Public Agenda

Measure Applications Partnership

Dual Eligible Beneficiaries Workgroup In-Person Meeting

Participant Instructions:

Web Streaming

- Direct your web browser to: http://nqf.commpartners.com
- Under "Enter a meeting" type in the meeting number for Day 1: **876080** or for Day 2: **765487**
- In the "Display Name" field, type in your first and last name and click "Enter Meeting"

Teleconference

- Dial **(877) 303-9138** for public members
- Use conference ID code for Day 1: **59178755** and for Day 2: **59182650**

Meeting Objectives:

- Identify potential measures for use with high-need behavioral/cognitive subgroups
- Discuss related activities and implications for applying measures
- Consolidate measures identified for high-need beneficiaries with Evolving Core Set to form a Family of Measures for dual eligible beneficiaries
- Finalize meeting themes and action items for HHS

Tuesday, May 21

9:00 am **Welcome, Introductions, and Review of Meeting Objectives**

9:15 am **Review Approach and Web Meeting Progress**

Alice Lind, Workgroup Chair
NQF Staff

- Method for constructing a family of measures
- Review of subgroup classification and updated key issues for measurement
- Introduction of measures that address key issues for behavioral/cognitive subgroups

10:00 am **Selection of Measures for High-Need Groups, Part 1**

Alice Lind

- Review available measures for Serious Mental Illness and Substance Use Disorders
- Workgroup discussion to select best available measures
- Review draft measure concepts for inpatient psychiatric care
- Document most prominent gaps in measures

12:00 pm **Opportunity for Public Comment**

12:15 pm **Lunch on Your Own**

12:45 pm **Selection of Measures for High-Need Groups, Part 2**

D.E.B. Potter, AHRQ
Chas Moseley, National Association of State Directors of Developmental Disabilities Services (NASDDDS)
Beth Mathis, Council on Quality and Leadership (CQL)

- Review available measures for acquired cognitive impairment and ID/DD
- Workgroup discussion to select best available measures
- Presentations from invited experts
- Document most prominent gaps in measures

2:15 pm **Opportunity for Public Comment**

2:30 pm **Break**

2:45 pm **Coordination with Related Activities and Implications for Applying Measures**

Alice Lind
Warren Taylor, Kaiser Permanente
Sarah Scholle, NCQA
Jessica Briefer French, NCQA

- Application of measures within state demonstration programs
    - Program alignment: parsimony and burden
    - Appropriate comparisons
    - Data sharing and confidentiality
- NCQA Quality Framework for Integrated Care
- Complementary quality monitoring and improvement approaches

4:15 pm **Opportunity for Public Comment**

4:30 pm **Summarize Progress and Adjourn Day 1**

Wednesday, May 22

8:30 am **Review of Progress from Day 1**

8:40 am **Selection of Measures for High-Need Groups, Part 3**

Alice Lind

- Review available measures common across behavioral/cognitive groups
- Workgroup discussion to select best available measures

10:00 am **Inputs and Methodology for the Family of Measures**

- Methodology for selecting the Family of Measures
- Review current Evolving Core Set of Measures for dual eligible beneficiaries
- Review measures identified for complex older adults and younger adults with physical disabilities

10:40 am **Break**

10:50 am **Prioritization and Selection of Measures for Family**

Alice Lind and NQF Staff

- High-leverage opportunity: quality of life

11:50 am **Opportunity for Public Comment**

12:00 pm **Lunch on Your Own**

12:30 pm **Continued Prioritization and Selection of Measures for Family**

Alice Lind and NQF Staff

- High-leverage opportunity: care coordination
- High-leverage opportunity: screening and assessment

2:00 pm **Break**

2:15 pm **Continued Prioritization and Selection of Measures for Family**

Alice Lind and NQF Staff

- High-leverage opportunity: mental health
- High-leverage opportunity: structural measures

3:15 pm **Review and Finalize Family of Measures for Dual Eligible Beneficiaries**

- Decide which alignment opportunity to feature as an example
- Threshold for identification of a “Starter Set”
- Follow-up exercise

3:50 pm **Opportunity for Public Comment**

4:00 pm **Finalize Meeting Themes and Action Items for Stakeholders**

- Key points from workgroup to HHS, measure developers, and end-users of measures
- Confirm next steps

4:30 pm **Adjourn Day 2**

Measure Applications Partnership

Dual Eligible Beneficiaries Workgroup In-Person Meeting

May 21-22, 2013

NATIONAL QUALITY FORUM

Welcome

Dual Eligible Beneficiaries Workgroup Membership

Chair: Alice Lind, MPH, BSN

Organizational Members

American Association on Intellectual and Developmental Disabilities	Margaret Nygren, EdD
American Federation of State, County and Municipal Employees	Sally Tyler, MPA
American Geriatrics Society	Jennie Chin Hansen, RN, MS, FAAN
American Medical Directors Association	Gwendolen Buhr, MD, MHS, MEd, CMD
Center for Medicare Advocacy	Alfred Chiplin, JD, M.Div.
Consortium for Citizens with Disabilities	E. Clarke Ross, DPA
Humana, Inc.	George Andrews, MD, MBA, CPE, FACP, FACC, FCCP
L.A. Care Health Plan	Laura Linebach, RN, BSN, MBA
National Association of Public Hospitals and Health Systems	Steven Counsell, MD
National Association of Social Workers	Joan Levy Zlotnik, PhD, ACSW
National Health Law Program	Leonardo Cuello, JD
National PACE Association	Adam Burrows, MD
SNP Alliance	Richard Bringewatt

Subject Matter Experts

Substance Abuse	Mady Chalk, MSW, PhD
Disability	Anne Cohen, MPH
Emergency Medical Services	James Dunford, MD
Care Coordination	Nancy Hanrahan, PhD, RN, FAAN
Medicaid ACO	Ruth Perry, MD
Measure Methodologist	Juliana Preston, MPA
Home & Community Based Services	Susan Reinhard, RN, PhD, FAAN
Mental Health	Rhonda Robinson-Beale, MD
Nursing	Gail Stuart, PhD, RN

Federal Government Members

Agency for Healthcare Research and Quality	D.E.B. Potter, MS
CMS Federal Coordinated Healthcare Office	Cheryl Powell
Health Resources and Services Administration	Samantha Meklir, MPP
Administration for Community Living	Jamie Kendall
Substance Abuse and Mental Health Services Administration	Lisa Patton, PhD
Veterans Health Administration	Daniel Kivlahan, PhD

Workgroup's Timeline

October 2011

Phase 1

Interim Report

Strategic Approach to Performance Measurement for Dual Eligible Beneficiaries

June 2012

Phase 1

Final Report

Core Set of Measures for Dual Eligible Beneficiaries

December 2012

Phase 2

Interim Report

Evolving Core Set of Measures

Specialized Measures for High-Need Subgroups

July 2013

Phase 2

"Preliminary Findings"

Behavioral/ Cognitive Subgroups

Family of Measures for Dual Eligible Beneficiaries

Future

Phase 2

Final Report

Commenting

Coordinating Committee Review

Meeting Objectives

- Identify potential measures for use with high-need behavioral/cognitive subgroups
- Discuss related activities and implications for applying measures
- Consolidate measures identified for high-need beneficiaries with Evolving Core Set to form a Family of Measures for dual eligible beneficiaries
- Finalize meeting themes and action items for HHS

Method for Constructing a Family of Measures

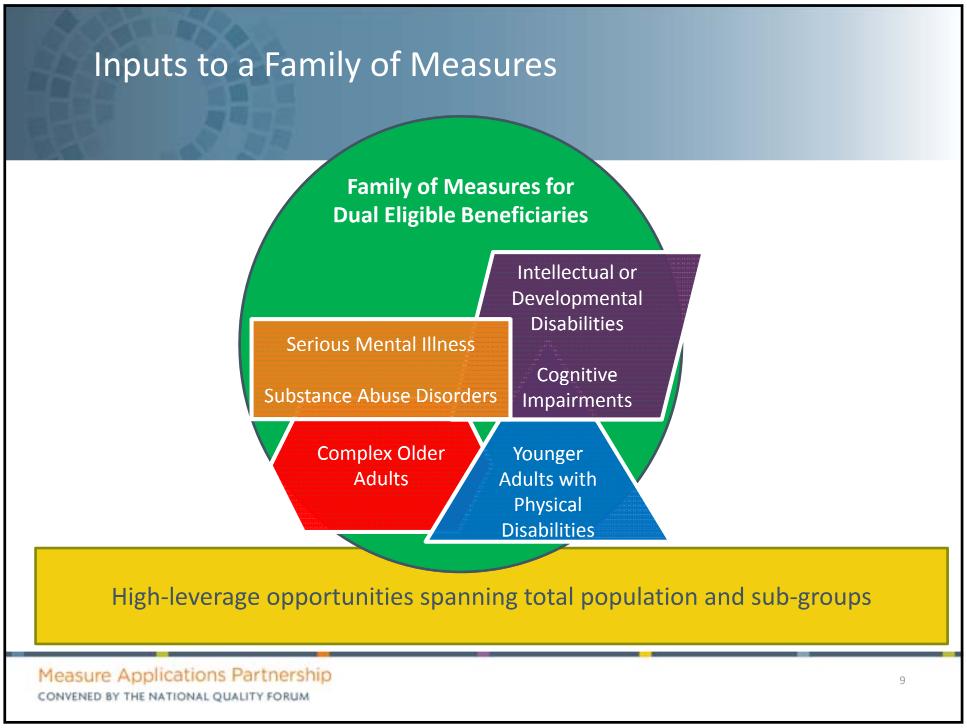
Why and how is a family of measures constructed?

Purpose

- A family of measures provides end-users with a pre-screened group of measures carefully selected to work together for a given topic
- Families of measures transcend any specific healthcare service location to evaluate an individual’s experience across health care settings over time

Methodology

- ✓ Establish framework
- ✓ Inventory measures
- Review measures and select best available
- Define the family of measures
- Identify gaps



Inputs to a Family of Measures

Family of Measures for Dual Eligible Beneficiaries

Intellectual or Developmental Disabilities

Cognitive Impairments

Serious Mental Illness

Substance Abuse Disorders

Complex Older Adults

Younger Adults with Physical Disabilities

High-leverage opportunities spanning total population and sub-groups

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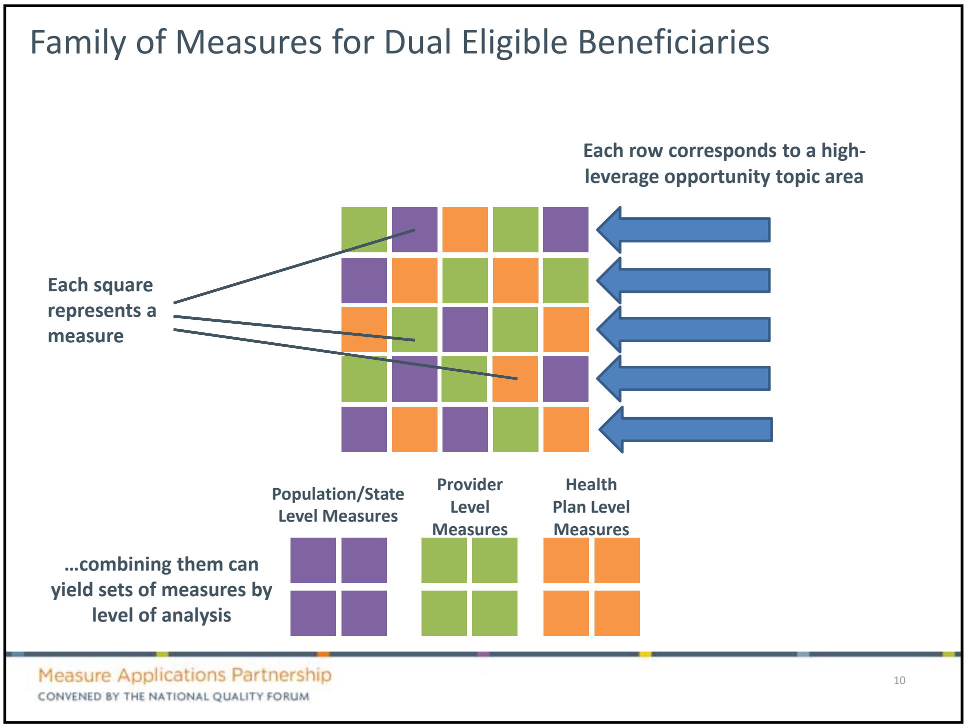

Family of Measures for Dual Eligible Beneficiaries

Each row corresponds to a high-leverage opportunity topic area

Each square represents a measure

Population/State Level Measures

Provider Level Measures

Health Plan Level Measures

…combining them can yield sets of measures by level of analysis

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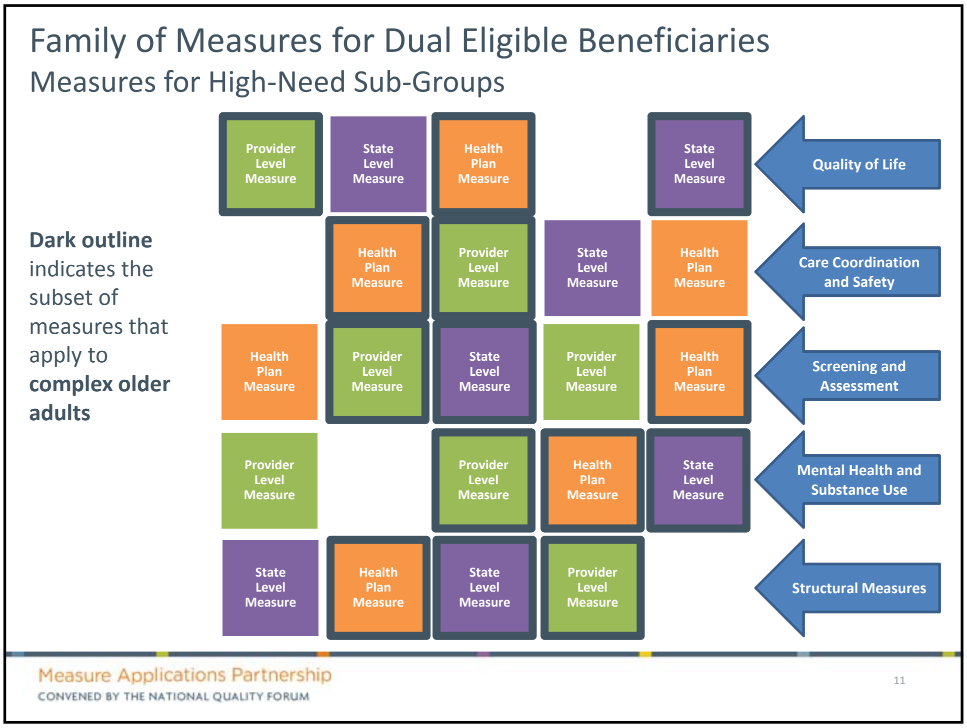
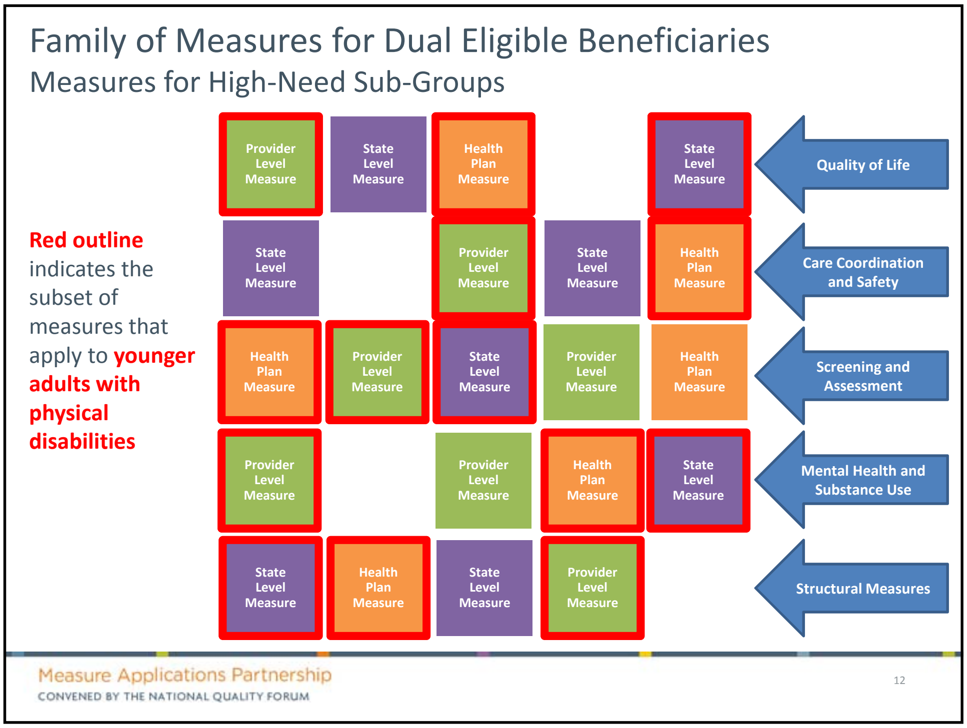


Family of Measures for Dual Eligible Beneficiaries

Measures for High-Need Sub-Groups

Dark outline indicates the subset of measures that apply to **complex older adults**

Provider Level Measure	State Level Measure	Health Plan Measure		State Level Measure	Quality of Life
	Health Plan Measure	Provider Level Measure	State Level Measure	Health Plan Measure	Care Coordination and Safety
Health Plan Measure	Provider Level Measure	State Level Measure	Provider Level Measure	Health Plan Measure	Screening and Assessment
Provider Level Measure		Provider Level Measure	Health Plan Measure	State Level Measure	Mental Health and Substance Use
State Level Measure	Health Plan Measure	State Level Measure	Provider Level Measure		Structural Measures

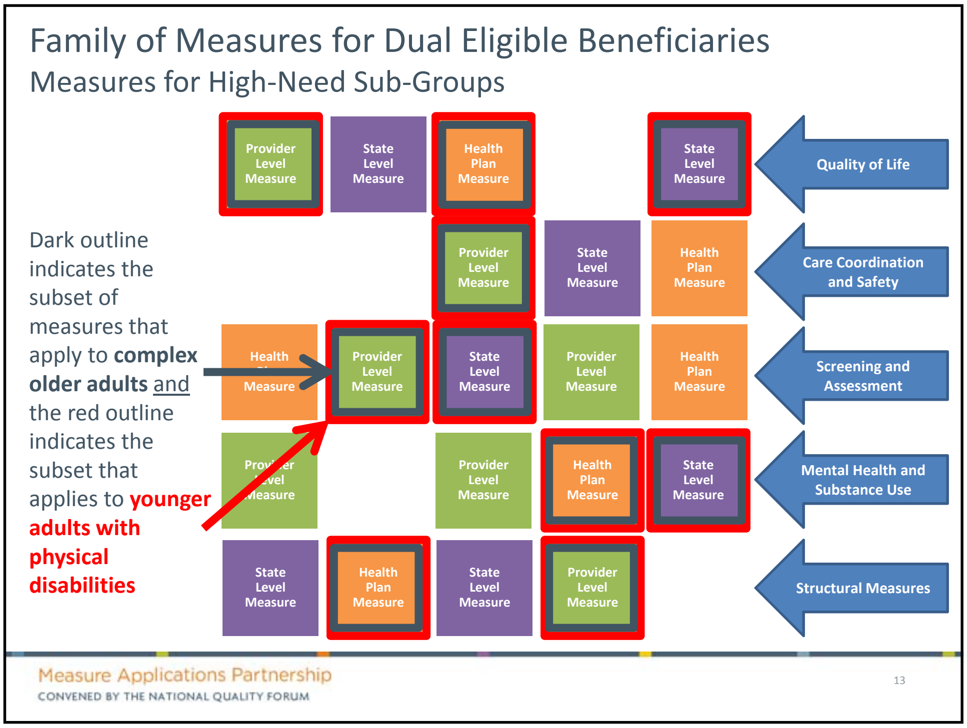


Family of Measures for Dual Eligible Beneficiaries

Measures for High-Need Sub-Groups

Red outline indicates the subset of measures that apply to **younger adults with physical disabilities**

Provider Level Measure	State Level Measure	Health Plan Measure		State Level Measure	Quality of Life
State Level Measure		Provider Level Measure	State Level Measure	Health Plan Measure	Care Coordination and Safety
Health Plan Measure	Provider Level Measure	State Level Measure	Provider Level Measure	Health Plan Measure	Screening and Assessment
Provider Level Measure		Provider Level Measure	Health Plan Measure	State Level Measure	Mental Health and Substance Use
State Level Measure	Health Plan Measure	State Level Measure	Provider Level Measure		Structural Measures



Family of Measures for Dual Eligible Beneficiaries

Measures for High-Need Sub-Groups

Dark outline indicates the subset of measures that apply to **complex older adults** and the red outline indicates the subset that applies to **younger adults with physical disabilities**

Provider Level Measure	State Level Measure	Health Plan Measure		State Level Measure	Quality of Life
		Provider Level Measure	State Level Measure	Health Plan Measure	Care Coordination and Safety
Health Measure	Provider Level Measure	State Level Measure	Provider Level Measure	Health Plan Measure	Screening and Assessment
Prov er vel easure		Provider Level Measure	Health Plan Measure	State Level Measure	Mental Health and Substance Use
State Level Measure	Health Plan Measure	State Level Measure	Provider Level Measure		Structural Measures

