DD is very thin in the worker quality evaluation area. The NCI-AD significantly improves upon this as it includes a battery of questions about the availability, quality and overall satisfaction with paid staff. It is important to note that the majority of the questions on the NCI AD are closed ended. Thus, it might be important to consider adding qualitative responses if the close-ended questions still omit important questions consumers want included.

Advisory Committee Input/Potential Supplemental Questions

Table 3. Workers’ Availability and Quality Subdomain

AC Committee Input	Potential Questions
<p>Unpaid Caregivers</p> <ul style="list-style-type: none"> • Client may be reluctant to ask family. Help not available currently to help clients ask for support from family. • Family caregiver: do they have the capacity to meet the needs of their LTSS family member? • Elders as caregivers may be unable to meet the needs of their family member. 	<p>Suggested questions from the NCI-AD (Note: These questions also fit under the “Paid Caregivers” category).</p> <ul style="list-style-type: none"> • Do you generally need help with basic self-care needs like bathing, dressing, going to the bathroom, eating or moving around your home? <ul style="list-style-type: none"> ○ Do you generally get enough of that help? • Do you generally need help with everyday activities like preparing meals, housework, shopping or taking your medications? <ul style="list-style-type: none"> ○ Do you get enough of that help?

AC Committee Input	Potential Questions
	<ul style="list-style-type: none"> • Do you generally need help with keeping track of your finances or doing bills? <ul style="list-style-type: none"> ○ Do you get enough of that help? • Is there someone who helps you on a regular basis (at least once a week)? We are talking about any kind of help – either with self-care needs, or everyday activities. • Who is the person who helps you the most? • Who else provides assistance for you when you need help?
<p>Paid Caregivers</p> <ul style="list-style-type: none"> • Workforce retention needs: Turnover concern. • Workforce sub group exploring a “certification”. • Consistency of paid staff/don’t send a different person every day. • Responsive. • Provide supports to avoid burnout. • Participant option should always be first option. 	<p>Suggested questions from the POMS</p> <ul style="list-style-type: none"> • How long have your support staff worked with you? • Do you have the consistency you need in the staff who work with you? • What would cause you to make changes in your current situation? • How is the importance of staff continuity defined for the person and addressed through the support process? <p>Suggested questions from NCI-AD</p> <ul style="list-style-type: none"> • Do the people who are paid to help you change too often? • Can you change the people who are paid to help you if you want to? • Do the people who are paid to help you come and leave when they are supposed to? • Do the people who are paid to help you do things for you the way you want them?

2. Domain: Supportive Environment

Subdomain: Accessibility and Accommodations

Subdomain Description: Home and community accessibility features, including home modifications; accommodating physical and social environment.

Measures in the NCI Instruments: The NCI-DD asks the following questions that would fit under this subdomain:

- Which of the following services/supports funded by the state (or county) agency does this person receive? (The range of answers includes options that would fit under the accessibility and accommodations category).
- How would you describe this person’s mobility?
- How would you characterize the place where this person lives?
- How do you usually get to places you need to go?
- When you want to go somewhere, do you always have a way to get there?

Remarks: The NCI-AD has a couple of questions that also address accessibility and accommodations subdomain. However, other tools such as the POMS contain many questions that can be adapted and added to an existing tool. The POMS has too many questions, but many of them are iterations of the same questions and not all questions are intended to be asked.

Advisory Committee Input/Potential Supplemental Questions

Table 4. Accessibility and Accommodations Subdomain

AC Committee Input	Potential Questions
<ul style="list-style-type: none"> • Affordable housing. 	<p>Suggested questions from the POMS Suggested questions for the person</p> <ul style="list-style-type: none"> • Is there something you wish you could do but can't or use because you don't have the proper equipment or modification? • Do you know how to use appliances or equipment? • Is there anything that would make it easier for you to get around your home, school, place of work, or community? • Is transportation available when you want to go somewhere?

AC Committee Input	Potential Questions
	<p><i>Questions about this outcome for the person:</i></p> <ul style="list-style-type: none"> • Is there anything the person has difficulty doing or cannot do because of the lack of modifications or adaptations? • What assistance do you provide to the person when modifications or adaptations are needed? • What resources are available within the organization and the community when modifications and adaptations are needed? <p><i>Questions about individualized supports:</i></p> <ul style="list-style-type: none"> • How do you determine the extent to which the person can use his or her environments? • How do you determine if adaptations or assistive technologies are needed? • What adaptations or modifications have been made for the person? • How are barriers to this outcome being addressed through supports for the person? • What organizational practices, values and activities support this outcome for the person? • Are there rules, practices or staff behaviors that interfere with the person using his or her environments? <p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • Many people need changes to their homes such as grab bars, ramps, bathroom modifications, emergency response systems, remote monitoring, and others to make it easier living at home. Do you currently have one of the following? • Do you need one of these changes to your home (or an upgrade from the one you have now)? (READ RESPONSE OPTIONS) (CHECK ALL THAT APPLY)

AC Committee Input	Potential Questions
	<p>Suggested questions from NCI Family-I/DD</p> <ul style="list-style-type: none"> • Does your family member have access to the special equipment or accommodations that he/she needs (for example, wheelchairs, ramps, communication boards)?

Subdomain: Technology

Subdomain Description: Availability and use of needed assistive and other technologies to support community living.

Measures in the NCI Instruments: The NCI-DD includes that following question related to technology:

- Which of the following services/supports funded by the state (or county) agency does this person receive? (The range of answers available includes some that fall under technology).