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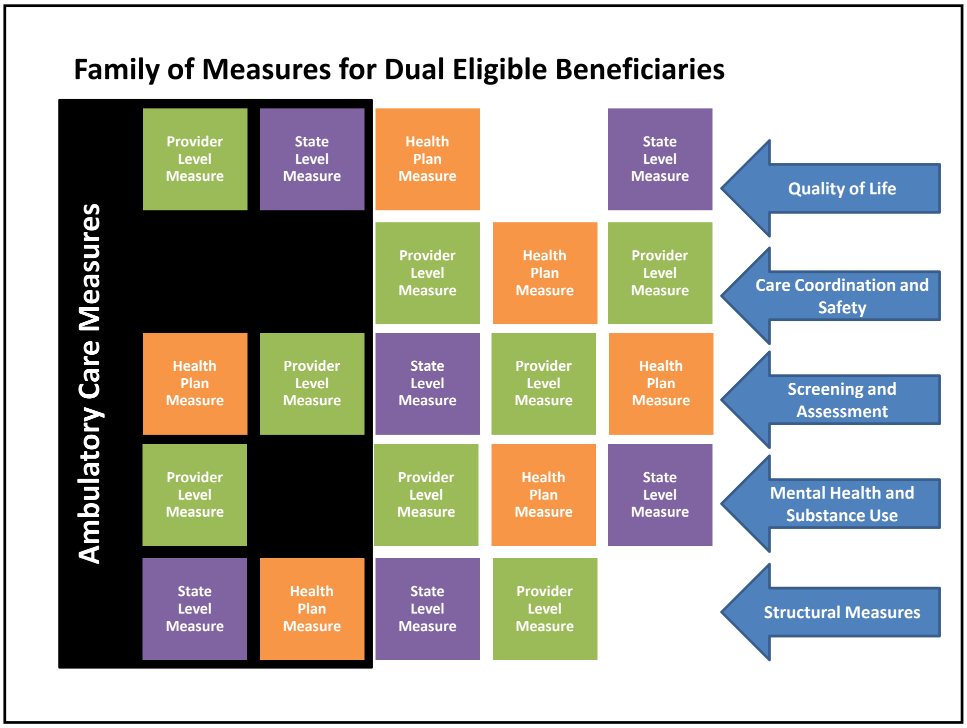
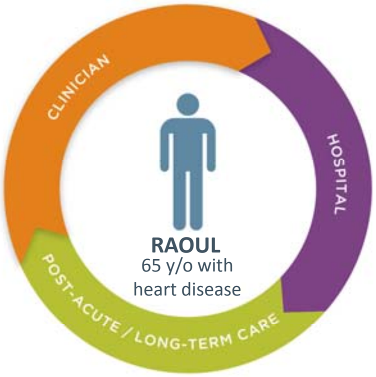


Family of Measures for Dual Eligible Beneficiaries

Ambulatory Care Measures

Provider Level Measure	State Level Measure	Health Plan Measure		State Level Measure	Quality of Life
		Provider Level Measure	Health Plan Measure	Provider Level Measure	Care Coordination and Safety
Health Plan Measure	Provider Level Measure	State Level Measure	Provider Level Measure	Health Plan Measure	Screening and Assessment
Provider Level Measure		Provider Level Measure	Health Plan Measure	State Level Measure	Mental Health and Substance Use
State Level Measure	Health Plan Measure	State Level Measure	Provider Level Measure		Structural Measures

A Patient-Centered Approach to Measure Sets



Primary Care

NQF #0018 **Blood Pressure Control**

NQF #0326 **Advance Care Plan**

Inpatient Hospital

NQF #0289 **Median Time to ECG**

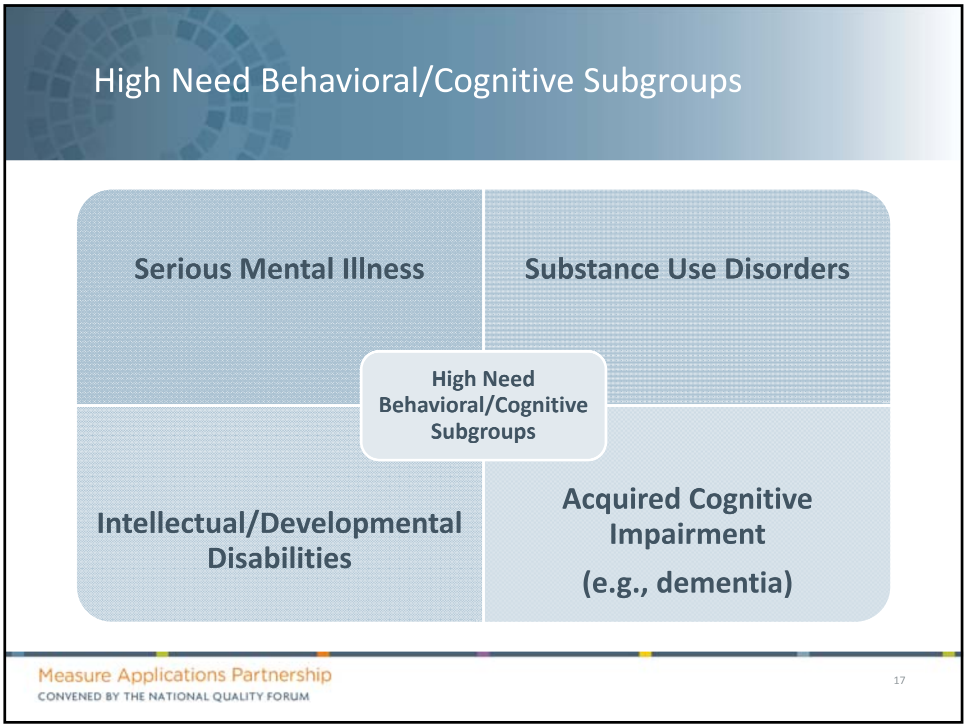
NQF #0141 **Patient Fall Rate**

Rehabilitation and Home Health

NQF #0648 **Timely Transmission of Transition Record**

NQF #0418 **Screening for Clinical Depression**

High-Need Subgroups
and
Key Issues for Measurement



High Need Behavioral/Cognitive Subgroups

Serious Mental Illness

Substance Use Disorders

High Need Behavioral/Cognitive Subgroups

Intellectual/Developmental Disabilities

Acquired Cognitive Impairment

(e.g., dementia)

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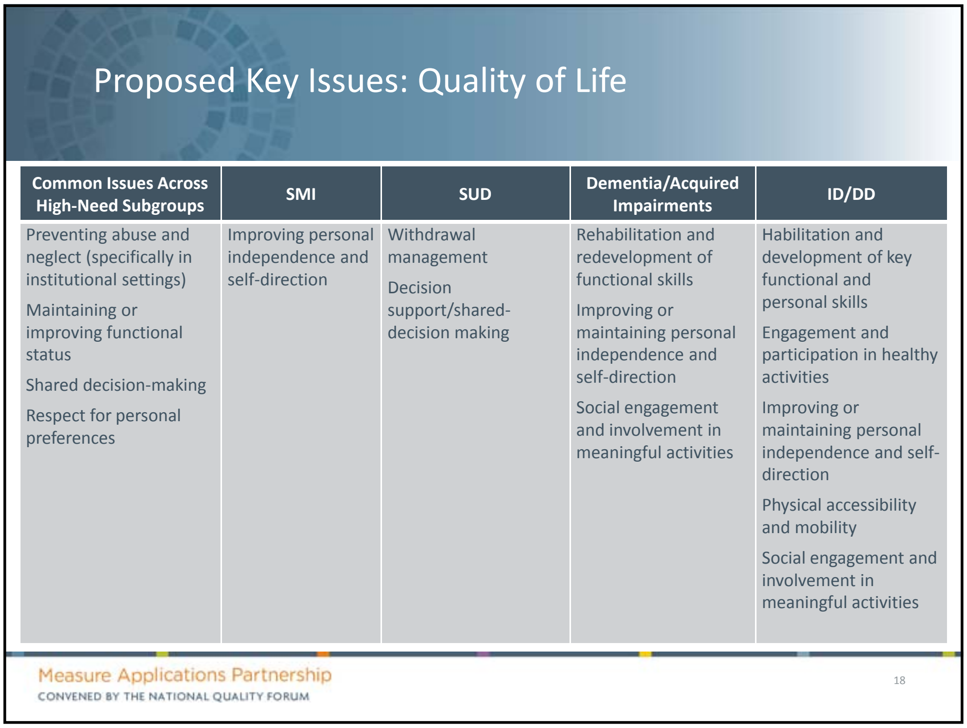

Proposed Key Issues: Quality of Life

Common Issues Across High-Need Subgroups	SMI	SUD	Dementia/Acquired Impairments	ID/DD
Preventing abuse and neglect (specifically in institutional settings) Maintaining or improving functional status Shared decision-making Respect for personal preferences	Improving personal independence and self-direction	Withdrawal management Decision support/shared-decision making	Rehabilitation and redevelopment of functional skills Improving or maintaining personal independence and self-direction Social engagement and involvement in meaningful activities	Habilitation and development of key functional and personal skills Engagement and participation in healthy activities Improving or maintaining personal independence and self-direction Physical accessibility and mobility Social engagement and involvement in meaningful activities

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Proposed Key Issues: Care Coordination and Safety

Common Issues Across High-Need Subgroups	SMI	SUD	Dementia/Acquired Impairments	ID/DD
Avoidable admissions, readmissions, complications Person-centered care planning Care transitions, discharge planning Communication between providers Communication between providers and beneficiaries Cultural competence Medication management: access, appropriateness, reconciliation, adherence Adverse drug events Advance directives/care planning Use of physical or chemical restraints	Use of seclusion Suicide prevention	Suicide prevention	Use of seclusion Avoidance of anticholinergic medications Home safety/environment	Use of seclusion

Proposed Key Issues: Screening and Assessment

Common Issues Across High-Need Subgroups	SMI	SUD	Dementia/Acquired Impairments	ID/DD
Oral Health Nutrition and weight management New or worsening chronic conditions, especially cardio-metabolic diseases Caregiver burden/burnout	Broad screening for SMIs Screening for substance use and/or risky behaviors Preventative and cancer screenings Sexual and gynecologic health	Broad screening for substance use/abuse Implications for treatment of asthma, sleep disorders, other conditions Screening individuals with SU for mental illness (e.g., schizophrenia) Sexual and gynecologic health Pain management	Broad screening for dementia Screening individuals with impairments for mental illness (e.g., depression) Cognitive functioning assessment Pain management Fall risk assessment Behaviors (e.g., aggression, wandering) Superimposed delirium, psychosis, or sleep disturbance Driving risk	Functional status assessment Screening for SMIs Preventive cancer screening Sexual and gynecologic health

Proposed Key Issues: Mental Health and Substance Use

Common Issues Across High-Need Subgroups	SMI	SUD	Dementia/Acquired Impairments	ID/DD
	Engagement and counseling Affective disorders (e.g., major depression, bipolar disorders) Schizophrenia Paranoid disorders Illicit drug use Tobacco and alcohol use	Engagement and counseling Tobacco and alcohol use Illicit drug use	Dementia Alzheimer's disease Tobacco and alcohol use	Screening for SMIs

Proposed Key Issues: Structural Measures

Common Issues Across High-Need Subgroups	SMI	SUD	Dementia/Acquired Impairments	ID/DD
Access to needed services (e.g., health home, primary care, specialty care, dental care, vision care, durable medical equipment, habilitation, rehabilitation, occupational therapy, social services, community mental health providers) Workforce adequacy, stability, and training Providers' linkages to community resources (e.g., special education, human services, transportation) Formal caregiver support Informal caregiver support Cultural competency Monitoring referrals				

Strategy to Identify Measures for Behavioral Health Subgroups

- Scan NQF portfolio for relevant measures
- Consult external sources for relevant measures
- Match measures to high-leverage opportunity areas and key issues
- Document and consider alignment opportunities (e.g., other programs, other families of measures, NQS)
- Staff performed initial prioritization to help target discussion

Orientation to the Measure Table

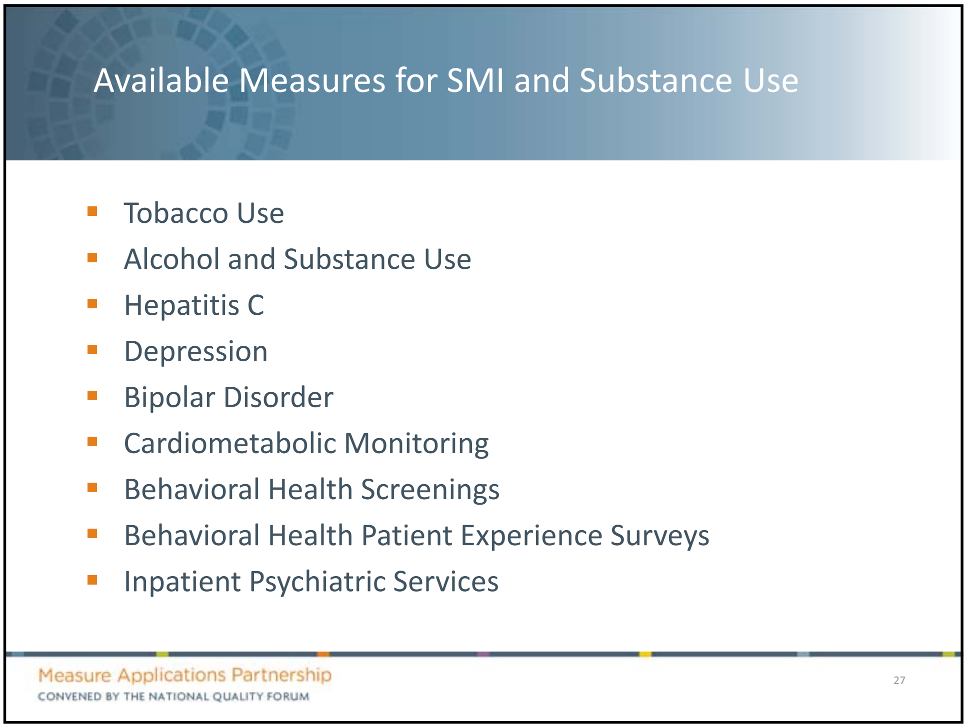
- Columns
  - Measure basics – gray
  - MAP factors – blue
  - Measure specification information – red
  - Measure use information – green
- Tabs
- Filtering and Sorting

Today's Expected Product

Intermediate List of Measures for Behavioral/Cognitive Subgroups

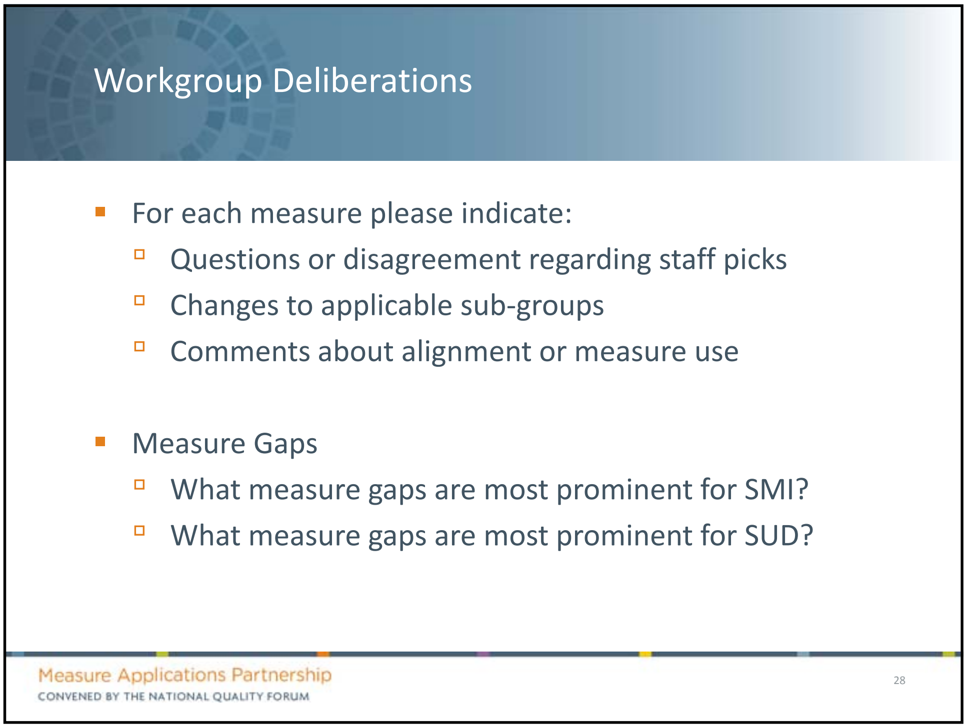
Measure	All Groups	SMI	SUD	Dementia/ Cognitive	ID/DD
NQF ####	✓	✓	✓	✓	✓
NQF ####		✓	✓		
NQF ####					✓
NQF ####	✓	✓	✓	✓	✓
NQF ####				✓	

Selection of Measures, Part 1



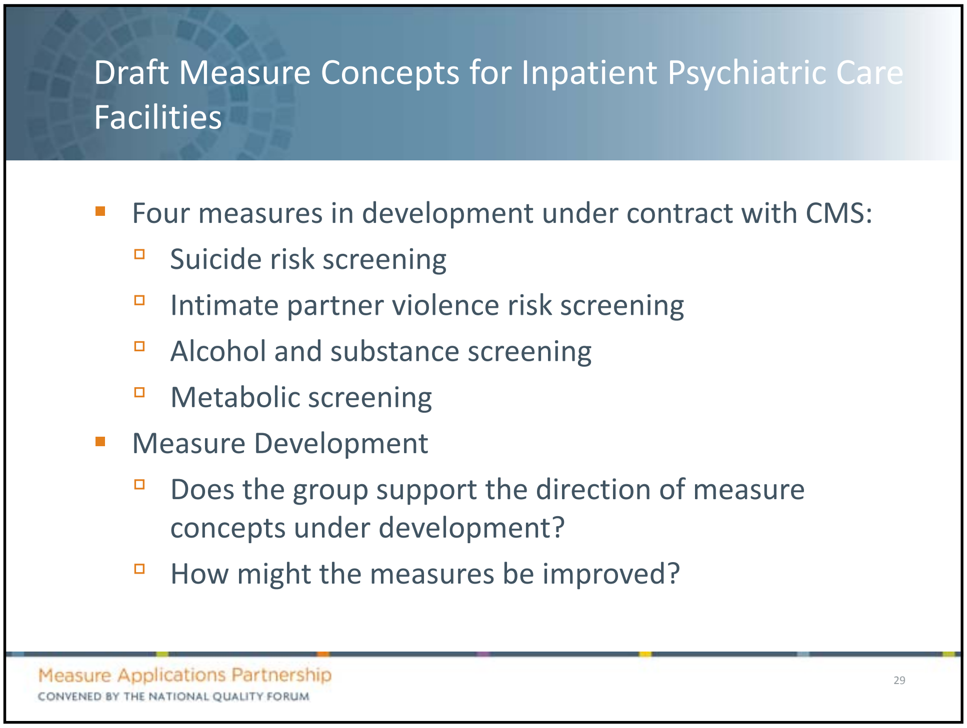
Available Measures for SMI and Substance Use

- Tobacco Use
- Alcohol and Substance Use
- Hepatitis C
- Depression
- Bipolar Disorder
- Cardiometabolic Monitoring
- Behavioral Health Screenings
- Behavioral Health Patient Experience Surveys
- Inpatient Psychiatric Services



Workgroup Deliberations

- For each measure please indicate:
  - Questions or disagreement regarding staff picks
  - Changes to applicable sub-groups
  - Comments about alignment or measure use
- Measure Gaps
  - What measure gaps are most prominent for SMI?
  - What measure gaps are most prominent for SUD?



Draft Measure Concepts for Inpatient Psychiatric Care Facilities

- Four measures in development under contract with CMS:
  - Suicide risk screening
  - Intimate partner violence risk screening
  - Alcohol and substance screening
  - Metabolic screening
- Measure Development
  - Does the group support the direction of measure concepts under development?
  - How might the measures be improved?

Opportunity for Public Comment

Selection of Measures, Part 2

National Alzheimer's Project Act

- In January 2011, the President signed the National Alzheimer's Project Act (NAPA) requiring HHS to:
  - Create and maintain an integrated national plan to overcome Alzheimer's disease.
  - Coordinate Alzheimer's disease research and services across all federal agencies.
  - Accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's disease.
  - Improve early diagnosis and coordination of care and treatment of Alzheimer's disease.
  - Improve outcomes for ethnic and racial minority populations that are at higher risk for Alzheimer's Disease.
  - Coordinate with international bodies to fight Alzheimer's globally.

National Plan to Address Alzheimer’s Disease

- In 2012, HHS published the *National Plan to Address Alzheimer's Disease*, calling for expanding data collection and surveillance efforts to track the prevalence and impact of Alzheimer's and other types of dementia
- Results from CDC analysis indicated that:
  - 12.7% aged 60 and over report increased confusion or memory loss in the previous year
    - Only 19% said they had discussed these changes with a health care provider
    - 35% reported that the memory problems caused functional difficulties, including ability to work or engage in household chores
- Memory loss varied by population groups and was highest among individuals with disabilities and Hispanics
- Results also show that about one-third of people with memory loss were living alone

US Department of Health and Human Services. National plan to address Alzheimer's disease. Washington, DC: US Department of Health and Human Services; 2012. Available at http://aspe.hhs.gov/daltcp/napa/natlplan.pd

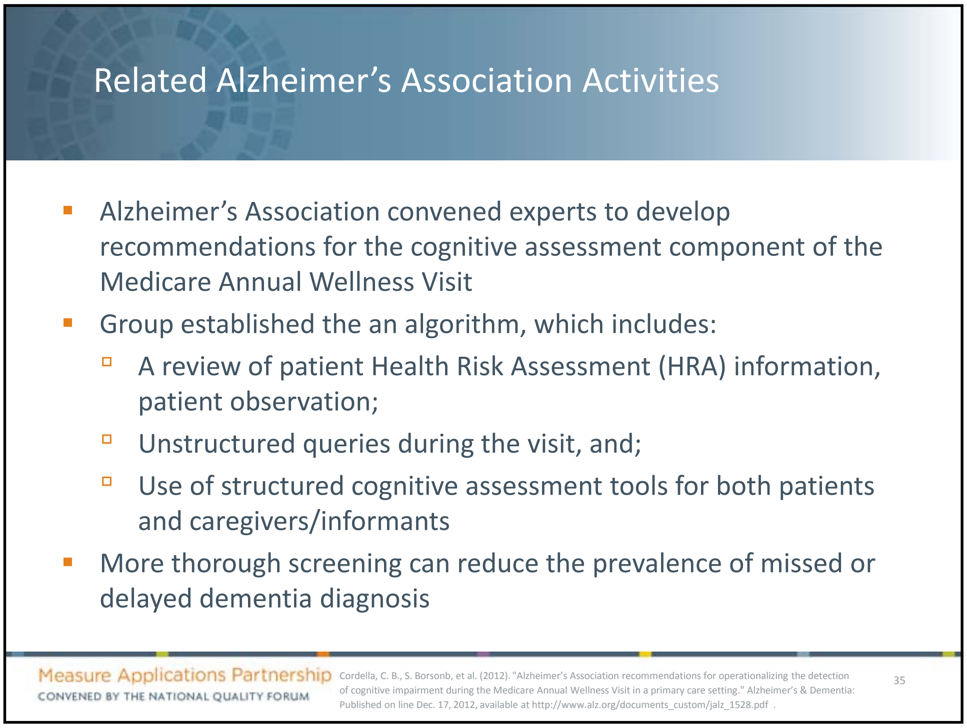
Quality Measurement Activities for Alzheimer’s Disease and Related Dementias: NAPA

National Plan to Address Alzheimer's Disease

- In the Plan, Strategy 2D states the need for the identification of “high-quality dementia care guidelines and measures across settings”

Advisory Council on Alzheimer’s Research, Care, and Services

- In January 2013, the 12 non-federal member council established by NAPA specifically recommended that HHS develop quality measures and indicators for the comprehensive care and treatment of individuals with Alzheimer’s Disease



Related Alzheimer’s Association Activities

- Alzheimer’s Association convened experts to develop recommendations for the cognitive assessment component of the Medicare Annual Wellness Visit
- Group established the an algorithm, which includes:
  - A review of patient Health Risk Assessment (HRA) information, patient observation;
  - Unstructured queries during the visit, and;
  - Use of structured cognitive assessment tools for both patients and caregivers/informants
- More thorough screening can reduce the prevalence of missed or delayed dementia diagnosis

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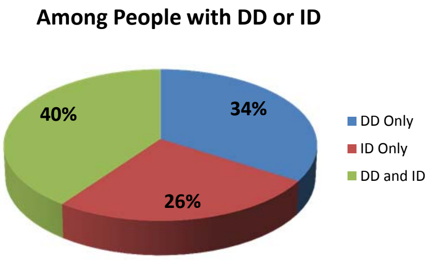
Cordella, C. B., S. Borsonb, et al. (2012). "Alzheimer’s Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting." Alzheimer’s & Dementia: Published on line Dec. 17, 2012, available at http://www.alz.org/documents_custom/jalz_1528.pdf .

ID/DD Definitions:

- **Developmental Disabilities** are severe, lifelong disabilities that occur during the developmental period, before age 22, and substantially limit functioning in three or more life activities: self-care, receptive and expressive language, learning, mobility, self-direction, independent living, and employment**.**
- **Intellectual Disability** is characterized by significant limitations in both intellectual functioning and in adaptive behavior, that occurs before age 18 years.

Intellectual and Developmental Disabilities are Related but Different



Larson, S., Lakin, C., Anderson, L., Kwak, N., Lee, J., H., & Anderson D. (2001).

- Not all individuals with intellectual disability can be labeled as having a developmental disability.
- Not all people with a developmental disability have an intellectual disability.
- The impact of intellectual disability varies for each individual

Prevalence Estimates

- Number of Persons with ID/DD **- 4.7 Million***
- Number Receiving DD Services (25%) **1.2 Million***

- It is estimated that 40% of all people with IDD receiving services are dually eligible - *NASDDDS*

**Lakin, C., Larson, S., Salmi, P. & Webster, A. (2010). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009. Institute on Community Integration, Minneapolis, MN.*

People with ID/DD Have Complex and Challenging Conditions

NCI Consumer Survey 2011-12 data
12,079 Respondents

- **34%** Co-occurring DD and mental illness
- **26%** Seizures/neurological conditions
- **15%** Cerebral Palsy
- **12%** Autism (4% in WY to 19% in NJ)
- **12%** Vision or hearing disorders
- **2.5%** TBI
- **2%** Alzheimer's

- **53%** take medications for mood disorders, anxiety, behavior problems, or psychotic disorders

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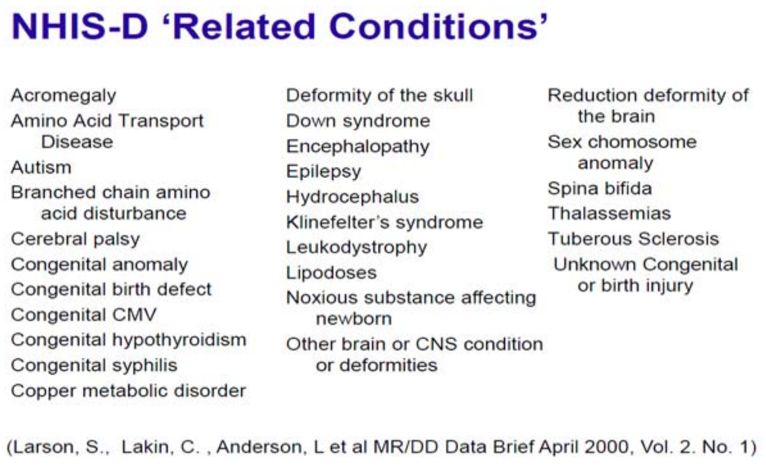
Additional Related Conditions



NHIS-D 'Related Conditions'

- Acromegaly
- Amino Acid Transport Disease
- Autism
- Branched chain amino acid disturbance
- Cerebral palsy
- Congenital anomaly
- Congenital birth defect
- Congenital CMV
- Congenital hypothyroidism
- Congenital syphilis
- Copper metabolic disorder
- Deformity of the skull
- Down syndrome
- Encephalopathy
- Epilepsy
- Hydrocephalus
- Klinefelter's syndrome
- Leukodystrophy
- Lipodoses
- Noxious substance affecting newborn
- Other brain or CNS condition or deformities
- Reduction deformity of the brain
- Sex chomosome anomaly
- Spina bifida
- Thalassemias
- Tuberous Sclerosis
- Unknown Congenital or birth injury

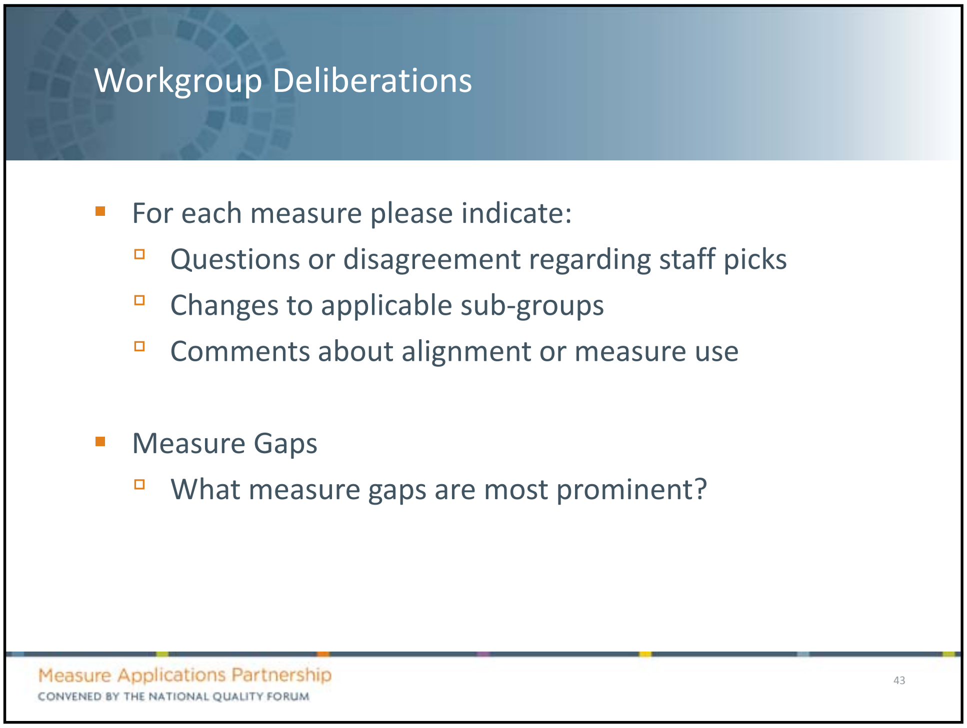
(Larson, S., Lakin, C. , Anderson, L et al MR/DD Data Brief April 2000, Vol. 2. No. 1)

People with ID/DD are Vulnerable

- At increased risk for abuse as compared to the general population (Gil, 1970; Ryan, 1994; Mahoney & Camilo, 1998).
- 4 to 10 more times as likely to be victims of crime than others without disabilities (Sobsey, et al., 1995).
- Twice the risk of physical and sexual abuse compared to children without disabilities (Crosse et. al., 1993).
- Children with ID are 4 times as likely as children without disabilities to be sexually abused. (Sullivan & Knutson, 2000).
- Individuals with disabilities are 2-to-10 times more likely to be sexually abused than those without disabilities (Westat Ind., 1993).
- Risk of abuse increases by 78 percent due to exposure to the "disabilities service system.“ (Sobsey & Doe, 1991). And, Sexual abuse incidents are almost four times as common in institutional settings as in the community (Blatt & Brown, 1986).
- Between 60% and 100% (depending on sample) of individuals with DD have experienced trauma, usually repeated incidents of abuse (Sobsey, 1994).

Available Measures for Acquired Cognitive Impairment and ID/DD

- Functional Status
- Nutrition
- Advanced Illness Care
- Acquired Cognitive Impairment



Workgroup Deliberations

- For each measure please indicate:
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  - Changes to applicable sub-groups
  - Comments about alignment or measure use

- Measure Gaps
  - What measure gaps are most prominent?

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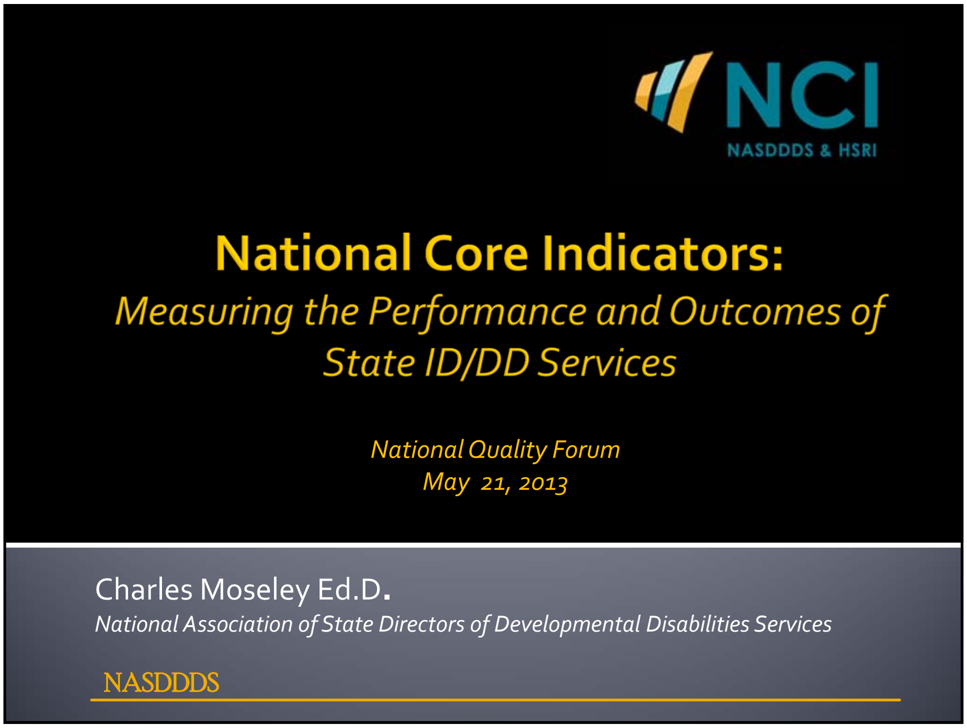


NCI
NASDDDS & HSRI

National Core Indicators:

Measuring the Performance and Outcomes of State ID/DD Services

National Quality Forum
May 21, 2013

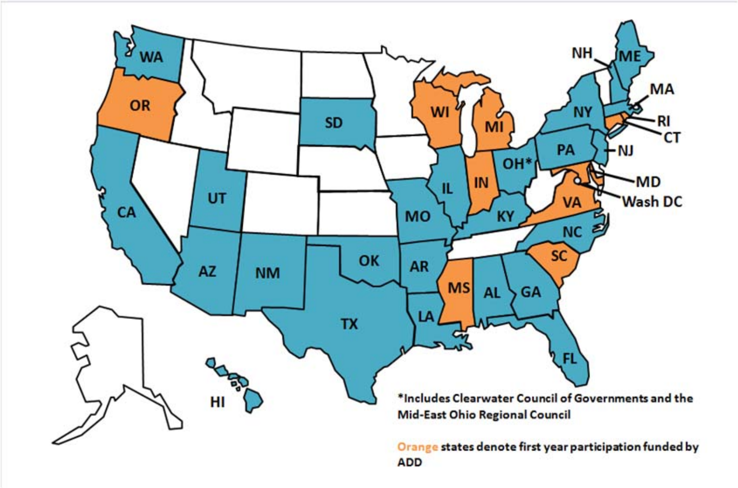
Charles Moseley Ed.D.
National Association of State Directors of Developmental Disabilities Services

NASDDDS

NCI Overview

- Launched in 1997 in 13 participating states
- Currently 36 states and 22 sub-state regions and counties
- Expanding to all states over the next 3 years
- Unparalleled 14-year database on over 12,000 individuals ~ 20,000
- Supported by participating states
- Collaboration between NASDDDS – HSRI – participating state DD agencies

NCI State Participation 2012-13



*Includes Clearwater Council of Governments and the Mid-East Ohio Regional Council

Orange states denote first year participation funded by ADD

Meeting the Needs of State Agency Administrators and Policy Makers for Data

- Document the effect of services on the day-to-day lives of the people who receive them
- Document the experience of program participants
- Manage service delivery and improve policy and practice
- Track key performance goals and outcomes
- Assess the impact of regulatory activities on individual experience
- Respond to the demands of consumers and families for information on system responsiveness
- Assess the impact of financial actions

Premise of NCI:
Performance Improvement

- What get measured, gets done

  If you don't measure key outcomes, there is no guarantee that they will occur
- NCI measures assess performance:
  - On key individual and state system outcome variables
  - Over time (change from baseline)
  - Against multi-state benchmarks from other states
  - Across key **person-centered objectives**: employment, choice, health, welfare and community engagement

NCI MEASURES OFFER A UNIQUE VIEW

- Individual characteristics of people receiving services and support
- The locations where people live
- The activities they engage in during the day including whether they are working
- The nature of their experiences with the supports that they receive (e.g., with case managers, ability to make choices
- The context of their lives – friends, community involvement, safety
- Health and well-being, access to healthcare

NCI System Performance Measures

Individual Outcomes

- Employment
- Community Participation
- Choice & Decision making
- Personal Relationships

Family Outcomes

- Choice and Control
- Family Involvement
- Information & Planning
- Access, community connections
- Response

Health, Welfare, System

- Health and Welfare
- Respect for Rights
- Medications
- Safety
- Service Coordination
- Staff Stability

National Core Indicators Design

Valid
- Measure what is intended to be measured

Reliable
- Provide consistent results over time

Risk Adjusted
- Provides multiple state comparisons

NCI Data Sources

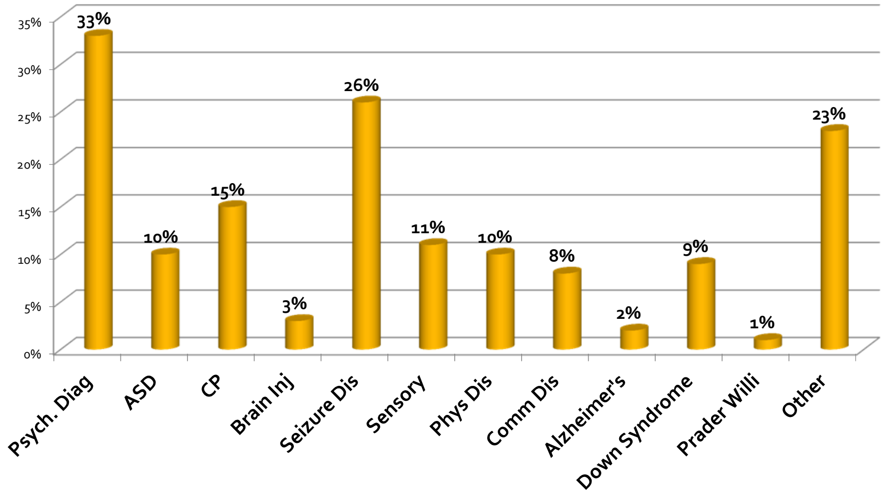
- **Consumer Survey**
  - ✓Random sample of adults
  - ✓In person interviews
- **Family Survey** (mail-in)
  - ✓Adult Family Survey (at home, 18+)
  - ✓Family Guardian Survey (out-of-home)
  - ✓Children Family Survey (at home, <18)
- **System Data**
  - ✓Specific protocols for reporting staff turnover, mortality and incidents

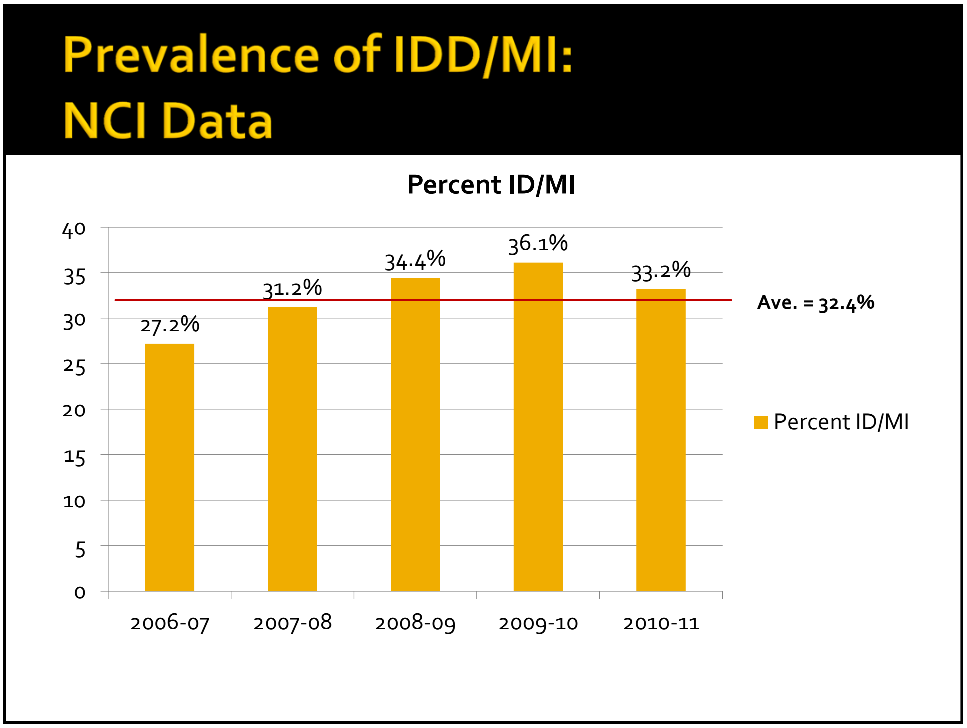
Selected NCI Findings

2010-2011

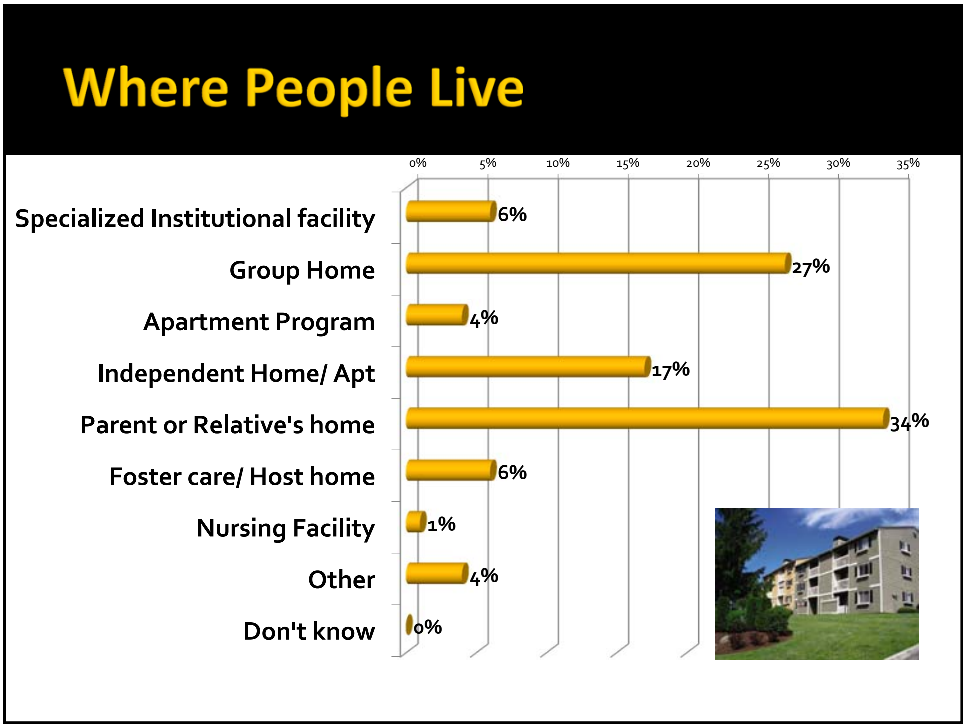
- *Homes*
- *Jobs*
- *Health*
- *Choice*
- *Life*