Remarks: The NCI-AD has a couple of questions that address issues about technology directly. However, the questions around this subdomain are limited in the NCI tools. Other tools such as the POMS also do not contain many questions addressing the availability and use of technology to support community living.

Advisory Committee Input/Potential Supplemental Questions

Table 5. Technology Subdomain

AC Committee Input	Potential Questions
<ul style="list-style-type: none"> • Assistive technology access is crucial. • Maintenance of technology. • Financial support to maintain technology. • Ease the process to receive support for assistive technologies. • People need access to technology. 	<p>Suggested questions from the POMS</p> <ul style="list-style-type: none"> • Is there something you wish you could do but can't or use because you don't have the proper equipment or modification? • Do you know how to use appliances or equipment? • How do you determine if adaptations or assistive technologies are needed?

AC Committee Input	Potential Questions
	<p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • Many people need assistive devices like a cane, a walker, a scooter, or a wheelchair to help them get around or to help with their everyday lives like hearing aids, communication devices, etc. Do you currently have one of the following? • Do you need one of these devices (or an upgrade to the one you have)?

Subdomain: Resources

Subdomain Description: Financial and personal resources, including social support.

Measures: The NCI-DD has the following questions about financial and personal resources:

- Does this person currently receive Medicare?
- What agency or program pays for the employment or day supports this person receives?
- Did this person work 10 out of the last 12 months in a community job?
- Does this person receive paid vacation and/or sick time at his/her job?
- Which of the following services/supports funded by the state (or county) agency does this person receive? (The range of answers includes answers that would fit under this category).
- Does this person receive either ICF/ID (formerly ICF/MR) or HCBS Waiver funding?
- Do you have a paid job in the community?
- Total gross wages (before taxed or deductions, earned at this activity during the two week period.
- Does someone talk with you about your budget and the services you can get?
- Is there someone who helps you decide how to use your budget/services?
- Can you make changes to your budget/services if you need to?
- Do you want more help deciding how to use your budget/services, or do you have enough help?
- Do you get information about how much money is left in your budget/services?
- If yes, is the information easy to understand?

In addition, the NCI-DD includes the following questions about social supports:

- Do you have friends you like to talk to or do things with? If s/he answers "yes," ask who the friends are and try to determine if they are family, staff, roommates, co-workers, etc. You can use prompts such as: Can you tell me their names? Are these friends staff or your family?
- Do you have a best friend, or someone you are really close to?
- Can you see your friends when you want to see them?
- Do you ever talk to your neighbors?
- Do you ever feel lonely? (Do you ever feel like you don't have anyone to talk to?)
- Do you have family that you see?
- Can you see your family when you want to?

Additionally, the NCI-DD includes other questions that would fit under this subdomain as well as under the domain *Consumer Outcomes* under the subdomains *Wellbeing* and *Participation*. Those questions are included under that domain below.

Remarks: The NCI-AD includes similar questions about financial and personal resources as the NCI-DD. However, the NCI-DD has many more questions about employment than the NCI-AD. However, neither the NCI -DD nor the NCI -AD asks questions about financial stability and security. Other tools such as the POMS include questions about this topic if additional questions were deemed necessary.

Advisory Committee Input/Potential Supplemental Questions

Table 6. Resources Subdomain

AC Committee Input	Potential Questions
<ul style="list-style-type: none"> • Assess social and financial needs. • Hierarchy of needs and resources. • Affordability of housing. • Awareness of resources available. • Public support for resources. • Outreach of resources available. • Training for family members about resources and how to access resources. 	<p>Suggested questions from the POMS</p> <ul style="list-style-type: none"> • What is your source of income? • Do you have enough money to pay expenses? • How do you protect your personal property and other resources? • Are there things you have to do without? If so, what are they and why can't you have them? • Is your financial situation acceptable? <p><i>Questions about this outcome for this person:</i></p> <ul style="list-style-type: none"> • Does the person feel secure in his/her working conditions?

AC Committee Input	Potential Questions
	<ul style="list-style-type: none"> • Does the person feel secure financially? <ul style="list-style-type: none"> ○ What has the person told you is important for continuity and security? • If the person has indicated concerns, what are they and what was done about them? <p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • Do you have a paying job, either full-time or part-time? • Would you prefer to have a full-time job? • Do you like your job? • Would you like a job?

Subdomain: Settings

Subdomain Description: Extent to which the setting is integrated, offers consumer control, and promotes participation and engagement.

Measures in the NCI Instruments:

- Do you like your home or where you live? (Do you like living here?)
- Would you like to live somewhere else?
- Do you ever talk with your neighbors?
- How do you usually get to places you need to go? (Check ALL that apply; however, we are looking for the most frequent mode(s) of transportation).
- When you want to go somewhere, do you always have a way to get there?

In addition, the NCI-DD contains questions about community inclusion that also fall under the domain *Consumer Outcomes* subdomain *Participation*. Those questions are included under that domain below.

Remarks: The NCI-AD significantly improves upon this domain. In particular, the NCI-AD probes more deeply into the barriers a person might encounter in their settings in terms of where they live and ability to be engaged. If needed, the POMS also contains a long list of questions that probe more deeply into this subdomain.

Advisory Committee Input/Potential Supplemental Questions

Table 7. Settings Subdomain

AC Committee Input	Potential Questions
<ul style="list-style-type: none"> • Location/transportation access. • True integrated and community living. • Actual transition from institution to community. • Availability of supports in place that are considered LTSS. • Having enough support to get them involved in the community. 	<p>Suggested questions from the POMS</p> <p><i>Suggested questions for the person:</i></p> <ul style="list-style-type: none"> • What do you do for work or your career? • What options did you have? • Who chose what you do? • Can you do something different if you want to? • How did others help you with this? • Are you satisfied with the decision either you or others made? • If not, what would you like instead? • Where do you live and work? • Do other people receiving services live and work with or near you? • Where do you go to have fun? • Are these places where other people in the community would go? • Do you spend time in other places used by people in the community? • How did you select these places? <p><i>Suggested questions for the person:</i></p> <ul style="list-style-type: none"> • Who do you know in your community? • With whom do you like to spend time? With whom do you spend most of your time? • When you go places, whom do you meet? Talk with? • What kinds of interactions do you have with people (order food in restaurants; pay for purchases; talk with people at church, synagogue or other places of worship; visit with neighbors)? • If you work, what kinds of social contacts do you have there (lunches, breaks, parties after work)?

AC Committee Input	Potential Questions
	<p>Suggested questions from the NCI-AD Living Space:</p> <ul style="list-style-type: none"> • In general, do you like where you are living right now? • Why don't you like where you live? • Would you prefer to live somewhere else? • Would you have to live somewhere else if you didn't have the services and help you are receiving? • To continue living here, do you need more or different types of supports or help? <ul style="list-style-type: none"> ○ What kind of supports? • Have you thought that you might need to move somewhere else in the next year? • What kind of place would you like to move to when you need to move? <ul style="list-style-type: none"> ○ What prevents you from living somewhere else?

3. Domain: Services and Supports Received

Subdomain: Adequacy

Subdomain Description: Receipt of sufficient services, satisfaction with services, met and unmet need among people receiving and not receiving services.

Measures in the NCI Instruments: The NCI includes the following questions that would fit under this subdomain:

- Have you met your case manager/service coordinator?
- Do you have a service plan? (Do you have a list of services your case manager/service coordinator will help you get?)
- Did you help make your service plan?
- Do you get the services you need?
- If additional services are needed, please note type of service or support below:

These questions also fit under the *Coordination* subdomain. They are repeated below not only because they fit under both categories but also because the NCI-DD does not include

as many questions about supports and services as other tools such as the NCI-AD and the POMS.

Remarks: The NCI-AD significantly improves on this subdomain. It contains a battery of questions that probe deeper into the adequacy of services and overall satisfaction with services. However, most of the questions are close-ended and advise the interviewer to try to classify the answers into the pre-selected categories for many of the questions. This could be problematic because some of the responses might not fit into the provided categories.

Advisory Committee Input/Potential Supplemental Questions

Table 8. Adequacy Subdomain

AC Committee Input	Potential Questions
<ul style="list-style-type: none"> • Quality of services. • Flexibility of services to meet changing health outcomes. • Shortage of LTSS workers. • Low wage for LTSS affect the growing need of LTSS services. • As more baby boomers start needing services and supports, our system is locked into a rigid, hard to change way of doing things, of getting people eligible for services, and of funding services. • Current system forces people into crisis mode that requires intensive, high cost services. • Need real mental health services including residential psychiatric rehab so people with SMI can get the support they need to move towards recovery. 	<p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • Do you have a case manager (STATE/SPECIFIC TERM MAY BE USED) – someone whose job it is to help set up and coordinate services with you? • Can you reach your case manager (STATE/SPECIFIC TERM OR NAME MAY BE USED) when you need to? • Do the services you receive meet your needs? • What kind of additional services might help with those needs? Again, we are talking about long-term care services, such as help with personal care, help with preparing meals, help doing housework, transportation, housing assistance, benefits information, and others. • Has your case manager (STATE/SPECIFIC TERM OR NAME MAY BE USED) talked to you about services that might help with your needs? • Are you in charge of the services and supports you receive (for example, can you determine what kind of services you get and when you get them?)

AC Committee Input	Potential Questions
	<ul style="list-style-type: none"> • If you have a question about the services you are getting, do you know who to call? • If you have a complaint about the services you are getting, do you know who to call? • In general, how satisfied are you with the services you receive? <p>Suggested questions from the NCI Family I/DD</p> <ul style="list-style-type: none"> • Residential Supports – your family member with an intellectual/developmental disability receives care and support in a residence outside of your home. • Do you get enough information to help you participate in planning services for your family member? • Is the information you receive easy to understand? • Are you kept informed about how your family member is doing? • Do you feel that services and supports have made a positive difference in the life of your family member? • Do you feel that services and supports have reduced your family’s out-of-pocket expenses for your family member’s care? • Have the services or supports that your family member received during the past year been reduced, suspended, or terminated? • If Yes, did the reduction, suspension, or termination of these services or supports affect your family member negatively?

Subdomain: Appropriateness

Subdomain Description: Includes: person-centeredness; consumer choice, direction, and control; support in making decisions about services; reliability; respect and dignity.

Measures in the NCI Instruments: The NCI-DD contains the following questions that fit under this domain:

- Do your staff treat you with respect?
- Is this person currently using a self-directed supports option?
 - If yes, who employs this person’s support workers?

Some of the questions related to the subdomain *Coordination* will also fit under this category. Those questions are included below under the *Coordination* subdomain.

Remarks: The NCI-DD has very few questions that inquire about the appropriateness of supports and services. The NCI-AD has a few more questions, but it seems to be lacking in this area as well. The NCI family (adult and child version) and the POMS surveys include many more questions about this subdomain, especially as it related to person-centeredness services and supports.