Other Disabilities

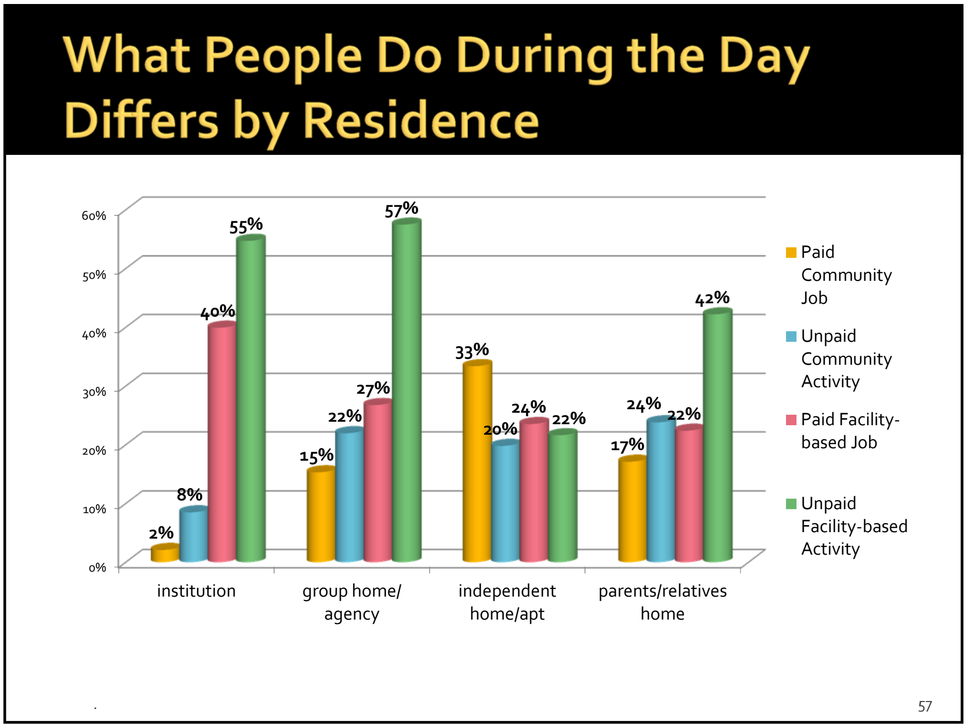




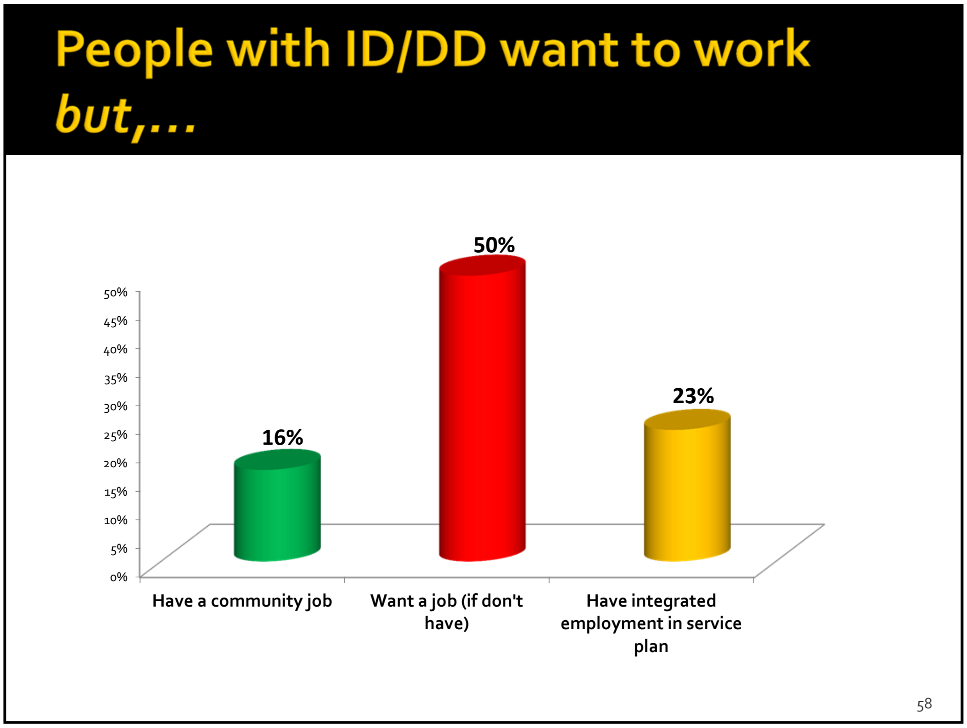
Prevalence of IDD/MI: NCI Data



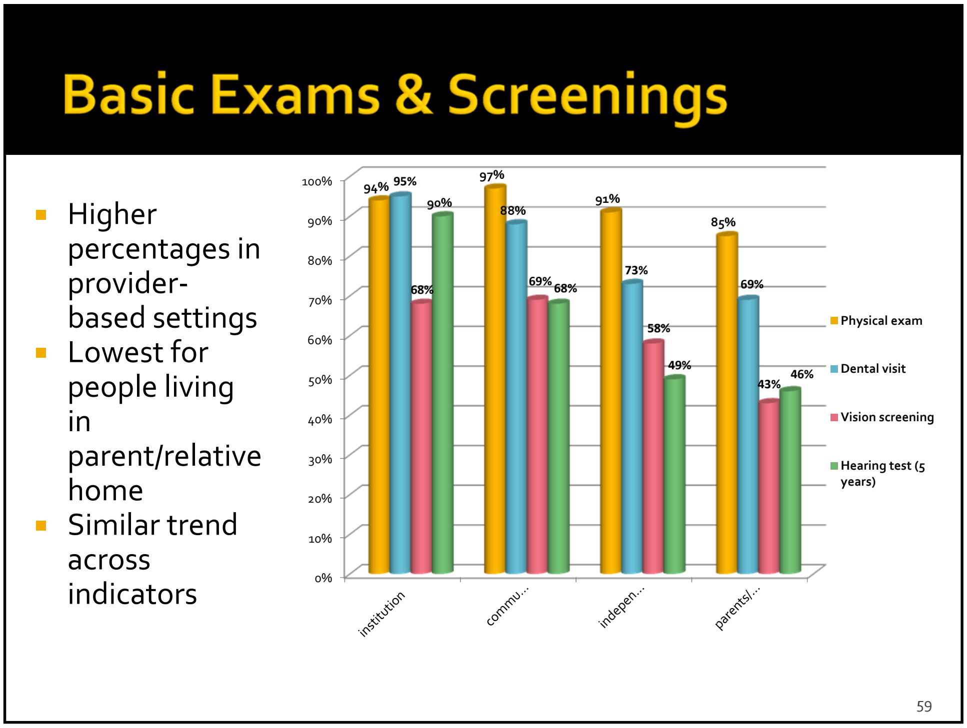
Where People Live



What People Do During the Day Differs by Residence

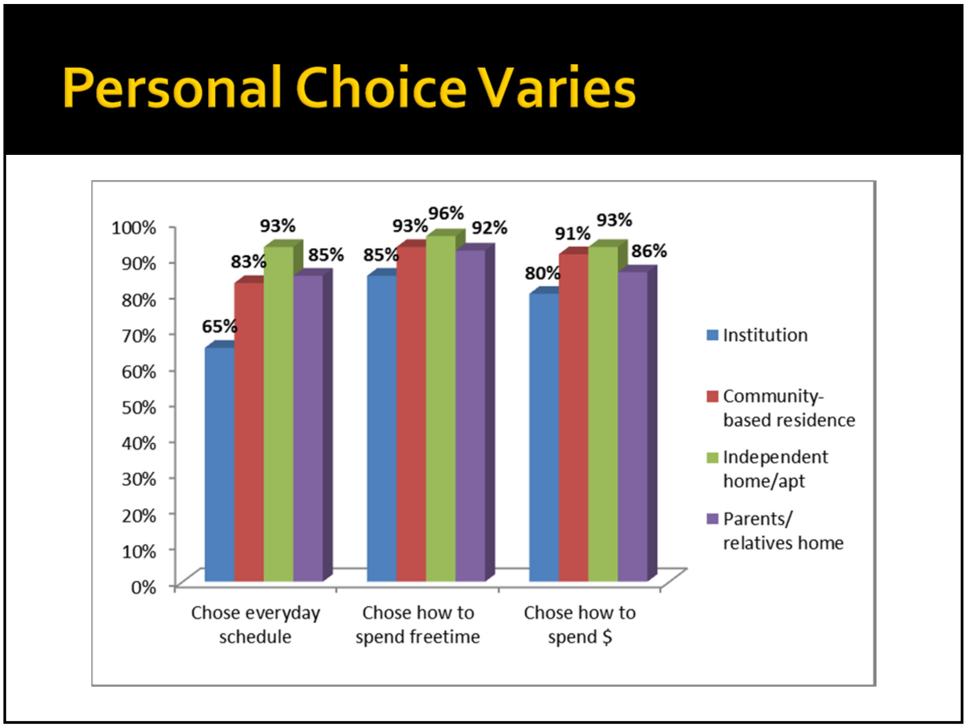


People with ID/DD want to work *but,…*

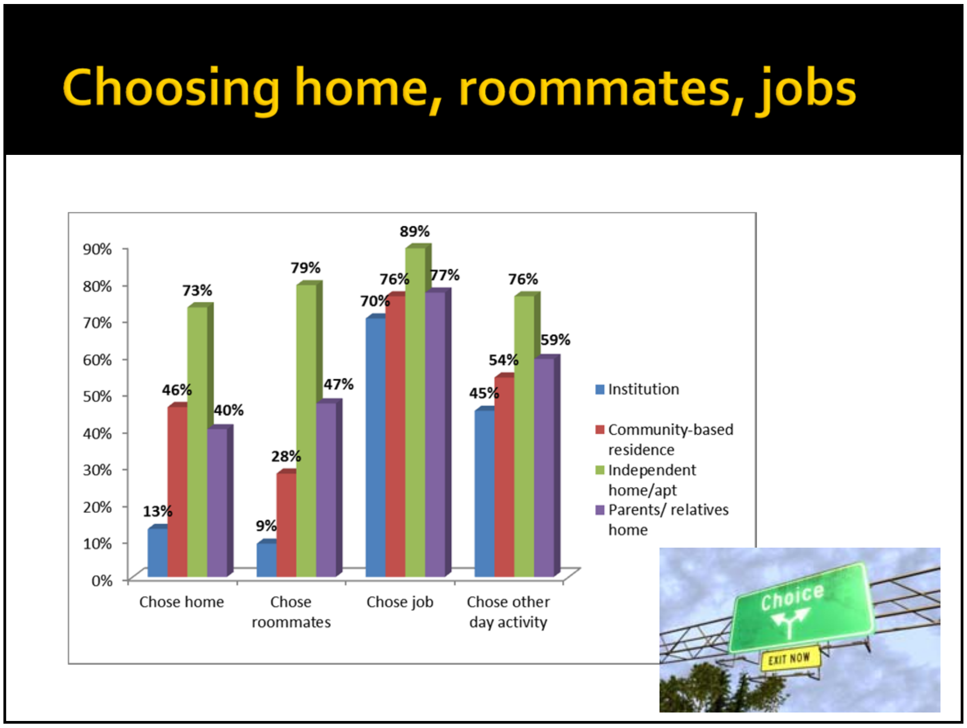


Basic Exams & Screenings

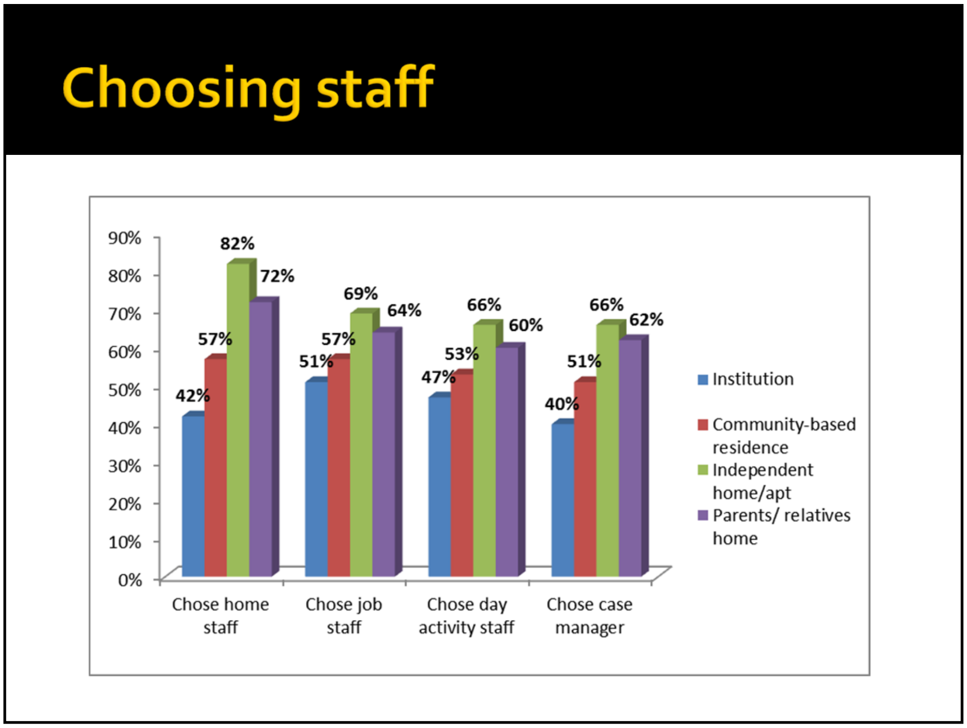
- Higher percentages in provider-based settings
- Lowest for people living in parent/relative home
- Similar trend across indicators



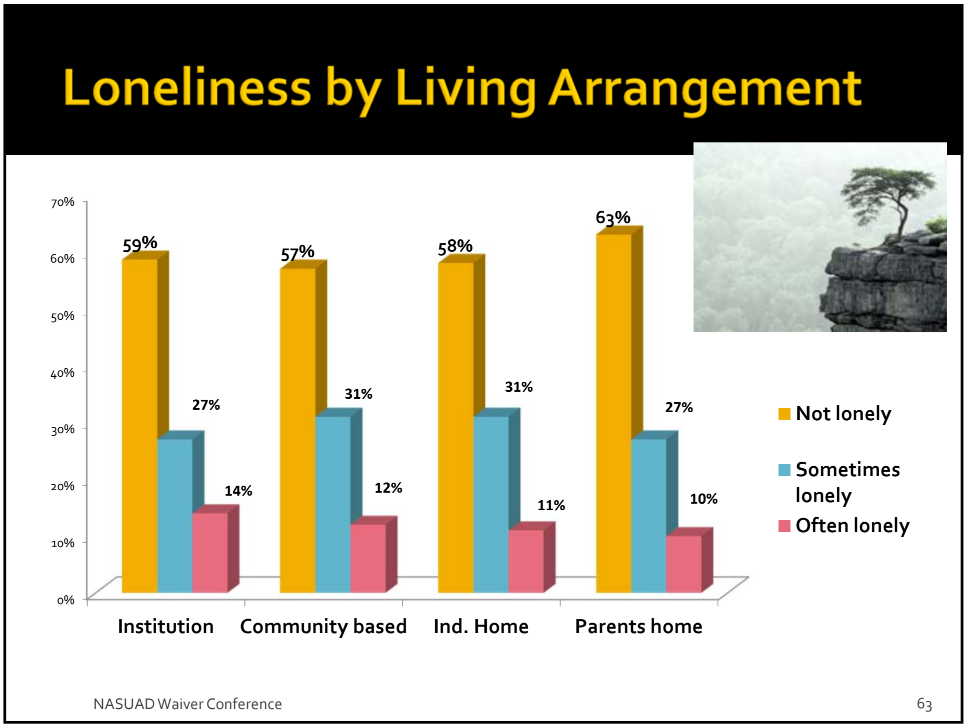
Personal Choice Varies



Choosing home, roommates, jobs

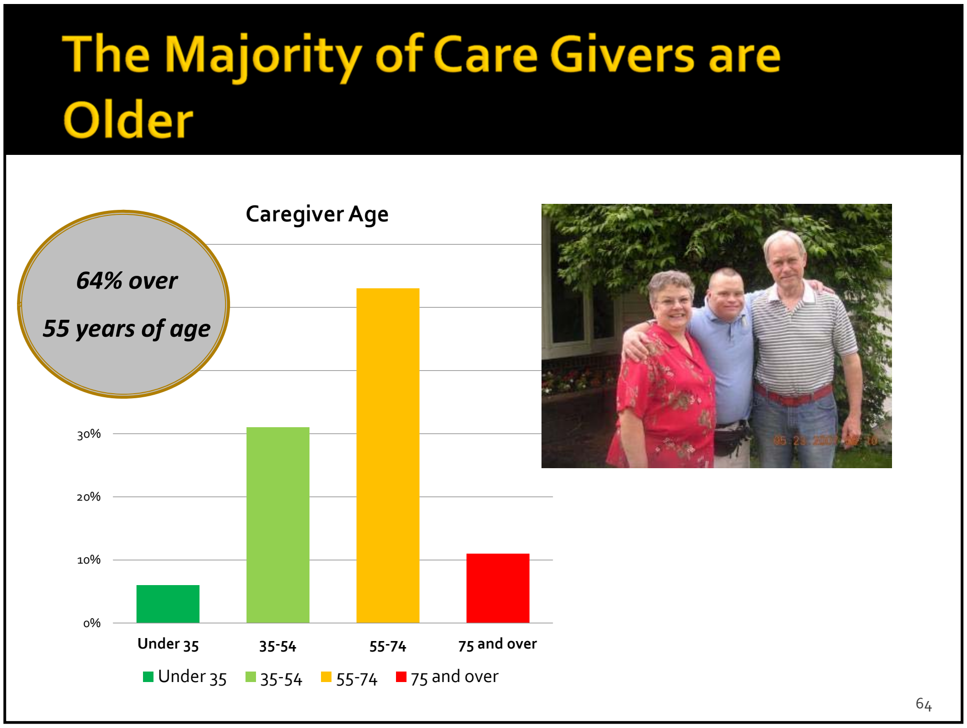


Choosing staff



Loneliness by Living Arrangement

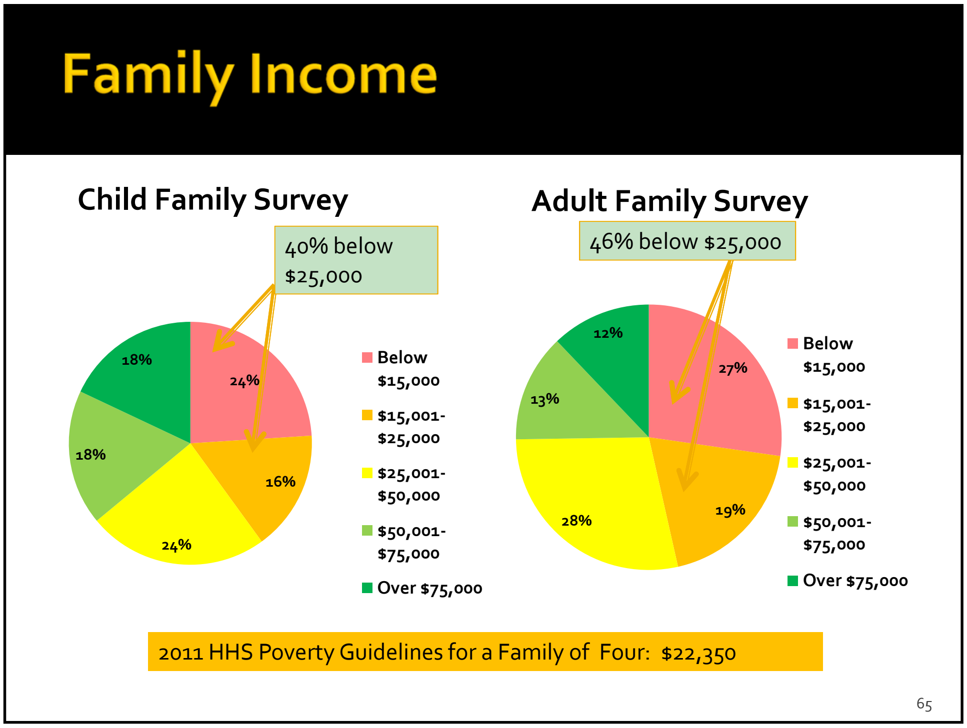
NASUAD Waiver Conference



The Majority of Care Givers are Older

64% over

55 years of age



Family Income

Child Family Survey

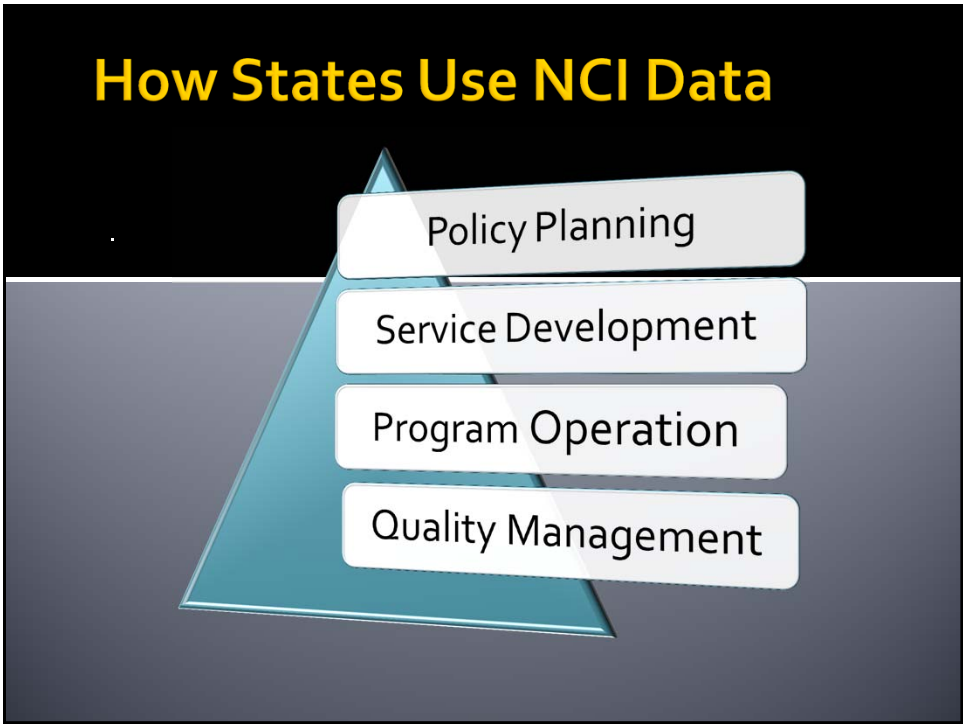
40% below $25,000

Adult Family Survey

46% below $25,000

2011 HHS Poverty Guidelines for a Family of Four: $22,350

65



How States Use NCI Data

- Policy Planning
- Service Development
- Program Operation
- Quality Management

Strengthening Service Delivery and Quality System-Wide

- Targeting areas for remediation and improvement at the state and system levels
- Assist in meeting CMS requirements
- Identifying quality concerns and prioritizing service improvement activities
- Providing NCI survey findings to state and regional quality councils for review, analysis and feedback
- Comparing the state’s performance against that of other states

How States Use NCI Data

New York

- Publishes comparison data against other states
- Targets campaigns to decrease obesity rates

Arizona

- Prioritizes actions and quality efforts on case manager choice, wellness, health, loneliness, employment

Kentucky

- Issues formal report on service quality and community participation

Washington State

- State DD agency issues report back on strategies to address recommendations.