Advisory Committee Input/Potential Supplemental Questions

Table 9. Appropriateness Subdomain

AC Committee Input	Potential Questions
<ul style="list-style-type: none"> • Clear training and definition of person centeredness and person-centered planning is needed. • If a client needs a service, they should be able to get it through whatever program they’re in even if it is not usually a need in that specific population. 	<p>Suggested questions from the POMS <i>Suggested questions for the person:</i></p> <ul style="list-style-type: none"> • What services are you receiving? • When, where and from whom do you receive services? • Who decided what services you would receive? • If you did not decide, what was the reason? • How did you decide who would provide the service? • Are these the services you want? • Do you have enough services? Are they meeting your needs? • Can you change services or providers if you choose so?

AC Committee Input	Potential Questions
	<p><i>Questions about the outcome for this person:</i></p> <ul style="list-style-type: none"> • What services does the person use? • What services were identified as beneficial by the person? • What options for services were presented for that person? <p><i>Questions about individualized supports:</i></p> <ul style="list-style-type: none"> • How do you determine the services desired by the person? • How were options for services and providers presented to the person? • How were the person’s preferences considered when presenting options? • If the person has limited ability to make decisions or limited experience in decision-making, what do you do? 5. How do you assist the person to overcome barriers to this outcome? <p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • How did you first learn about services that you are getting? • Did you get enough information about the services you are getting now? • Did you get that information in the language you prefer? • Did you help plan the services you are now getting? We are still talking about your long-term care services.

Subdomain: Coordination

Subdomain Description: Includes care coordination and integration of acute care and LTSS.

Measures in the NCI Instruments: The NCI-DD includes the following questions about coordination.

- Have you met your case manager/service coordinator?
- Do you have a service plan? (Do you have a list of services your case manager/service coordinator will help you get?)
- Did you help make your service plan?

- Does your case manager/service coordinator ask you what you want?
- If you ask for something, does your case manager/service coordinator help you get what you need?

Remarks: The NCI –DD and NCI-AD both have few questions about the coordination of services.

Advisory Committee Input/Potential Supplemental Questions

Table 10. Coordination Subdomain

AC Committee Input	Potential Questions
<ul style="list-style-type: none"> • Care coordination should include advocacy if there are issues like with dual-diagnosis. • Definition of care coordination separate from medical and hospital model. • The person receiving the services should be directing the services they are receiving. • Care coordination focuses on “safety” which often means how are you kept safe medically rather than asking the person if they have safety concerns. • Care coordination should include advocacy if there are issues like with dual-diagnosis. 	<p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • Do you have a case manager (STATE/SPECIFIC TERM MAY BE USED) – someone whose job it is to help set up and coordinate services with you? • Planning for the future <ul style="list-style-type: none"> ○ Have you planned or are you planning for your future need for services or supports? ○ Do you know how to get information or help when you are planning for your future need for services or supports?

Subdomain: Utilization

Subdomain Description: Healthcare & LTSS utilization, barriers to utilization and maintenance of or transition to community living.

Measures in the NCI Instruments: The NCI-DD includes the following questions that fit under this domain:

- What amount of paid support does this person receive at home? (Include any paid support, regardless of funding source) (Check ONE)
- Which of the following services/supports funded by the state (or county) agency does this person receive? (Check one column for each service):
 - Service coordination/case management

- Respite/family support Transportation
- Assistance finding, maintaining, or changing jobs
- Education or Training
- Health care
- Dental care
- Assistance finding, maintaining, or changing housing
- Social/relationships issues, meeting people
- Communication technology
- Environmental adaptations/home modifications
- Benefits/insurance information
- Other

Remarks: The NCI-DD does not have many questions about this domain. The NCI-AD includes quite a few questions that can help collect data on this subdomain. However, *both the NCI-AD and NCI-DD lack questions that get at the barriers for utilization of services.*

Advisory Committee Input/Potential Supplemental Questions

Table 11. Utilization Subdomain

AC Committee Input	Potential Questions
<p>Many barriers to utilization:</p> <ul style="list-style-type: none"> • It is almost impossible to find a doctor in the Medicaid system. • Reimbursement rates are abysmally low. • Many doctor’s offices are not accessible for folks. • Not enough funding to transition people back to the community. 	<p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • Are you currently getting any services to help you with your life, such as help with personal care (like taking a bath or getting dressed), help with preparing meals, help doing housework, grocery shopping, or transportation? To clarify, we are talking about formal services – paid services that are not provided by family members. • What help are you currently getting? • How did you first learn about services that you are getting?

4. Domain: Consumer Outcomes

Subdomain: Health and Function

Subdomain Description: Includes mental health and secondary conditions, and ability to maintain physical and cognitive functioning.

Measures in the NCI Instruments:

- Is this person diagnosed with an intellectual disability?
 - BI-9a. If yes, what level of ID?
 - __ 0 NOT APPLICABLE – no ID diagnosis
 - __ 1 Mild ID
 - __ 2 Moderate ID
 - __ 3 Severe ID
 - __ 4 Profound ID
 - __ 5 Unspecified level of ID
 - __ 6 ID level unknown
- What other disabilities or conditions are noted in this person's record?
- Overall, how would you describe this person's health?
- Does this person have a primary care doctor?
- When was his/her last complete annual physical exam? (We are referring to a routine exam, not a visit for a specific problem or illness.) (Check ONE)
- When was his/her last dentist visit? (Check ONE)
- When was the last time this person had an eye examination/vision screening?
- When was the last time this person had a hearing test?
- Does this person routinely engage in any moderate physical activity?
- Does this person smoke or chew tobacco?
- If female, when was her last Pap test screening?
- If female, when was her last mammogram?
- When was the last time this person had a screening for colorectal cancer (either sigmoidoscopy or colonoscopy)?
- How often does this person require medical care?
- If this person has seizures, how often do they occur?
- Does this person currently take medications to treat... mood disorders, anxiety, behavioral challenges, and psychotic disorders?