Massachusetts

- Tracks and acts on health and wellness and safety data

Interactive Website www.nationalcoreindicators.org

- Annual Data Reports
- State Summary Reports
- Data Briefs
- Articles
- National State Data
- Make a Chart function
- Technical Reports

For more information

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Val Bradley	vbradley@hsri.org

Quality of Life:
Measurement, Management and Improvement
NQF Workgroup - May 2013

CQL

CQL | The Council on Quality and Leadership

Who we are …

International not-for-profit organization dedicated to the definition, measurement and improvement of personal quality of life for people receiving human services and supports.

Personal Quality of Life

Personal Outcome Measures®

My Self

My World

My Dreams

Outcomes: A Matter of Definition

Clinical Outcomes
- Cure and symptom reduction

Functional Outcomes
- Increasing functional status

Personal Outcomes
- Issues that matter most to people in their lives

We Measure Two Things

- Outcomes = Quality of Life
- Supports = Quality of Services

My Self, My World, My Dreams

Each outcome includes:

- Introduction and intent of outcome
- Values underlying outcome
- Principles for organizations
- Suggested questions for the person
- Suggested questions about individualized supports
- Outcome decision making questions
- Individualized support decision making questions
- Additional considerations

My Focus

To learn as much as possible about the person's…

- Priorities
- Preferences
- Perspective

Decision-making with the Personal Outcome Measures®

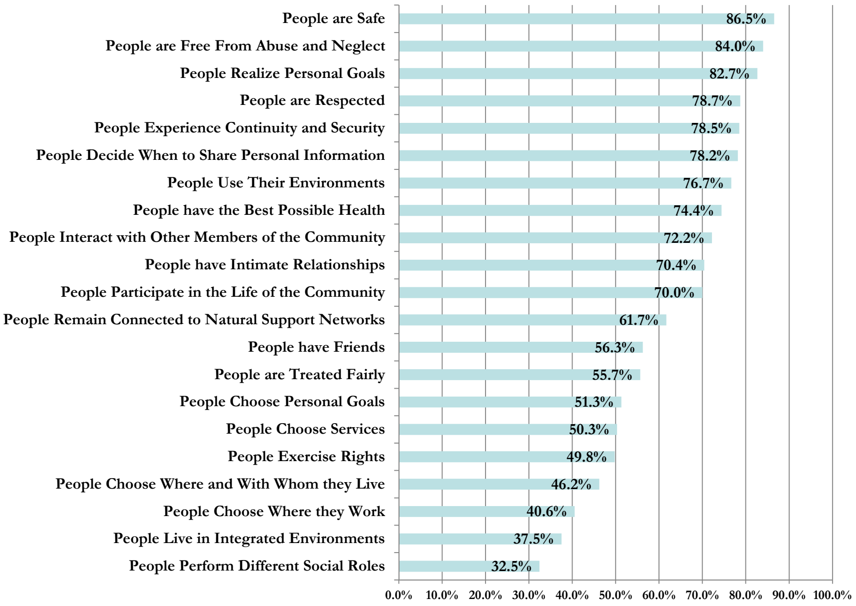
- How is the outcome defined by the person?
- How does the person's situation match with his or her desired outcomes?
- Is the outcome present or not?
- How closely are supports aligned with outcomes?

Understanding Personal Outcome Measures®

- We measure the *presence* of the outcome (yes or no)
- Each person is a unique sample of one … There is no norm or standard definition for an outcome
- We aggregate data on items that are personally defined rather than standardized in the traditional analysis
- We link outcomes to the services and supports that facilitate – or are needed to facilitate – the outcome
- The Personal Outcome Measures® conversation provides information for the design and provision of person-centered services

Personal Outcome Measures®

Personal Outcome Measures® January 2010 (N=7,879)



Personal Outcome Measures®

Specific Outcomes Correlated with Total Outcomes – Predictors	
HIGHEST	
Exercise rights	.537
Choose where and with whom they live	.528
Treated fairly	.521
Choose where to work	.507
Interact with other members of the community	.500
Perform different social roles	.487
LOWEST	
Decide when to share personal information	.332
Have the best possible health	.309
Free from abuse and neglect	.287
Experience continuity and security	.276
Are safe	.189

A world of dignity, opportunity and community for all people

www.c-q-l.org

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Workgroup Discussion

- Can state participation in the National Core Indicators be used as a proxy for improving quality, or at minimum a commitment for doing so?
- How can MAP support further measure development and/or expansion of these survey tools to other populations?

Opportunity for Public Comment

Coordination with Related Activities and Implications for Applying Measures

Perspective from State Activities

Alice Lind

Perspective from Kaiser Permanente

Dr. Warren Taylor

Improving & Streamlining Measurement & Evaluation of Care for Dual Eligibles

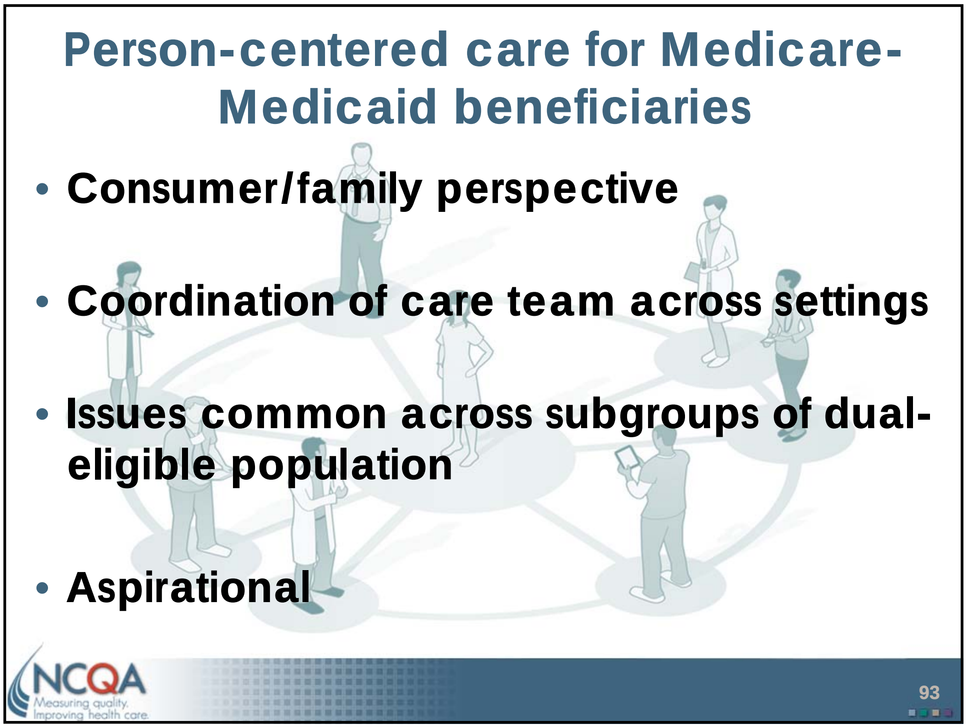
May 21, 2013

NCQA
Measuring quality.
Improving health care.

Agenda

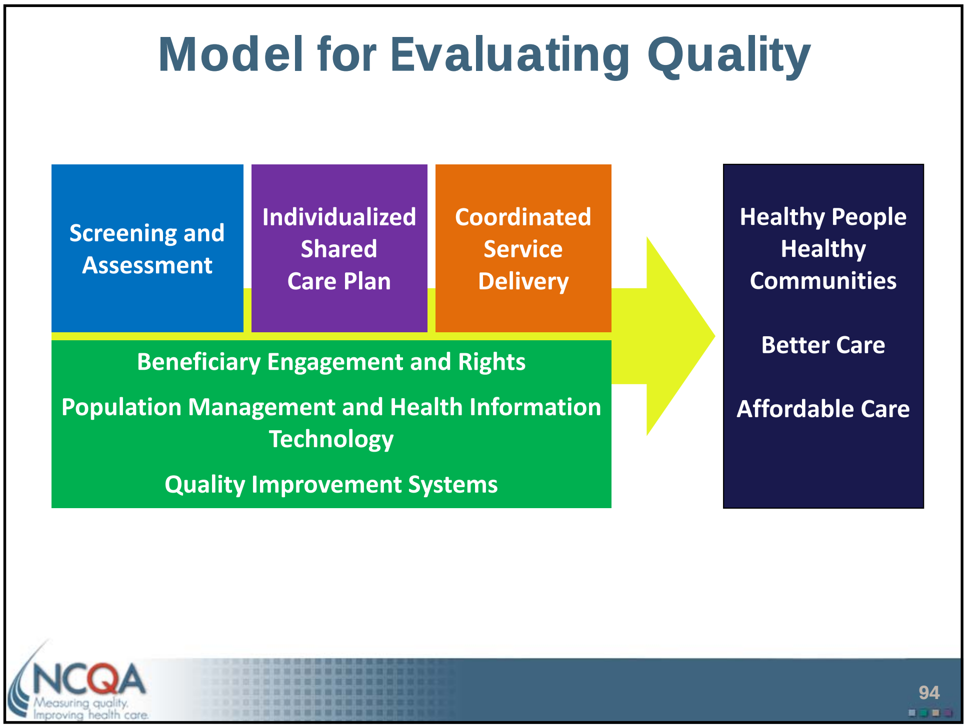
- Framework for Quality for Duals
- Pilot Test Results for New Measures of Integrated Care of People with Both Medicare & Medicaid ("Duals")
- Overlap in Current Requirements
- Opportunities to Improve

NCQA
Measuring quality.
Improving health care.



Person-centered care for Medicare-Medicaid beneficiaries

- Consumer/family perspective
- Coordination of care team across settings
- Issues common across subgroups of dual-eligible population
- Aspirational



Model for Evaluating Quality

Screening and Assessment

Individualized Shared Care Plan

Coordinated Service Delivery

Beneficiary Engagement and Rights

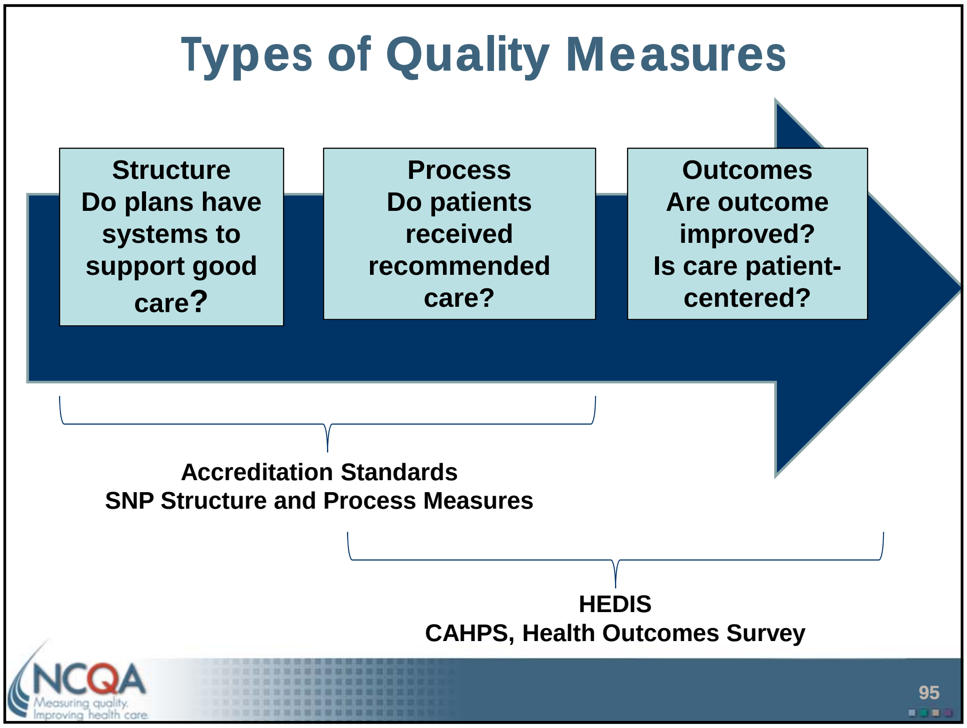
Population Management and Health Information Technology

Quality Improvement Systems

Healthy People Healthy Communities

Better Care

Affordable Care



Types of Quality Measures

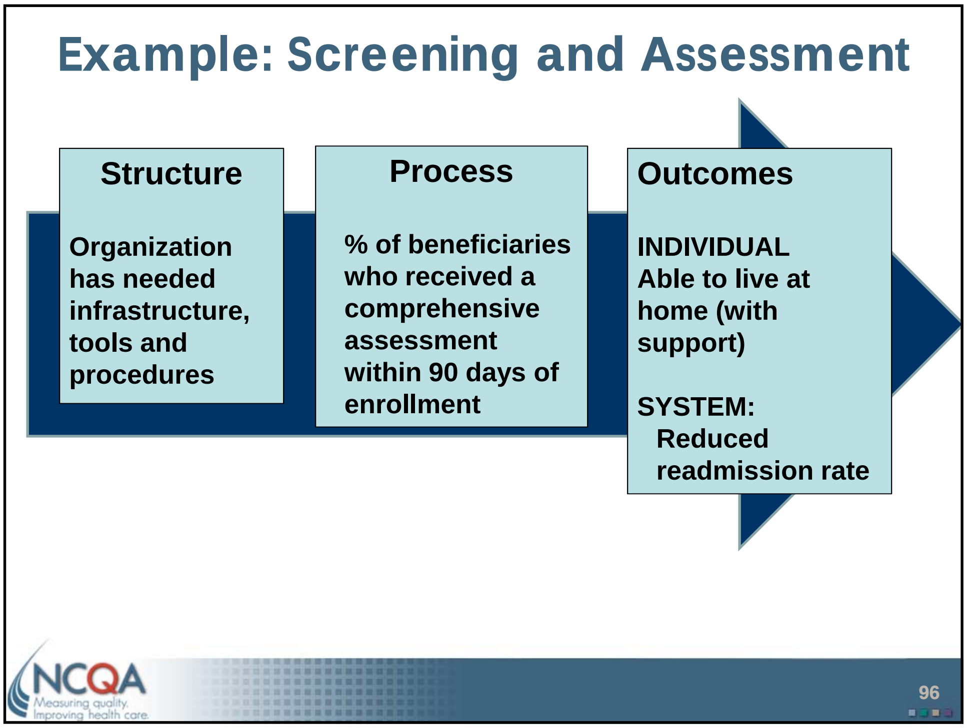
Structure
Do plans have systems to support good care?

Process
Do patients received recommended care?

Outcomes
Are outcome improved?
Is care patient-centered?

Accreditation Standards
SNP Structure and Process Measures

HEDIS
CAHPS, Health Outcomes Survey



Example: Screening and Assessment

Structure

Organization has needed infrastructure, tools and procedures

Process

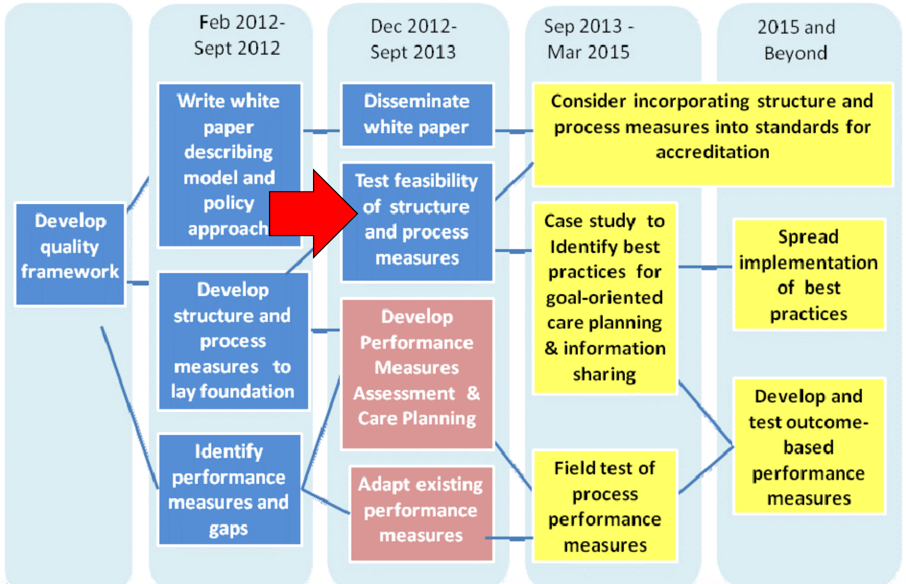
% of beneficiaries who received a comprehensive assessment within 90 days of enrollment

Outcomes

INDIVIDUAL
Able to live at home (with support)

SYSTEM:
Reduced readmission rate

Evaluating the Quality of Care for Duals



Feb 2012- Sept 2012

Dec 2012- Sept 2013

Sep 2013 - Mar 2015

2015 and Beyond

Develop quality framework

Write white paper describing model and policy approach

Develop structure and process measures to lay foundation

Identify performance measures and gaps

Disseminate white paper

Test feasibility of structure and process measures

Develop Performance Measures Assessment & Care Planning

Adapt existing performance measures

Consider incorporating structure and process measures into standards for accreditation

Case study to Identify best practices for goal-oriented care planning & information sharing

Field test of process performance measures

Spread implementation of best practices

Develop and test outcome-based performance measures

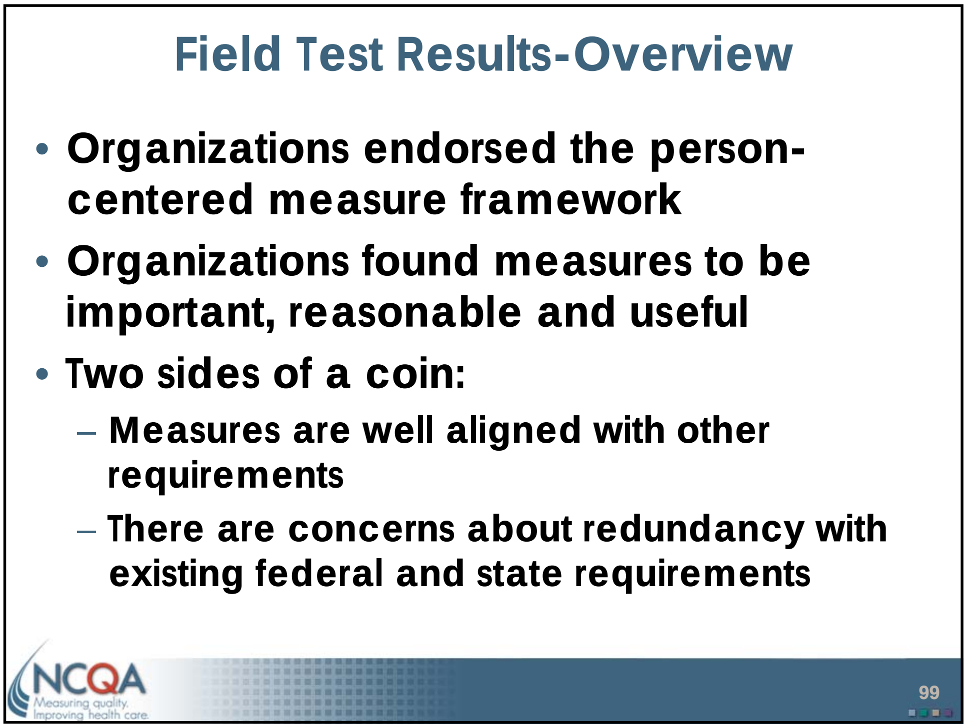
Field Test Goals and Methods

Goals

- Assess feasibility
- Assess utility

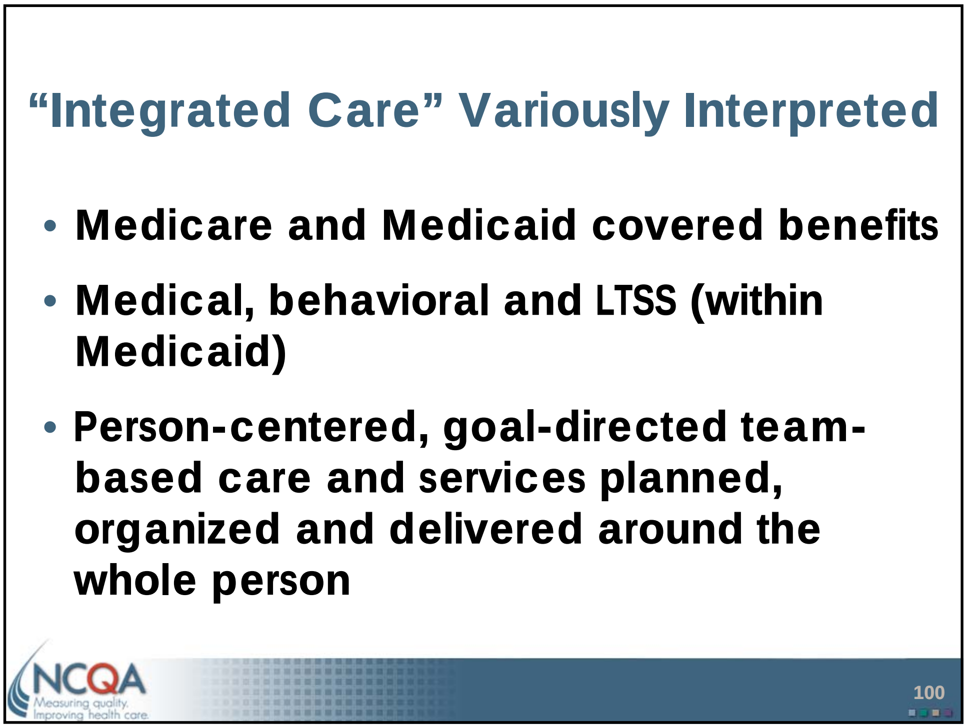
Methods

- Select plans already providing integrated care
- Plan written self-assessment
- Follow-up interviews