- Does this person need support for Self Injurious Behavior, Disruptive Behavior, and Destructive Behavior?
 - If yes, level of support needed.

Remarks: *The NCI-AD and NCI-DD have very different questions about health, in part is because of the focus population for each of the tools.* However, the NCI-AD contains a lot more questions related to a person’s overall health including mental health questions.

Advisory Committee Input/Potential Supplemental Questions

Table 12. Health and Function Subdomain

AC Committee Input	Potential Questions
<ul style="list-style-type: none"> • ALL clients who display challenging behaviors need to be thoroughly checked for medical problems. • Do not assume a behavioral problem is purely behavioral. • Freedom from abuse and victimization agencies, including CCBs should have investigations done by a non-biased outside agency. • LTSS should lead to reduce doctor and ER visits. • People with significant disabilities do have other medical issues so we cannot set up a system that will punish people in any way for needing medical care. 	<p>Suggested questions from the POMS <i>Suggested questions for the client:</i></p> <ul style="list-style-type: none"> • Do you feel healthy? If not, what bothers you? • What do you do to stay healthy? • What health concerns (physical and mental do you have? • Do you discuss your health concerns with anyone? How are your questions or concerns addressed? • Are you seeing a doctor, dentist, and other health care professionals? • Do you receive regular exams? What kind? • Are you taking any medications? If so, what is it and how does it help? • What advice has your health care professional given you? Are you following it? If yes, is it working? • If you think the medications, treatments or interventions are not working, what is being done? <p><i>Questions about the outcome for this person:</i></p> <ul style="list-style-type: none"> • How has the person defined best possible health? • What preventive health care measures are in place for the person? • How is the person involved in his, her own health care?

AC Committee Input	Potential Questions
	<ul style="list-style-type: none"> • Is the person following the health care professional's recommendations? If no, why do you think that is? • Do you feel the person feels health interventions are working? • If not, what is being done about it? <p><i>Questions about individualized supports:</i></p> <ul style="list-style-type: none"> • How have you explored health issues with the person? • What supports does the person need to achieve or maintain best possible health? • Who provides the support? • How was this decided? • How do you assist the person to overcome barriers to this outcome? <p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • How would you describe your overall health? (READ RESPONSE OPTIONS) • Do you have trouble remembering basic things (like where you are, what date it is, what you did earlier)? • Have you talked to someone about having trouble remembering things? • How often do you feel lonely? (Or feel like you don't have anyone to talk to?) • How often do you feel sad or depressed? (READ RESPONSE OPTIONS) • Do you have someone you can talk to about your feelings? • Do you take any medications that help you feel less sad or depressed? • During the last 12 months, did you talk to a doctor or other professional about feeling sad and depressed? • Do you have a primary care doctor? • Can you get an appointment to see your primary care doctor when you need to? • In the past 6 months, did you have to go the emergency room?

AC Committee Input	Potential Questions
	<ul style="list-style-type: none"> • In the last 6 months, have you stayed overnight in the hospital or a rehab/nursing facility? • When leaving the hospital or the rehab/nursing facility, did you feel comfortable going home/ready to go home? • After leaving the hospital or rehab/nursing facility and going home, did someone follow-up with you to make sure you had the services, supports and help you needed? • Have you had the following preventive care? • Have you been diagnosed with a chronic condition or conditions, such as arthritis, heart disease, high blood pressure, diabetes, asthma, or others? • Do you get enough information and support to help you manage that chronic condition or conditions? • Do you get enough help with understanding your medications? • Do you ever split or skip a pill because of price?

Subdomain: Well-being

Subdomain Description: Includes questions on life satisfaction, happiness, sense of autonomy, self-efficacy and other consumer-assessed QOL measures.

Measures in the NCI Instruments: The NCI-DD includes the following questions related to this subdomain:

Rights and Privacy:

- Do people let you know before they come into your home?
- Do people let you know before coming into your bedroom?
- Do you have enough privacy at home?
- Do people read your mail or email without asking you first?

- Can you be alone with friends or visitors at your home, or does someone have to be with you?
- Are you allowed to use the phone and Internet when you want to?

Choices

- Is this person currently using a self-directed supports option?
- If yes, who employs this person’s support workers?
- Who chose (or picked) the place where you live?
- Did you choose (or pick) the people you live with (or did you choose to live by yourself)? (Did anyone ask you who you’d like to live with? Were you given choices, did you get to interview people?)
- Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)?
- Who decides how you spend your free time (when you are not working, in school or at the day program)?
- Who chose (or picked) the place where you work? (Did you help make the choice?)
- Who chose (or picked) where you go during the day? (Did you help make the choice?)
- Do you choose what you buy with your spending money?

In addition to these questions, the relationship questions under the *Participation* subdomain also tap into this subdomain.

Remarks: *The NCI-AD has similar questions as the NCI-DD for this subdomain.* However, the NCI-AD breaks down some of the broad questions in the NCI-DD into several, more specific questions. In addition, the NCI-AD has more questions that probe more in depth about a person’s sense of autonomy and self-efficacy.

Advisory Committee Input/Potential Supplemental Questions

Table 13. Well-being Subdomain

AC Committee Input	Potential Questions
<ul style="list-style-type: none"> • LTSS should lead to increased quality of life. 	<p>Suggested questions from the POMS</p> <ul style="list-style-type: none"> • What do you know about your rights as a citizen? • Do you have access to information about your rights as a citizen? As an employee? As a person receiving services?