Field Test Results-Overview

- Organizations endorsed the person-centered measure framework
- Organizations found measures to be important, reasonable and useful
- Two sides of a coin:
  - Measures are well aligned with other requirements
  - There are concerns about redundancy with existing federal and state requirements



“Integrated Care” Variously Interpreted

- Medicare and Medicaid covered benefits
- Medical, behavioral and LTSS (within Medicaid)
- Person-centered, goal-directed team-based care and services planned, organized and delivered around the whole person

Person-Centered Care

- Assessment drives care plan
- Assessment may be telephonic or in person
- Frequency and method of contact between person and care coordinator varies
- Care coordinator may be “go to” person or one more stranger asking questions

Goals not Universally Person-Centered

- Some organizations identified goals from the assessment
  - Any identified need → goal
  - Goals often clinical (blood pressure, HbA1c)
- Others started with goals generated from the assessment, and negotiated priorities
- Still others asked the person
  - Often personal vs. purely clinical (attend church, get out in the community)

Interdisciplinary Care Team

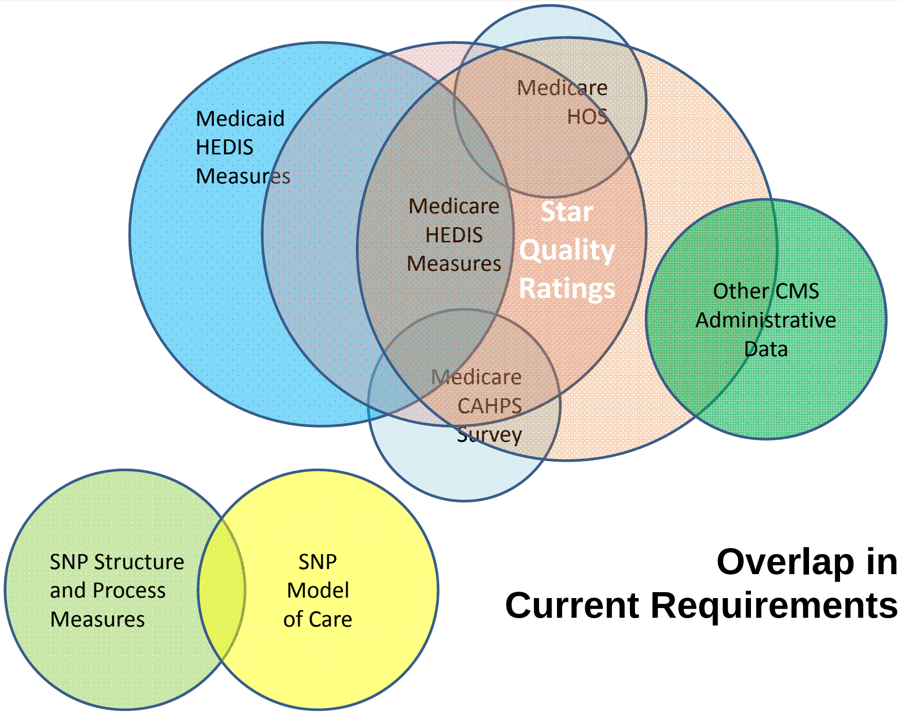
- Always includes care coordinator and PCP
- May be virtual or real
- Varying degrees of integration
  - Involvement of non-medical providers
  - How care plan is developed
  - How and with whom care plan is shared

Challenges Harnessing Information Technology

- Use of electronic health records varies across and within organizations
- Complex organizational structures create challenges in integrating & sharing information
  - Delegation and contract arrangements
  - Not all providers electronic, esp. LTSS
  - Communications from outside organizations, such as hospitals, are not always timely

Challenges and Opportunities

- Implementation in the midst of multiple players:
  - CMS Medicare
  - CMS Medicare-Medicaid Coordination Office
  - State Medicaid Agencies
- Limited experience with full integration
  - Building culture and relationships
  - Building infrastructure
  - Engaging providers across disciplines



Overlap in Current Requirements

Challenges and Opportunities, cont.

- Limited experience with full integration
  - Building culture and relationships
  - Building infrastructure
  - Engaging providers across disciplines

Policy Implications

- Clarity needed to define responsibility for coordination when services carved out
- Greater clarity & integration needed between CMS & states for oversight
- Rapid ID & dissemination of best practices needed for plans new to LTSS & integration
  - Person-centered goal assessment, documentation and use
  - Sharing assessment/care plan
- Independent review needed to assess organization readiness and performance

Opportunities to Improve

- **Use duals S&P measures to assess Medicare-Medicaid Plans, SNPs and Medicaid only plans**
  - **NCQA is exploring adding to health plan accreditation for Medicaid plans**
- **Address redundancy with other federal and state requirements**

Complementary Quality Monitoring and Improvement Approaches

- Where can we expect performance measurement strategies to be most successful?
- Where do we anticipate difficulties in implementation? What can be done to mitigate them?
- What additional quality monitoring and quality improvement tools can be leveraged?

Opportunity for Public Comment

Review Progress of Day 1

Selection of Measures, Part 3

Available Measures for Issues Common to High-Need Behavioral/Cognitive Populations

- Preventive Services
- Falls
- Pressure Ulcers
- Medication Safety
- Restraints
- Care Transitions and Communication
- Structural Measures

Workgroup Deliberations

- For each measure please indicate:
  - Questions or disagreement regarding staff picks
  - Changes to applicable sub-groups
  - Comments about alignment or measure use
- Measure Gaps
  - What measure gaps are most prominent?

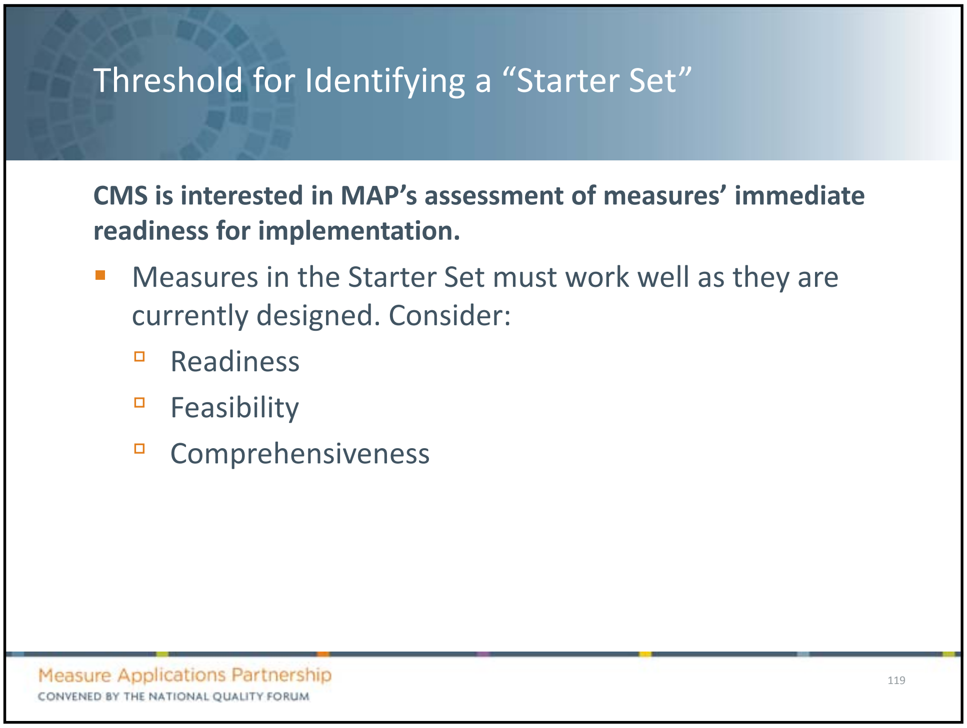
Inputs and Methodology for the Family of Measures

Review Draft Deliverable Outline

Considerations for Selecting a Family of Measures

See handout titled "Assessing Measure Readiness …"

- NQF Endorsement
- Potential Impact
- Improvability
- Relevance
- Person-centeredness
- Alignment
- Reach

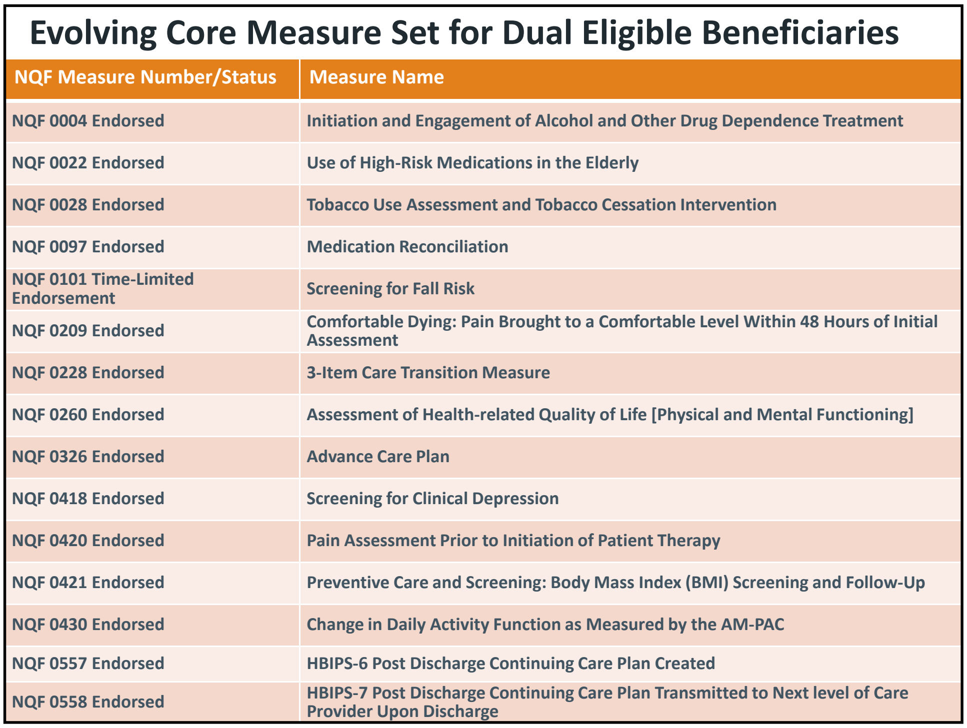


Threshold for Identifying a “Starter Set”

CMS is interested in MAP’s assessment of measures’ immediate readiness for implementation.

- Measures in the Starter Set must work well as they are currently designed. Consider:
  - Readiness
  - Feasibility
  - Comprehensiveness

Measure Applications Partnership
CONVENED BY THE NATIONAL QUALITY FORUM



Evolving Core Measure Set for Dual Eligible Beneficiaries

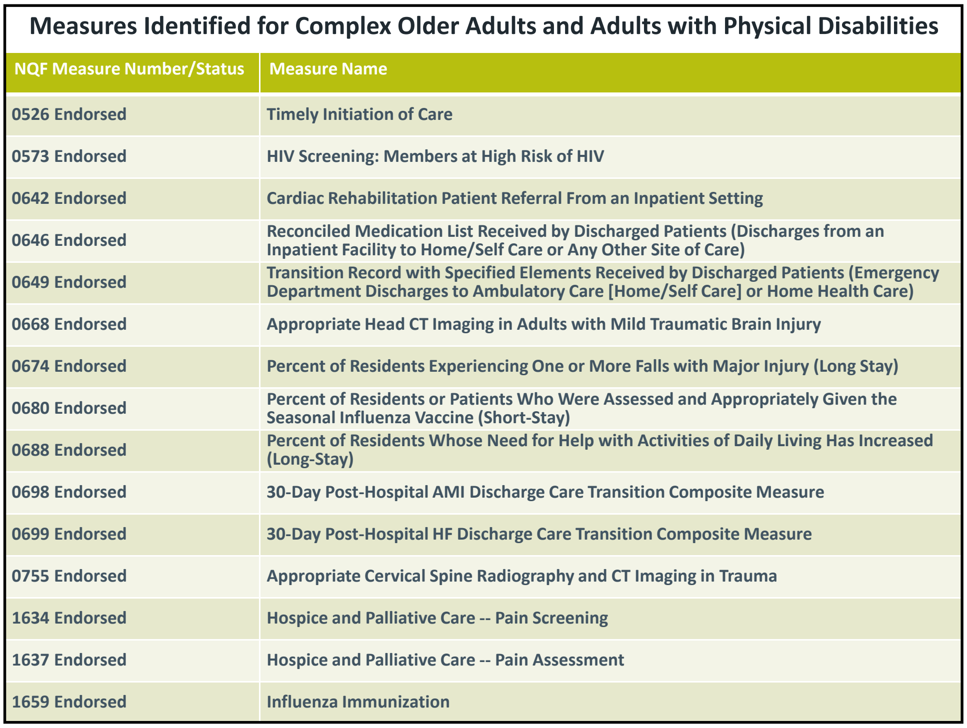
NQF Measure Number/Status	Measure Name
NQF 0004 Endorsed	Initiation and Engagement of Alcohol and Other Drug Dependence Treatment
NQF 0022 Endorsed	Use of High-Risk Medications in the Elderly
NQF 0028 Endorsed	Tobacco Use Assessment and Tobacco Cessation Intervention
NQF 0097 Endorsed	Medication Reconciliation
NQF 0101 Time-Limited Endorsement	Screening for Fall Risk
NQF 0209 Endorsed	Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment
NQF 0228 Endorsed	3-Item Care Transition Measure
NQF 0260 Endorsed	Assessment of Health-related Quality of Life [Physical and Mental Functioning]
NQF 0326 Endorsed	Advance Care Plan
NQF 0418 Endorsed	Screening for Clinical Depression
NQF 0420 Endorsed	Pain Assessment Prior to Initiation of Patient Therapy
NQF 0421 Endorsed	Preventive Care and Screening: Body Mass Index (BMI) Screening and Follow-Up
NQF 0430 Endorsed	Change in Daily Activity Function as Measured by the AM-PAC
NQF 0557 Endorsed	HBIPS-6 Post Discharge Continuing Care Plan Created
NQF 0558 Endorsed	HBIPS-7 Post Discharge Continuing Care Plan Transmitted to Next level of Care Provider Upon Discharge

Evolving Core Measure Set for Dual Eligible Beneficiaries

NQF Measure Number/Status	Measure Name
NQF 0576 Endorsed	Follow-up after Hospitalization for Mental Illness
NQF 0647 Endorsed	Transition Record with Specified Elements Received by Discharged Patients
NQF 0648 Endorsed	Timely Transmission of Transition Record
NQF 0729 Endorsed	Optimal Diabetes Care
NQF 1632 Endorsed	CARE – Consumer Assessments and Reports of End of Life
NQF 1626 Endorsed	Patients Admitted to ICU who Have Care Preferences Documented
NQF 1641 Endorsed	Hospice and Palliative Care – Treatment Preferences
NQF 1768 Endorsed	Plan All-Cause Readmissions
NQF 1789 Endorsed	Hospital-Wide All-Cause Unplanned Readmissions
NQF 1825 Endorsed	COPD – Management of Poorly Controlled COPD
NQF 1909 Endorsed	Medical Home System Survey
NQF 1919 Endorsed	Cultural Competency Implementation Measure
Multiple Surveys Endorsed	Consumer Assessment of Healthcare Providers and Systems (CAHPS) Surveys
Not Endorsed; to be added pending endorsement	Unhealthy Alcohol Use: Screening and Brief Counseling
Not Endorsed	SNP 6: Coordination of Medicare and Medicaid Coverage

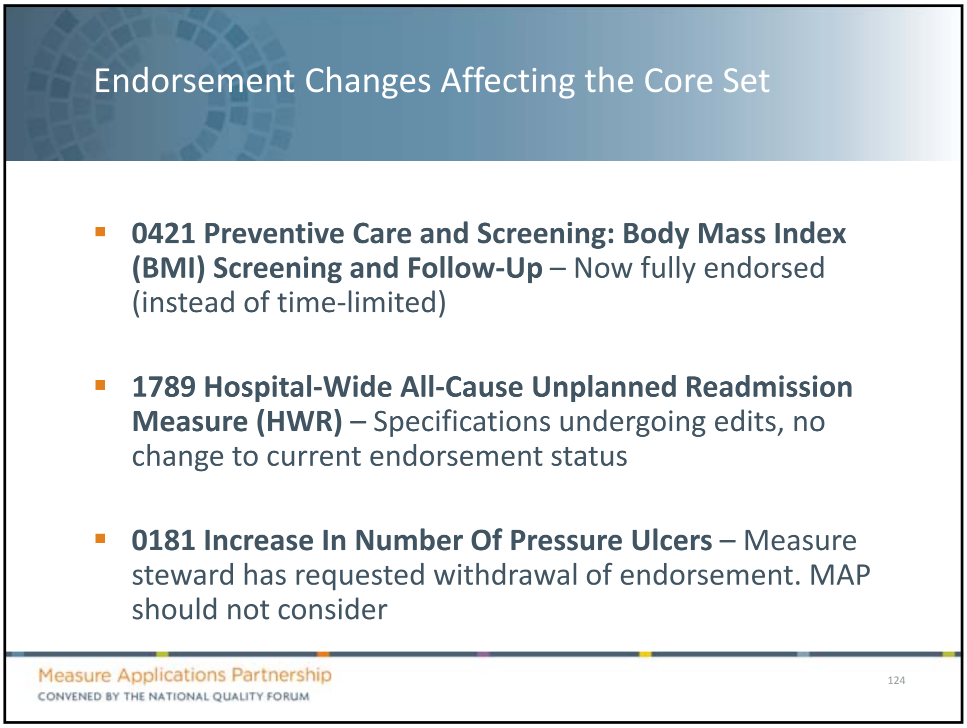
Measures Identified for Complex Older Adults and Adults with Physical Disabilities

NQF Measure Number/Status	Measure Name
0018 Endorsed	Controlling High Blood Pressure
0032 Endorsed	Cervical Cancer Screening
0043 Endorsed	Pneumonia vaccination status for older adults
0138 Endorsed	National Healthcare Safety Network (NHSN) Catheter-associated Urinary Tract Infection (CAUTI) Outcome Measure
0141 Endorsed	Patient Fall Rate
0173 Endorsed	Emergency Department Use without Hospitalization
0176 Endorsed	Improvement in management of oral medications
0177 Endorsed	Improvement in pain interfering with activity
0201 Endorsed	Pressure ulcer prevalence (hospital acquired)
0202 Endorsed	Falls with injury
0265 Endorsed	Hospital Transfer/Admission
0266 Endorsed	Patient Fall
0280 Endorsed	Dehydration (PQI 10)
0419 Endorsed	Documentation of Current Medications in the Medical Record
0486 Endorsed	Adoption of Medication e-Prescribing



Measures Identified for Complex Older Adults and Adults with Physical Disabilities

NQF Measure Number/Status	Measure Name
0526 Endorsed	Timely Initiation of Care
0573 Endorsed	HIV Screening: Members at High Risk of HIV
0642 Endorsed	Cardiac Rehabilitation Patient Referral From an Inpatient Setting
0646 Endorsed	Reconciled Medication List Received by Discharged Patients (Discharges from an Inpatient Facility to Home/Self Care or Any Other Site of Care)
0649 Endorsed	Transition Record with Specified Elements Received by Discharged Patients (Emergency Department Discharges to Ambulatory Care [Home/Self Care] or Home Health Care)
0668 Endorsed	Appropriate Head CT Imaging in Adults with Mild Traumatic Brain Injury
0674 Endorsed	Percent of Residents Experiencing One or More Falls with Major Injury (Long Stay)
0680 Endorsed	Percent of Residents or Patients Who Were Assessed and Appropriately Given the Seasonal Influenza Vaccine (Short-Stay)
0688 Endorsed	Percent of Residents Whose Need for Help with Activities of Daily Living Has Increased (Long-Stay)
0698 Endorsed	30-Day Post-Hospital AMI Discharge Care Transition Composite Measure
0699 Endorsed	30-Day Post-Hospital HF Discharge Care Transition Composite Measure
0755 Endorsed	Appropriate Cervical Spine Radiography and CT Imaging in Trauma
1634 Endorsed	Hospice and Palliative Care -- Pain Screening
1637 Endorsed	Hospice and Palliative Care -- Pain Assessment
1659 Endorsed	Influenza Immunization



Endorsement Changes Affecting the Core Set

- **0421 Preventive Care and Screening: Body Mass Index (BMI) Screening and Follow-Up** – Now fully endorsed (instead of time-limited)
- **1789 Hospital-Wide All-Cause Unplanned Readmission Measure (HWR)** – Specifications undergoing edits, no change to current endorsement status
- **0181 Increase In Number Of Pressure Ulcers** – Measure steward has requested withdrawal of endorsement. MAP should not consider

Prioritization and Selection of Measures for Family

Quality of Life

- Order#/Topics:
  - 1.1 Patient Experience
  - 1.2 Health-Related Quality of Life
  - 1.3 Advanced Illness Care

- Input from reviewers?
- Do the measures meet the considerations for inclusion?
- Can relatively less valuable measures be excluded?

Opportunity for Public Comment

Care Coordination and Safety

- Order#/Topics:
    - 2.1 Care Planning/Transitions
    - 2.2 Safety
    - 2.3 Medication Management
    - 2.4 Falls
    - 2.5 Imaging
    - 2.6 Cultural Competence

- Input from reviewers?
- Do the measures meet the considerations for inclusion?
- Can relatively less valuable measures be excluded?

Screening and Assessment

- Order#/Topics:
  - 3.1 Preventive Care
  - 3.2 Vaccinations/Immunizations
  - 3.3 Chronic Disease Management
  - 3.4 Functional Status

- Input from reviewers?
- Do the measures meet the considerations for inclusion?
- Can relatively less valuable measures be excluded?

Mental Health and Substance Use

Order #4

- Input from reviewers?
- Do the measures meet the considerations for inclusion?
- Can relatively less valuable measures be excluded?

Structural Measures

Order #5

- Input from reviewers?
- Do the measures meet the considerations for inclusion?
- Can relatively less valuable measures be excluded?

Review and Finalize Family of Measures for Dual Eligible Beneficiaries

Alignment Opportunities

- What alignment analysis is most important to present in the draft findings?
    - Medicaid Adult Core
    - HEDIS
    - Medicaid Health Home
    - Medicare Advantage reporting requirements
    - Other?

Threshold for Identifying a “Starter Set”

CMS is interested in MAP’s assessment of measures’ immediate readiness for implementation.

- Measures in the Starter Set must work well as they are currently designed. Consider:
    - Readiness
    - Feasibility
    - Comprehensiveness

Follow-Up Exercise

- Online survey will be distributed
- Rank measures selected for the family on whether they meet the “threshold” set by the group
- Submit to NQF by **Friday, May 31**
- Opportunity to review results in draft product in June

Meeting Themes and Action Items for Stakeholders

Action Items for Stakeholders

- What are the workgroup’s key messages for HHS?
- For measure developers?
- For end-users of measures in the field?

Important Dates

- **June:** Workgroup review of preliminary findings on behavioral health subpopulations and the family of measures for dual eligible beneficiaries
- **July 13:** Findings due to HHS

Opportunity for Public Comment

Adjourn

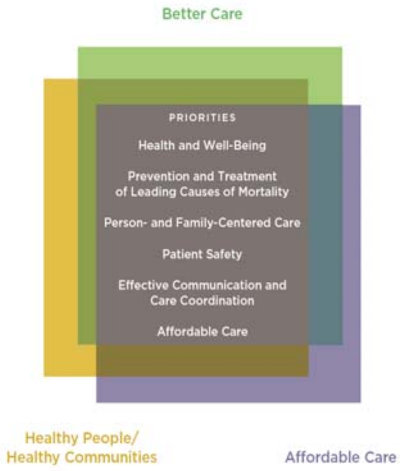
Reference Material

Workgroup Charge for 2012/2013

- Identify opportunities to improve measurement for dual eligible beneficiaries.
- Determine the most suitable performance measures currently available, concentrating on high-need subgroups to include:
  - Older adults with functional limitations and chronic conditions
  - Adults younger than 65 with physical disabilities
  - Individuals with serious mental illness
  - Individuals with cognitive impairment
- Document potential strategies to address measurement limitations.
- Delineate specific gaps in measures and available evidence to inform future measure development.
- Advise the Coordinating Committee on cross-cutting measurement issues and ensure alignment. These include MAP's strategic plan, families of measures, and pre-rulemaking input.

MAP Framework for Aligned Performance Measurement: National Quality Strategy

- Working with communities to promote wide use of best practices to **enable healthy living**
- Promoting the most effective **prevention and treatment practices** for the leading causes of mortality, starting with cardiovascular disease
- Ensuring that each **person and family are engaged** as partners in their care
- **Making care safer** by reducing harm caused in the delivery of care
- Promoting effective **communication and coordination** of care
- **Making quality care more affordable** for individuals, families, employers, and governments by developing and spreading new health care delivery models



Better Care

PRIORITIES

Health and Well-Being

Prevention and Treatment of Leading Causes of Mortality

Person- and Family-Centered Care

Patient Safety

Effective Communication and Care Coordination

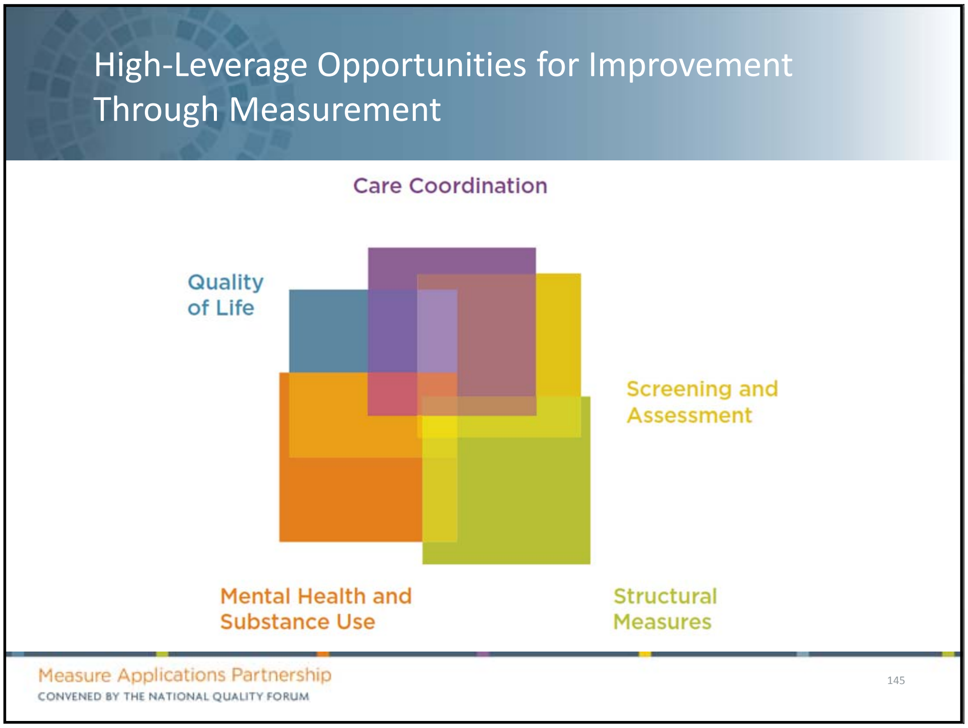
Affordable Care

Healthy People/ Healthy Communities

Affordable Care

Dual Eligible Beneficiaries Workgroup Vision for High-Quality Care

In order to promote a system that is both sustainable and person- and family-centered, individuals eligible for both Medicare and Medicaid should have timely access to appropriate, coordinated healthcare services and community resources that enable them to attain or maintain personal health goals.



High-Leverage Opportunities for Improvement Through Measurement

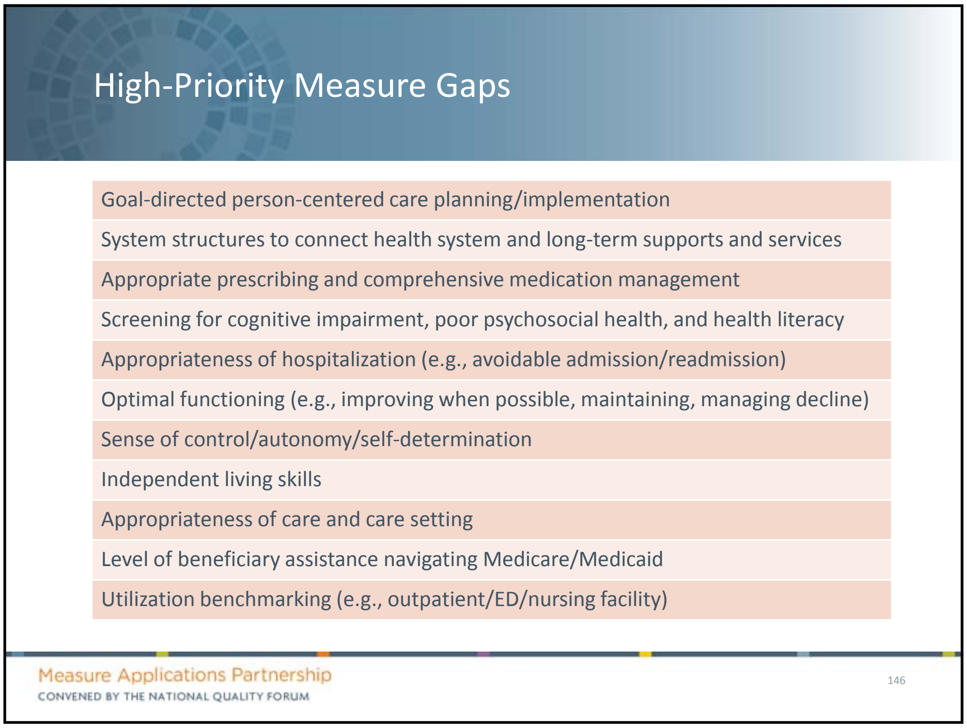
Care Coordination

Quality of Life

Screening and Assessment

Mental Health and Substance Use

Structural Measures



High-Priority Measure Gaps

Goal-directed person-centered care planning/implementation
System structures to connect health system and long-term supports and services
Appropriate prescribing and comprehensive medication management
Screening for cognitive impairment, poor psychosocial health, and health literacy
Appropriateness of hospitalization (e.g., avoidable admission/readmission)
Optimal functioning (e.g., improving when possible, maintaining, managing decline)
Sense of control/autonomy/self-determination
Independent living skills
Appropriateness of care and care setting
Level of beneficiary assistance navigating Medicare/Medicaid
Utilization benchmarking (e.g., outpatient/ED/nursing facility)

Proposed Key Issues for Measurement in High-Need Subgroups of Dual Eligible Beneficiaries: Serious Mental Illness (SMI), Substance Use Disorder (SUD), Dementia and Other Acquired Impairments, and Intellectual/Developmental Disabilities (ID/DD)

High-Leverage Opportunities	Common Issues Across High-Need Subgroups	Serious Mental Illness	Substance Use Disorders	Dementia/Acquired Cognitive Impairments	Intellectual and Developmental Disabilities
Quality of Life	**Preventing abuse and neglect (specifically in institutional settings)** **Maintaining or improving functional status** **Shared decision-making** **Respect for personal preferences**	Improving personal independence and self-direction	Withdrawal management Decision support/shared-decision making	Rehabilitation and redevelopment of functional skills Improving or maintaining personal independence and self-direction Social engagement and involvement in meaningful activities	Habilitation and development of key functional and personal skills Engagement and participation in healthy activities Improving or maintaining personal independence and self-direction Physical accessibility and mobility Social engagement and involvement in meaningful activities
Care Coordination and Safety	**Avoidable admissions, readmissions, complications** **Person-centered care planning** **Care transitions, discharge planning** **Communication between providers** **Communication between providers and beneficiaries** **Cultural competence** **Medication management: access, appropriateness, reconciliation, adherence** **Adverse drug events** **Advance directives/care planning** **Use of physical or chemical restraints**	Use of seclusion Suicide prevention	Suicide prevention	Use of seclusion Avoidance of anticholinergic medications Home safety/environment	Use of seclusion

Proposed Key Issues for Measurement in High-Need Subgroups of Dual Eligible Beneficiaries: Serious Mental Illness (SMI), Substance Use Disorder (SUD), Dementia and Other Acquired Impairments, and Intellectual/Developmental Disabilities (ID/DD)

High-Leverage Opportunities	Common Issues Across High-Need Subgroups	Serious Mental Illness	Substance Use Disorders	Dementia/Acquired Cognitive Impairments	Intellectual and Developmental Disabilities
Screening and Assessment	**Oral Health** **Nutrition and weight management** **New or worsening chronic conditions, especially cardio-metabolic diseases** **Caregiver burden/burnout**	Broad screening for SMIs Screening for substance use and/or risky behaviors Preventative and cancer screenings Sexual and gynecologic health	Broad screening for substance use/abuse Implications for treatment of asthma, sleep disorders, other conditions Screening individuals with SU for mental illness (e.g., schizophrenia) Sexual and gynecologic health Pain management	Broad screening for dementia Screening individuals with impairments for mental illness (e.g., depression) Cognitive functioning assessment Pain management Fall risk assessment Behaviors (e.g., aggression, wandering) Superimposed delirium, depression, psychosis, or sleep disturbances Driving risk	Functional status assessment Screening for SMIs Preventive cancer screening Sexual and gynecologic health
Mental Health and Substance Use		Engagement and counseling Affective disorders (e.g., major depression, bipolar disorders) Schizophrenia Paranoid disorders Illicit drug use Tobacco and alcohol use	Engagement and counseling Tobacco and alcohol use Illicit drug use	Dementia Alzheimer's disease Tobacco and alcohol use	Screening for SMIs
Structural Measures	**Access to needed services (e.g., health home, primary care, specialty care, dental care, vision care, durable medical equipment, habilitation, rehabilitation, occupational therapy, social services, community mental health providers)** **Workforce adequacy, stability, and training** **Providers' linkages to community resources (e.g., special education, human services, transportation)** **Formal caregiver support** **Informal caregiver support** **Cultural competency** **Monitoring referrals**				

Draft Measure Concepts for Inpatient Psychiatric Care

Measure Concept Draft Title	Measure Concept Draft Numerator	Measure Concept Draft Denominator	Harmonization Opportunities
IPF Suicide Risk Screening completed within one day of admission	Number of admissions with a detailed screening of suicide risk within the first day of admission.	All individuals discharged from hospital-based IPFs during the measurement year.	Contractor plans to work with The Joint Commission for measure harmonization with HBIPS-1
IPF Violence Risk Screening completed within one day of admission	Number of admissions with a documented assessment for violence risk within the first day of admission.	Total number of psychiatric inpatient discharges during the measurement period.	Contractor plans to work with The Joint Commission for measure harmonization with HBIPS-1
IPF Alcohol and Substance Screening completed within one day of admission.	Number of admissions with a detailed screening of substance use within the first day of admission.	Total number of psychiatric inpatient discharges during the measurement period.	Contractor plans to work with The Joint Commission for measure harmonization with HBIPS-1 and SUB-1
IPF Metabolic Screening	Number of inpatients who received a comprehensive metabolic screening for metabolic disorders during the measurement year. Comprehensive screening currently defined to include: Body mass index A1C or glucose test Blood pressure Lipid panel Total cholesterol Low density lipoprotein High density lipoprotein Triglycerides	Total number of psychiatric inpatients admitted during the measurement period.	

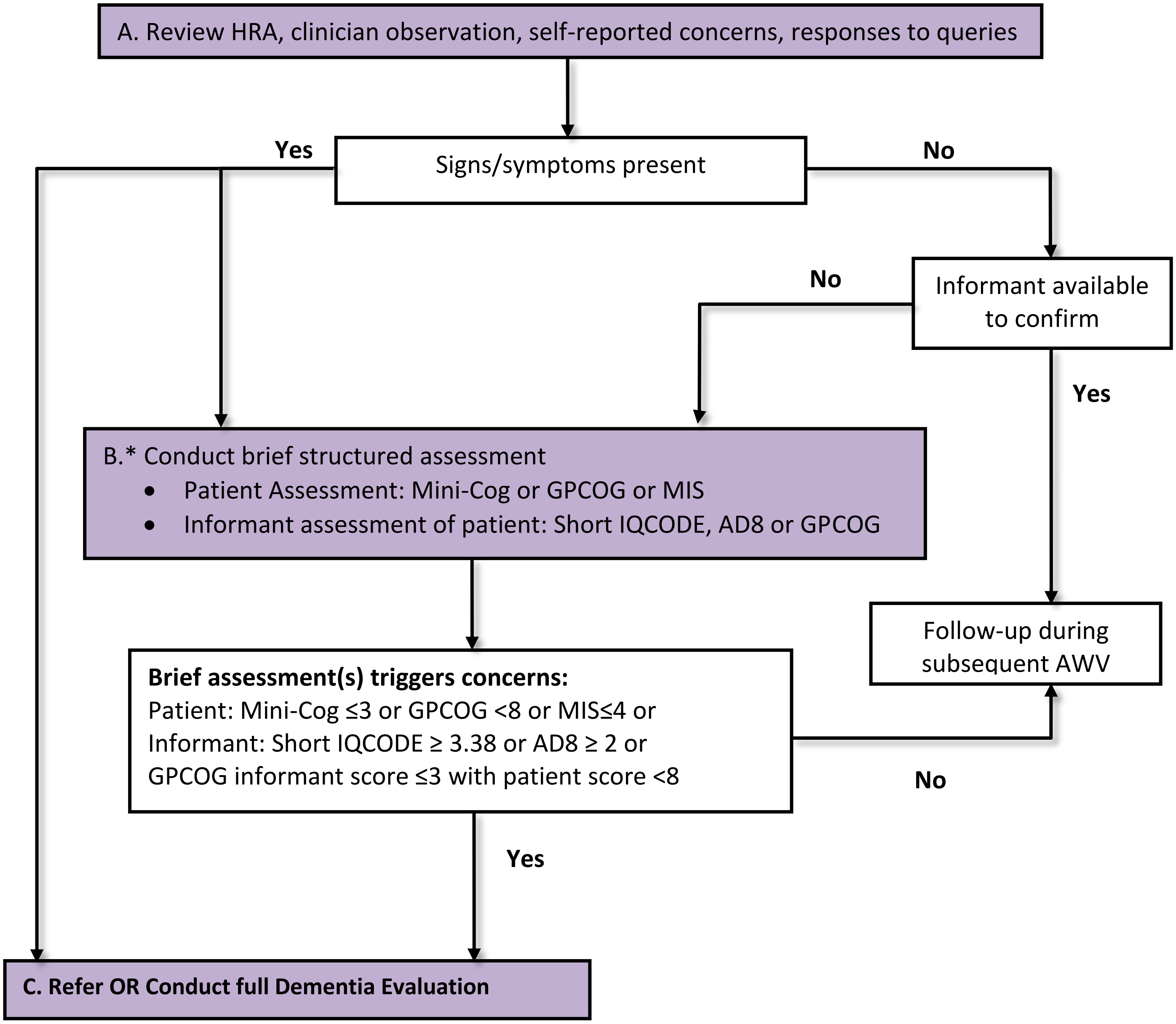
Measure Type: Process

Care Setting: Inpatient psychiatric facility (IPF) or IPF units within acute care hospitals

Data source: chart

Measure development proceeding under contract with CMS, expected completion Fall 2014

Alzheimer’s Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition



A. Review HRA, clinician observation, self-reported concerns, responses to queries

Signs/symptoms present

Informant available to confirm

B.* Conduct brief structured assessment

- Patient Assessment: Mini-Cog or GPCOG or MIS
- Informant assessment of patient: Short IQCODE, AD8 or GPCOG

Follow-up during subsequent AWV

Brief assessment(s) triggers concerns:
Patient: Mini-Cog ≤3 or GPCOG <8 or MIS≤4 or
Informant: Short IQCODE ≥ 3.38 or AD8 ≥ 2 or
GPCOG informant score ≤3 with patient score <8

C. Refer OR Conduct full Dementia Evaluation

* No one tool is recognized as the best brief assessment to determine if a full dementia evaluation is needed. Some providers repeat patient assessment with an alternate tool (eg, SLUMS, or MoCA) to confirm initial findings before referral or initiation of full dementia evaluation.

AWV = Annual Wellness Visit; GPCOG = General Practitioner Assessment of Cognition; HRA = Health Risk Assessment; MIS = Memory Impairment Screen; MMSE = Mini Mental Status Exam; MoCA = Montreal Cognitive Assessment; SLUMS = St. Louis University Mental Status Exam; Short IQCODE = short Informant Questionnaire on Cognitive Decline in the Elderly

Cordell CB, Borson S, Boustani M, Chodosh J, Reuben D, Verghese J, et al. Alzheimer’s Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. *Alzheimers Dement*. 2012. In press.

alz.org |800.272.3900

alzheimer’s association

PERSONAL OUTCOME MEASURES®

My Self

People are connected to natural support networks
People have intimate relationships
People are safe
People have the best possible health
People exercise rights
People are treated fairly
People are free from abuse and neglect
People experience continuity and security
People decide when to share personal information

My World

People choose where and with whom they live
People choose where they work
People use their environments
People live in integrated environments
People interact with other members of the community
People perform different social roles
People choose services

My Dreams

People choose personal goals
People realize personal goals
People participate in the life of the community
People have friends
People are respected

DEFINING QUALITY WITH PERSONAL OUTCOME MEASURES®

INSPIRED BY A VISION of a world of dignity, opportunity, and community for all people, CQL challenged the field of human services when we redefined quality as ***responsiveness to people*** rather than compliance with standards. In 1991, CQL published the *Personal Outcome Measures®* offering people an opportunity to define their own quality of life outcomes and exert choice and self-determination.

The *Personal Outcome Measures®* focus on the items and issues that matter most to people. Organizations committed to Personal Outcomes recognize the connections between the service/intervention and the whole person. The *Personal Outcome Measures®* represent a valid and reliable quality of life tool that can be incorporated in all human services for people of all ages.

The *Personal Outcome Measures®* contains 21 items that define quality from the individual's perspective. These are the key indicators and experiences that people and their families have said are most important to them. The *Personal Outcome Measures®* are organized into the following 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.

THE *WHAT REALLY MATTERS* INITIATIVE

CQL has always been at the forefront of defining quality in services and supports. With each edition of standards, measures, or indicators (from 1971 to the present), CQL has asked and heard from people about the real meaning of quality. Those definitions have changed dramatically over 40 years.