AC Committee Input	Potential Questions
	<ul style="list-style-type: none"> • What rights are most important to you? • Are you able to exercise your rights without difficulty? • What information or support do you need to help you to exercise your rights? • With whom can you talk about your questions or concerns regarding rights? • Have there been times when you thought you were treated unfairly or that your rights were violated? • With whom can you talk when you have concerns about your rights or how you are treated? • Are any of your rights formally limited? • If yes, did you agree to the limitation? • What is being done to change the situation? <p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • Do you feel that you have enough privacy in your home? • Can you use the phone whenever you want to? • Have people entered your home/room (DETERMINE WHETHER TO SAY “HOME” OR “ROOM” BASED ON WHERE THE PERSON LIVES) without permission in the last 30 days? • Have people opened your mail or email without permission in the last 30 days? • Are you able to be alone at home with visitors if you want to? • Do you like how you typically spend your time during the day? • Can you eat your meals at the time when you want to (or does someone else decide when you should eat)? • Do you get up and go to bed at the time when you want to (or does someone else decide for you when you should get up or go to bed)?

AC Committee Input	Potential Questions
	<ul style="list-style-type: none"> • Independence/functional wellbeing • Do you feel that you are as independent as you can be? • Do you feel in control of your life? • Please tell me, out of these four things (READ LIST BELOW OUT LOUD), which one is the most important to you right now? <p>Suggested questions from the NCI Family I/DD</p> <ul style="list-style-type: none"> • Does your family member have friends or relationships with persons other than paid staff or family? • Does your family member have enough support (e.g., support workers, community resources) to work or volunteer in the community? • What are you most satisfied with regarding community connections? (Please write your answer below) • What do you feel needs the most improvement regarding community connections?

Subdomain: Participation

Subdomain Description: Social and economic participation, relationships and social inclusion, and community engagement and integration.

Measures in the NCI Instruments: The NCI-DD includes the following questions that fall under this category:

Economic Participation

- Paid job in a community based setting...
 - Was this person engaged in this activity during the two period?
 - Number of hours worked or spent at this activity during the two-week period.
 - Does this person get publically funded or supports to participate in this activity?

- Is the job or activity done primarily by a group of people with disabilities?
- Unpaid activity in a community based setting...
 - Was this person engaged in this activity during the two period?
 - Number of hours worked or spent at this activity during the two-week period.
 - Is the job or activity done primarily by a group of people with disabilities?
- Paid worked performed in a facility-based setting.
 - Was this person engaged in this activity during the two week period?
 - Number of hours worked or spent at this activity during the two-week period.
- Unpaid activity in a facility based setting...
 - Was this person engaged in this activity during the two weel period?
 - B. Number of hours worked or spent at this activity during the two-week period.
 - Is the job or activity done primarily by a group of people with disabilities?
- Is community employment a goal in this person's service plan?
- Is this person enrolled in the public school system?
- Do you have a paid job in the community?
 - (Do you work at?)
 - If No, ask: Would you like to have a job in the community?
 - Do you like working there?
 - Would you like to work somewhere else?

Social Relationships

- Do you have friends you like to talk to or do things with? If s/he answers "yes," ask who the friends are and try to determine if they are family, staff, roommates, co-workers, etc. You can use prompts such as: Can you tell me their names? Are these friends staff or your family?
- Do you have a best friend, or someone you are really close to?
- Can you see your friends when you want to see them?
- Can you go on a date if you want to?

Community Inclusion

- Do you go to a day program or do some other regularly scheduled activity during the day?
 - Do you like going there/doing this activity?

- Would you like to go somewhere else or do something else during the day?
- In the past month, did you go shopping?
 - If yes, how many times in the past month?
 - If yes, who did you usually go with?
- In the past month, did you go out on errands or appointments?
 - If yes, how many times in the past month?
 - If yes, who did you usually go with?
- In the past month, did you go out for entertainment?
 - If yes, how many times in the past month?
 - If yes, who did you usually go with?
- In the past month, did you go out to a restaurant or coffee shop?
 - If yes, how many times in the past month?
 - If yes, who did you usually go with?
- In the past month, did you go out to a religious service or spiritual practice?
 - If yes, how many times in the past month?
 - If yes, who did you usually go with?
- In the past month, did you go out for exercise?
 - If yes, how many times in the past month?
- In the past year, did you go away on a vacation?
 - If yes, how many times in the past year?
 - If yes, who did you usually go with?
- Have you ever participated in a self-advocacy group meeting, conference, or event?

Remarks: *The NCI-DD has more questions that focus on employment than the NCI-AD. Additionally, the NCI-DD has many specific questions about community inclusion that the NCI-AD is lacking. However, neither the NCI-DD nor the NCI –AD probe as to why a person might not be engaged in the community or what is a person’s role in the community in addition to doing those activities mentioned above. The POMS includes a battery of questions that dig deeper into understanding the role of the person within their community.*

Advisory Committee Input/Potential Supplemental Questions

Table 14. Participation Subdomain

AC Committee Input	Potential Questions
<ul style="list-style-type: none"> • Community participation must be driven by the client’s desire for community participation. • Some people might not desire social interaction or might prefer less than what others consider adequate. • Provide support/funding for assistance in the home if the person prefers/needs this setting. • LTSS should lead to increased: <ul style="list-style-type: none"> ○ Employment ○ Volunteer hours ○ Relationships ○ Number of days out of the house 	<p>Suggested questions from the POMS <i>Suggested questions for the person:</i></p> <ul style="list-style-type: none"> • Do you know about different groups, clubs, organizations, etc., to be involved in? • What kinds of involvement and responsibilities do you have in your neighborhood or community (for example, neighborhood watch, civic groups, social clubs, volunteer, church, synagogue or other place of worship)? • What kinds of things do you do with other people? • Is there something you would like to be doing that you don’t do now? <p><i>Questions about this outcome for the person:</i></p> <ul style="list-style-type: none"> • What social roles do you think the person performs? • Why do you think these are social roles for the person? • What roles do you see the person having the potential or interest to perform? • If the person stopped participating, would he or she be missed? <p><i>Questions about individualized supports:</i></p> <ul style="list-style-type: none"> • How have the person’s interests been identified? • How do you know what social roles the person would like to perform? • What opportunities have been provided? • What supports does the person need to develop or maintain social roles? • Have those supports been provided? • Are there any barriers that affect the outcome for the person? • How do you assist the person to overcome barriers to this outcome?

AC Committee Input	Potential Questions
	<p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • In the last 30 days, have you participated in some type of social activity, either inside or outside your home? <ul style="list-style-type: none"> ○ Why not? • Do you get to do things outside of your home when you want to (like visit friends, go for entertainment, go to a movie or a show, out to eat, to religious functions, etc)? <ul style="list-style-type: none"> ○ Why not? • Do you have transportation when you want to do things outside of your home, like visit a friend, go for entertainment, or do something for fun?

Subdomain: Safety

Subdomain Description: Includes sense of security, freedom from abuse and victimization, injury prevention.

Measures in the NCI Instruments: The NCI-DD includes the following questions related to safety.

- Are you ever afraid or scared when you are at home?
- Are you ever afraid or scared when you are out in your neighborhood?
- Are you ever afraid or scared at work or at your day program/other activity?
- If you ever feel afraid, is there someone you can talk to?

Remarks: The NCI-AD includes more questions that address other safety issues such as risk of injury and security of belongings. However, neither the NCI-AD nor the NCI-DD contain questions that directly asks about personal safety concerns such as abuse and neglect. *Other tools such as the POMS include a battery of questions that probe more deeply into these safety issues.*

Advisory Committee Input/Potential Supplemental Questions

Table 15. Safety Subdomain

AC Committee Input	Potential Questions
<ul style="list-style-type: none"> • Definition of safety might be too broad • Define safety as it relates to the various aspects of a person’s life 	<p>Suggested questions from the POMS</p> <ul style="list-style-type: none"> • Is there any place you don’t feel safe? • What would you do if there were an emergency (fire, illness, injury, severe weather)? • Do you have safety equipment at home (smoke alarm, fire extinguisher, a way to see who is at the door before you open it)? • Do you have safety equipment at work (protective eye and ear wear, safety devices on machinery)? • Is this equipment maintained in working order? • Do you feel safe in your neighborhood? • How do you react if a stranger approaches you? • Are your living and working environments clean and free of health risks? <p><i>Suggested questions for the person:</i></p> <ul style="list-style-type: none"> • Do you have any complaints about how you are treated by anyone? • Have you been hurt by anyone? • Has anyone taken advantage of you? • Does anyone yell or curse at you? If so, who do you tell? • What was done to address your concerns? • Who would you tell if someone hurt you or did something to you that you didn’t like? • Do you know what abuse is? Do you know what neglect is? • Have you been abused? Have you been neglected?

AC Committee Input	Potential Questions
	<ul style="list-style-type: none"> • Where are the safe places, people or other resources that you can get in touch with if you have been abused, mistreated or feel threatened? <p>Suggested questions from the NCI-AD</p> <ul style="list-style-type: none"> • Are you afraid of falling when at home? • Has somebody worked with you to reduce your risk or fear of falling? • Are you concerned for your safety at home? • If you are concerned for your safety or if you were to ever feel unsafe, do you have somebody to talk to that could help you feel safe? • Are you ever worried for the security of your belongings? • Do you feel that someone around you has been using your money in a way that you did not give them permission to?

FINAL REMARKS

The NCI-AD significantly improves upon the NCI-DD. It has more questions that are able to capture a richer understanding of the LTSS consumer and, importantly, there are follow-up questions intended to provide a clear picture of the experiences and views of the respondents. However, some sections of the NCI-AD are lacking when considering the four Conceptual Framework domains that have been identified as important areas for QOL measures. Additionally, both of these tools offer primarily closed-ended questions.

Input from the Advisory Committee about what each of the Conceptual Framework subdomains should capture in QOL issues provided guidance for identifying and selecting supplemental questions from the other survey instruments analyzed in the crosswalk. This cafeteria approach of selecting specific questions from existing validated instruments ensures the questions are appropriately worded to elicit responses that capture the intent of the question. Dr. Kaye endorses this method to capture the LTSS consumer experiences missing in current instruments.

During the time this project was underway, the state of Colorado was beginning to implement new data collection efforts and pursuing additional data collection methods. The Advisory Committee and Technical Work Group were excited to see these changes and to partner with the state as it moves forward. The timing of the state's new efforts is well-aligned with the work undertaken in this project. As the state pilots several new instruments and examines their usefulness, interviewing individual LTSS consumers about their QOL outcomes and experiences of care will add the "voices" of consumers needed to provide context and understanding of the aggregated data collected by the state. Peer-to-peer interviewing is seen as an important method by which to conduct the QOL interviews as it allows for the LTSS consumer to feel more at ease sharing what can be difficult experiences to reveal.

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APPENDIX A: FEDERAL COMMISSION ON LONG-TERM CARE PANEL HEARINGS

Panel 1: Diversity of LTSS Demand: Subpopulations and Their LTSS Needs

- David Braddock, Ph.D., Executive Director, Coleman Institute for Cognitive Disabilities
- *H. Stephen Kaye, Ph.D., Assoc. Professor, University of California at San Francisco*
- Kevin Martone, Executive Director, Technology Assistance Collaborative
- Robyn Stone, Ph.D. Executive Director, LeadingAge Center for Applied Research

Panel 2: Meeting LTSS Needs: Coordination of Care and Workforce Issues

- Randall S. Brown, Ph.D., Vice-President and Director Health Research, Mathematica
- Josephina Carbonell, Senior Vice-President, Independent Living Systems, LLC
- Lynn Feinberg, Senior Strategic Policy Advisor, AARP Public Policy Institute
- Joanne Lynn, M.D., Director, Altarum Center for Elder Care and Advanced Illness
- Carol Regan, Government Affairs Director, Paraprofessional Healthcare Institute

Panel 3: Strengthening Medicaid LTSS

- Diane Rowland, MACPAC
- Patti Killingsworth, TennCare
- Gary Alexander, formerly Rhode Island Office of Health and Human Services
- Melanie Bella, CMS, Medicare-Medicaid Coordination Office

Panel 4: Strengthening Medicare for LTSS

- Joseph Antos, American Enterprise Institute
- Barbara Gage, Brookings Institute
- Marilyn Moon, American Institute for Research

Panel 5: Strengthening Private Long-Term Care Insurance

- David Grabowski, Harvard Medical School
- Lane Kent, formerly Univita
- Jason Brown, US Treasury
- Bonnie Burns, California Health Advocates

Panel 6: Interaction of Insurance, Private Resources, and Medicaid

- Eric French, Federal Reserve Bank of Chicago
- Jeffrey Brown, University of Illinois

- Rich Johnson, Urban Institute
- Ellen O'Brien, formerly MACPAC

Panel 7: Service Delivery and Provider Innovation and Issues

- Eric Berger, CEO, Partnership for Quality Home Healthcare
- Lisa Alecxih, SVP and Director, Lewin Center for Aging & Disability Policy
- Loren Colman, Assistant Commissioner, MN Department of Human Services, Continuing Care Administration
- Laura Taylor, Director of the Caregiver Support Program, Department of Veterans Affairs

Panel 8: Workforce Innovation and Issues

- Tracy Lustig, D.P.M., M.P.H., Sr. Program Officer, Institute of Medicine
- Suzanne Mintz, Founder, Family Caregiver Advocacy
- Charissa Raynor, Executive Director, SEIU Healthcare NW Training Partnership and Health Benefits Trust
- Charlene Harrington, PhD, Professor Emeritus of Sociology and Nursing, University of California at San Francisco

APPENDIX B: FINAL REPORT PRESENTATION FROM THE COMMISSION ON LONG-TERM CARE – RECOMMENDATIONS³

SERVICE DELIVERY

Vision Statement

A more responsive, integrated, and financially sustainable LTSS delivery system that ensures people can access quality services in settings they choose at a lower overall cost of care.

Recommendations

- Rebalancing – incentivize state provision of LTSS to enable individuals to live in the most integrated setting informed by an objective assessment of need.
- Care Integration –
 - Align incentives to improve integration of LTSS and health services in a person- and family-centered approach.
 - Establish a single point of contact for LTSS on the care team.
 - Use technology more effectively to mobilize and integrate resources
 - Create livable communities
- Uniform Assessment – implement a standardized assessment tool that can produce a single care plan across care settings
- Consumer Access – expand “No Wrong Door” to provide enhanced options counseling.
- *Quality – accelerate development of LTSS quality measures for home and community-based services and make them available to consumers.*
- Payment Reform – promote payment for post-acute and LTSS based on the service rather than the setting.

WORKFORCE

Vision Statement

An LTSS system that is able to attract and retain a competent, adequately-sized workforce capable of providing high quality, person-centered care to individuals across all LTSS settings.

³ Verbatim text from the presentation on the Final Report from the Long-Term Care Commission. Retrieved from <http://ltccommission.lmp01.lucidus.net/wp-content/uploads/2013/12/Final-Report-Presentation-9-18-13.pdf>

Recommendations

- Family Caregiving
 - Require HHS to develop a national strategy to maintain and strengthen family caregiving.
 - Include family caregivers in the needs assessment and care planning process.
 - Encourage expansion of caregiver interventions.
- Paid Workforce
 - Encourage states to revise scope of practice to permit delegation with supervision to direct care workers.
 - Enable criminal background checks for LTSS workforce.
- Direct Care Workforce
 - Create meaningful ladders and lattices for career advancement.
 - Integrate direct workers in care teams.
 - Collect detailed data on LTSS workforce.
 - Encourage standards and certification for home-care workers.

FINANCING

Vision Statement

A full array of financing options for LTSS that provide greater certainty for individuals using or likely to use LTSS by protecting against extreme long-term costs, enabling and encouraging individual planning and preparation, and providing an effective safety net for those without the income or assets to provide for themselves.

Recommendations

The Commission did not agree on a single approach, but offered two different approaches that might achieve the common vision.

- Private options to strengthen financing
 - Savings
 - Allow individuals with disabilities and their families to set up section 529 savings funds.
- Social insurance
 - Medicaid Improvement
 - Create a demonstration program to provide LTSS to persons with disabilities to remain employed.
 - Assist states to achieve greater uniformity in Medicaid Buy-In programs.

- Medicare Improvement
 - Eliminate the 3-day prior hospitalization requirement for SNF
 - Reconsider the “homebound” requirement for home health services.