We have seen the successes, as well as the often slow pace of change, in the reality of most people's lives. CQL continues to lead with a clear focus on excellence in person-centered services and supports. Building on our own accomplishments in impacting quality for life for people, we continue to bring forward fresh insights and new methods.

Beginning in the fall of 2009 through our *What Really Matters* initiative, CQL engaged a diverse group of thought leaders and stakeholders across the fields of mental health, aging and disabilities. We came together to say that it's time to strip away unnecessary distractions and focus on what really matters — personal choice and person-centered services and supports. Person-centered services give people the control over the decisions that affect their lives. CQL's approach to quality is about focusing on the real meaning of things — personal choice and person-centered services. We believe that organizations need to focus on what really matters to people.

With this Initiative, our focus lands squarely on the real meaning of quality in person-centered services and supports. CQL works with organizations, systems, and communities who are dedicated to achieving excellence through person-centered service models — across all disciplines. We support those organizations through our assessment, consultation, measurement, and improvement strategies.

Personal Outcome Measures® remain at the foundation of this work.

THE DIFFERENCE IN PERSONAL OUTCOME MEASURES®

CQL's *Personal Outcome Measures®* have been a hallmark of our work for the last 20 years and have been a powerful data set for the valid and reliable measurement of individual quality of life. Instead of looking at the quality of how the services are being delivered, the *Personal Outcome Measures®* approach looks at whether the services and supports are having the desired results or outcomes that matter to the person.

IN TRADITIONAL SYSTEMS:	**WITH PERSONAL OUTCOMES:**
The focus is on program standards	The focus on the person
Service action is based on professional criteria	Service action is based on the person's criteria
The person is assigned to program	Services and supports are designed for the person
Expectations for performance are defined by program	Expectations for performance are defined by the person

Each of the three words in *Personal Outcome Measures®* shows how this approach is different

PERSONAL	Starts with the person's own view of his or her life
OUTCOME	Defines what is important to the person
MEASURES	Offers an objective determination of whether people are getting what is personally important

1. They're PERSONAL

What we do is determined by each person for him/herself. Each person's assessment for quality of life is unique to him or her. The definitions for quality of life are set by the person, with the help of people who care about him/her and know him/her very well.

2. They're OUTCOME Based

How we work is guided by what's happening in the person's life – so that the individual is experiencing real outcomes related to the personal expectations for quality that he/she has defined.

3. They're MEASURED Differently

We can't look at personal outcomes without measuring quality differently. Traditional systems measure how services are delivered or what the organization does. CQL's approach to measurement looks at personal quality of life and addresses questions of priority and relevance for the person, based individual life priorities.

KEY FEATURES OF THE *PERSONAL OUTCOME MEASURES*®

- A powerful tool for evaluating personal quality of life and the degree to which organizations individualize supports to facilitate outcomes.
- A way for organizations to redefine their role in the lives of the people they support.
- A conversation with people receiving supports is the most powerful source of knowledge and understanding when it comes to defining excellence and person-centeredness.

WHY CHOOSE PERSONAL OUTCOMES?

CQL's *Personal Outcome Measures*® form the foundation for organizational quality enhancement. CQL is committed to helping your organization's leadership, management, and staff use person-centered principles and proven strategies in all aspects of your service delivery.

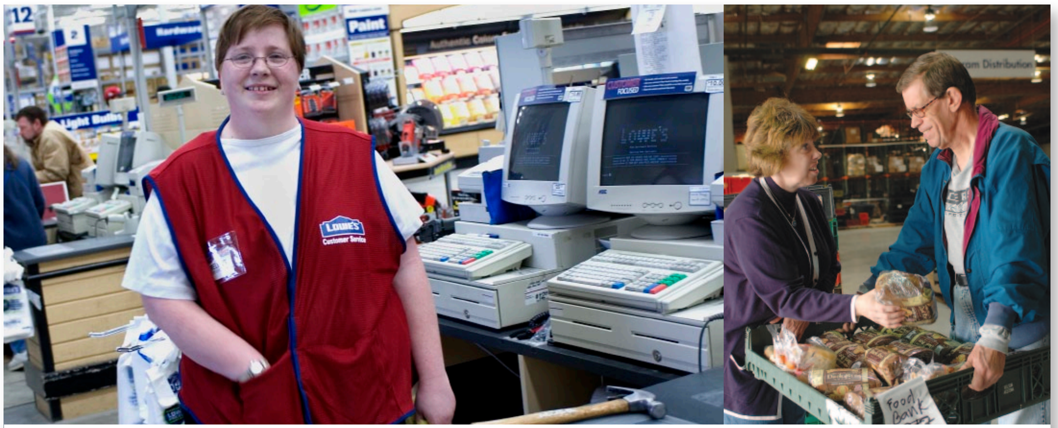
We start with the belief that knowledge about people is the foundation for delivering quality services. With a clear understanding of what people want and need from the services and supports they receive — their Personal Outcomes — staff can marshal the organization's resources toward that end.

Personal Outcome Measures® help you learn about people's personal definition of quality of life and gather information about the person's priorities and preferences in order to support their personal outcomes. *Personal Outcome Measures*®:

- Offer the best tool for evaluating personal quality of life and quality of services
- Put listening to and learning about the person at the center of your work
- Guide the delivery of individualized supports based on people's priorities
- Help you focus your limited resources and organizational energy on what really matters
- Provide data and analysis for evidence-based practice
- Demonstrate the link between person-centered/recovery-based services, quality of life and cost effectiveness

Work provides a source of income, an opportunity to meet other people, a sense of accomplishment and self-esteem. Finding and choosing a job and a career is an important life decision.

CQL's Personal Outcome Measures®



EMPLOYMENT REALLY MATTERS

CQL | The Council on Quality and Leadership   100 West Road, Suite 300, Towson, MD 21204   www.c-q-l.org

Work provides a source of income, an opportunity to meet other people, a sense of accomplishment and self-esteem. Finding and choosing a job and a career is an important life decision.

People have productive lives whether or not they have paid employment. Some people do not work because they are too young, do not need the money or because they have retired. For children, we define work as going to school and doing household chores. During adolescence, we begin to look at career development and planning for work. When people are retired or do not work, they have meaningful activities that provide the same social and personal rewards that a paid job offers. This can be accomplished through volunteering, continued learning or leisure activities.

People choose where they work.

Organizations learn about people's preferences for work, the type of job, the hours, the location and the responsibilities. People learn what is available and consider a wide range of work choices. People's preferences, interests and desires are key to job and career selection.

With access to supports and technology, most people with disabilities can enter the job market. Options for jobs and places to work increase when people have support services, assistive technology and environmental adaptations. Organizations assist people to make work-related decisions by finding out what they would like, providing opportunities to see what is available and honoring the final choice. Some people will need more help than others to make these decisions.

Organizations use a variety of methods to learn about people's preferences. Decisions about work involve matching individual characteristics and preferences with available options, since we cannot always control what options are available.

Options for work may be limited due to particular circumstances that are beyond the person's or organization's control, such as no job openings at a given company. Organizations assist people to identify the "next best" alternative. Planning addresses ways to change the circumstances, while the person experiences the "next best" option.

Values

- The same array of options for work available to others is available to people with disabilities.
- For the majority of adults in our society, work provides a significant amount of economic support and self-esteem.
- If people have alternate means of support and do not wish to work, that choice is respected.
- People who do not work spend their time in meaningful and productive activities.
- Assistive technology enhances people's employment potential and productivity.

Principles for Organizations

- Assist people to locate employment that matches their goals, desires, skills and aptitudes.
- A full array of work, training and other opportunities is made available to people.
- Provide opportunities for different experiences and explore and respect individual preferences.

Tips for Information Gathering

Use the following questions as a guide for gathering information from the people you support.

CONVERSATION WITH THE PERSON

Suggested Questions for the Person:

1. What do you do for work or your career?
2. What options did you have?
3. Who chose what you do?
4. Can you do something different if you want to?
5. How did others help you with this?
6. Are you satisfied with the decision either you or others made?
7. If not, what would you like instead?

FOLLOW-UP QUESTIONS

Suggested Questions for Those Who Know the Person Best

Questions about this Outcome for the Person:

1. How was it decided where the person would work?
2. What options/experiences did the person have?
3. Who made the decision about where the person works? If it wasn't the person, why not?
4. Is the current work situation satisfactory to the person? If not, what is being done?
5. How are the person's concerns addressed if there is not a good match?
6. How does the person's current job relate to his or her preferences, skills and interests?

Questions about Individualized Supports:

1. How do you learn about the person's preferences for work?
2. How do you present options to the person so he or she can make informed choices?
3. Is the person working where he or she wishes? If not, what is the barrier?
4. What are you doing to overcome the barrier?
5. How do you learn about the person's job satisfaction?
6. What organizational practices, values and activities support the person to maintain or achieve this outcome?

Decision-Making with Personal Outcome Measures®

Based on the information gathered from meeting and talking with the person, follow-up meetings with others who know the person best, observations and documentation checks, if needed, you will be able to answer the following questions about the presence of the outcome for the person and the presence of individualized organizational supports.

Personal Outcome Questions:

1. Does the person have opportunity to experience different options?
2. Does the person decide where to work or what to do?
3. If the answers to #1 and 2 are yes, the outcome is present.

Individualized Support Questions:

1. Does the organization know the person's interests for work, or are efforts being made to learn what the person would like to do?
2. Does the organization provide the person with access to varied job experiences and options?
3. Has the organization responded to the person's desires for pursuing specific work or career options with supports?
4. Has the organization supported the person to address any identified barriers to achieving this outcome?
5. Based on the answers to these questions, are there individualized supports in place that facilitate this outcome?

Additional Considerations:

- If the person has not been presented with options about where to work, and his or her preferences have not been determined, then the outcome is not present.
- Planning for work begins during high school years. For preadolescent children, this outcome is present as long as they are involved in educational activities.
- Choice may mean exploring options, expressing preferences and finally choosing the only option available at that time.

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My World: Where I work, live, socialize, belong or connect.
My Dreams: How I want my life (self and world) to be.

CQL'S PERSONAL OUTCOME MEASURES®

My Self

People are connected to natural support networks.

People have intimate relationships.

People are safe.

People have the best possible health.

People exercise rights.

People are treated fairly.

People are free from abuse and neglect.

People experience continuity and security.

People decide when to share personal information.

My World

People choose where and with whom they live.

People choose where they work.

People use their environments.

People live in integrated environments.

People interact with other members of the community.

People perform different social roles.

People choose services.

My Dreams

People choose personal goals.

People realize personal goals.

People participate in the life of the community.

People have friends.

People are respected.

Primary care of adults with developmental disabilities

Canadian consensus guidelines

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Abstract

Objective To update the 2006 Canadian guidelines for primary care of adults with developmental disabilities (DD) and to make practical recommendations based on current knowledge to address the particular health issues of adults with DD.

Quality of evidence Knowledgeable health care providers participating in a colloquium and a subsequent working group discussed and agreed on revisions to the 2006 guidelines based on a comprehensive review of publications, feedback gained from users of the guidelines, and personal clinical experiences. Most of the available evidence in this area of care is from expert opinion or published consensus statements (level III).

Main message Adults with DD have complex health issues, many of them differing from those of the general population. Good primary care identifies the particular health issues faced by adults with DD to improve their quality of life, to improve their access to health care, and to prevent suffering, morbidity, and premature death. These guidelines synthesize general, physical, behavioural, and mental health issues of adults with DD that primary care providers should be aware of, and they present recommendations for screening and management based on current knowledge that practitioners can apply. Because of interacting biologic, psychoaffective, and social factors that contribute to the health and well-being of adults with DD, these guidelines emphasize involving caregivers, adapting procedures when appropriate, and seeking input from a range of health professionals when available. Ethical care is also emphasized. The guidelines are formulated within an ethical framework that pays attention to issues such as informed consent and the assessment of health benefits in relation to risks of harm.

Conclusion Implementation of the guidelines proposed here would improve the health of adults with DD and would minimize disparities in health and health care between adults with DD and those in the general population.

Résumé

Objectif Mettre à jour les lignes directrices canadiennes de 2006 sur les soins primaires aux adultes ayant une déficience développementale (DD) et présenter des recommandations pratiques fondées sur les connaissances actuelles pour traiter des problèmes de santé particuliers chez des adultes ayant une DD.

Qualité des preuves Des professionnels de la santé expérimentés participant à un colloque et un groupe de travail subséquent ont discuté et convenu des révisions aux lignes directrices de 2006 en se fondant sur une recherche documentaire exhaustive, la rétroaction obtenue des utilisateurs

KEY POINTS As a group, adults with developmental disabilities (DD) have poorer health and greater difficulty accessing primary care than does the general population. They have different patterns of illness and complex interactions among comorbidities. These guidelines update the general, physical, behavioural, and mental health recommendations for adults with DD, especially for those conditions not screened for by routine health assessments of the general population. Ethical issues, such as informed consent and assessment of benefits in relation to risks, are addressed. Among the most important updates are consideration of atypical manifestations of pain and distress in adults with DD and a strong recommendation to avoid inappropriate long-term use of antipsychotic medications to address behavioural issues.

POINTS DE REPÈRE Collectivement, les adultes ayant des déficiences développementales (DD) sont en moins bonne santé et ont plus de difficultés à avoir accès aux soins primaires en comparaison de l'ensemble de la population. Les maladies évoluent différemment et présentent entre elles des interactions complexes chez ces personnes. Les lignes directrices font la mise en jour des recommandations pour la santé générale, physique, comportementale et mentale des adultes ayant une DD, en particulier pour les problèmes qui ne sont pas dépistés dans les évaluations systématiques de la santé dans la population en général. Elles traitent des questions d'ordre éthique, comme le consentement éclairé et l'évaluation des bienfaits par rapport aux risques. Parmi les mises à jour les plus importantes, on peut mentionner les manifestations atypiques de la douleur et de la détresse chez les adultes ayant une DD et une très forte recommandation d'éviter l'utilisation à long terme inappropriée des antipsychotiques pour les problèmes comportementaux.

This article has been peer reviewed.
Cet article a fait l'objet d'une révision par des pairs.
Can Fam Physician 2011;57:541-53

La traduction en français de cet article se trouve à www.cfp.ca dans la table des matières du numéro de mai 2011 à la page e154.

du guide de pratique et les expériences cliniques personnelles. La plupart des preuves disponibles dans ce domaine viennent de l'opinion d'experts ou de déclarations consensuelles publiées (niveau III).

Message principal Les adultes ayant une DD ont des problèmes de santé complexes, dont plusieurs diffèrent de ceux de la population en général. De bons soins primaires permettent d'identifier les problèmes de santé particuliers dont souffrent les adultes ayant une DD pour améliorer leur qualité de vie et leur accès aux soins de santé et prévenir la morbidité et le décès prématuré. Ces lignes directrices résument les problèmes de santé générale, physique, comportementale et mentale des adultes ayant une DD que devraient connaître les professionnels des soins primaires et présentent des recommandations pour le dépistage et la prise en charge en se basant sur les connaissances actuelles que les cliniciens peuvent mettre en pratique. En raison de l'interaction des facteurs biologiques, psychoaffectifs et sociaux qui contribuent à la santé et au bien-être des adultes ayant une DD, ces lignes directrices insistent sur la participation des aidants, l'adaptation des interventions, au besoin, et la consultation auprès de divers professionnels de la santé quand ils sont accessibles. Elles mettent aussi en évidence la nature éthique des soins. Les lignes directrices sont formulées dans le contexte d'un cadre éthique qui tient compte des questions comme le consentement éclairé et l'évaluation des bienfaits pour la santé par rapport aux risques de préjudice.

Conclusion La mise en œuvre des lignes directrices proposées ici améliorerait la santé des adultes ayant une DD et minimiserait les disparités sur les plans de la santé et des soins de santé entre les adultes ayant une DD et la population en général.

The terms *developmental disabilities* (DD) or *intellectual disabilities* are used synonymously in Canada (equivalent to *learning disabilities* in the United Kingdom) to refer to a range of conditions in which lifelong limitations in intellectual functioning and conceptual, social, and practical skills are noticeable before age 18 years.[1] Estimates of the prevalence of DD vary between 1% and 3% of Canadians. Most reside and receive health care in the community.[2] A growing proportion of them are living longer than in the past.[2,3] Their health needs and access to primary care vary individually with factors such as the etiology of their DD, coexisting physical and mental health characteristics, severity of functional limitations, quality of environment and social supports, and age.[4]

Health disorders in people with DD frequently differ from those encountered in the general population in terms of prevalence, age of onset, rate of progression, degree of severity, and presenting manifestations. These disorders are also more likely to be multiple and complex in those with DD.[3] They therefore require the support of health professionals who are willing, knowledgeable, and skilled to address their particular challenges and vulnerabilities in maintaining health.

Various studies in Canada, the United States, the United Kingdom, and Australia have shown that people with DD, as a group, are poorly supported by health care systems.[5] The United Nations' *Convention on the Rights of Persons with Disabilities*,[6] which has been ratified by Canada, includes the right to health care. Primary care providers are the lynchpin in efforts to ameliorate health care for people with DD. Primary care providers are often the most consistently available health professionals involved in caring for people with DD and in interacting with regular caregivers. Their contribution is vital for disease prevention, early detection, and appropriate management. They can help to assess the need for referral to specialized and interdisciplinary health services when these are available. They also provide continuity and coordination of care. Reliable guidelines, however, are required to inform primary care providers about the particular health needs of people with DD and the best approaches to management.

There is an especially pressing need for such guidelines concerning adults with DD. Adulthood, usually after 18 years of age, is when people with DD are no longer deemed eligible for pediatric and adolescent services, although this age varies provincially in Canada. In the Canadian health care system, service gaps resulting from transition to the adult care system, which generally has fewer resources and is less specialized and more fragmented than the pediatric and adolescent care systems, present enormous challenges to adults with DD and their caregivers. These challenges are complicated by recent increases in life expectancy and the aging of people with DD, and by their integration into the community. Thus, while more people with DD are moving into the adult care system than in the past, there are insufficient numbers of knowledgeable and experienced primary care providers to support them. To compound the situation, there have been fewer publications addressing the screening, assessment, and management of health disorders and challenges of adults with DD, relative to such publications for infants and children with such disabilities.

In 2005, a consensus colloquium involving knowledgeable and experienced clinicians and researchers in DD from across Canada and abroad formulated the "Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities" (hereafter referred to as the *2006 Guidelines*).[7] Subsequent consultations with users of the 2006 Guidelines, as well as developments in research and practice, led to expanding and updating those guidelines, which remain, to our knowledge, the only comprehensive guidelines for the primary care of adults with

DD in Canada. References to various clinical tools that might help in applying the guidelines have also been added.

Methods

A consensus development method was used to update the 2006 Guidelines. This consisted of 2 steps: meticulous electronic and manual searches for relevant publications and discussion of recommended changes to the 2006 Guidelines by knowledgeable and experienced Canadian clinicians and researchers on primary health care of adults with DD who participated in a consensus colloquium in March 2009 and in a subsequent working group.

A librarian familiar with research on DD undertook ongoing, comprehensive electronic searches in PubMed and PsycINFO for publications in English from 1990 to 2010 that were indexed under, or contained in their title, abstract, or text, the terms *mental retardation*, *intellectual disability (disabilities),* or *developmental disability (disabilities)*. Publications from Great Britain were also searched for the terms *learning difficulties*, *learning disability (disabilities),* or *learning disorders*. These were cross-referenced with a long list of physical and mental health key words relating to medical assessment, diagnosis, treatment, prognosis, health care access, need, planning, services, and delivery. The search was then expanded to include specific health issues highlighted in the 2006 Guidelines. In addition, the librarian undertook manual searches using cited references in Scopus and Internet searches for relevant publications that had not been indexed by any of the above-mentioned electronic databases.

Search results were downloaded to and organized in an electronic database management system known as RefWorks. Two family physicians, a psychologist, and a psychiatrist drew on this database and on comments regarding the 2006 Guidelines gained from various users and reviewers. They were each assigned a section of the 2006 Guidelines for which they were to propose revisions.

Participants who helped to formulate the 2006 Guidelines and others who had completed training courses on the guidelines between 2006 and 2009 were invited to a day-long colloquium in Toronto, Ont, in March 2009. Among the 39 participants were practitioners in family medicine, nursing, pediatrics, psychiatry, psychology, occupational therapy, and speech-language pathology. Before the colloquium, all had access to the librarian's entries into the RefWorks database and received a summary of feedback from users and reviewers of the 2006 Guidelines. The prepared proposals for revisions were discussed in small groups and in plenary sessions, and a summary of accepted revisions was presented and discussed at the end of the colloquium in relation to the priority criteria adopted in the 2006 Guidelines (**Table 1**).[8] A working group consisting of 7 participants, with a family physician in the leading role, met monthly between March 2009 and March 2010 to draft the first version of the updated guidelines. They incorporated into the 2006 Guidelines the changes discussed and accepted during the colloquium. This working group also reviewed published supporting evidence for all the guidelines, including those from supplementary electronic and manual searches for publications undertaken after the colloquium to address particular issues that were not foreseen in the original literature searches. The working group judged the level of evidence supplied for any modified or new guidelines, using the classification scheme adopted in the 2006 Guidelines (**Table 2**).

The first draft of the updated guidelines was circulated for review by participants in the colloquium as well as several invited consultants who were unable to attend the colloquium. Based on the feedback received, the working group prepared the second and final draft between March and October of 2010. This version was sent to participants in the colloquium and review process for their approval; it was then submitted for review for publication.

Table 1. Guideline priority criteria

CRITERIA	EXPLANATION
Importance	Guidelines that address the most prevalent health issues for people with developmental disabilities, especially the leading causes of ill health and death
Disparity	Guidelines that address an issue that would not be identified by public health initiatives or illness prevention measures that target the general population
Usefulness	Guidelines that can be practically implemented and evaluated; these refer to health problems that are easy to detect, for which the means of prevention and care are readily available, and which have health outcomes that can be monitored
Information	Guidelines that are supported by reliable clinical information and research evidence

Adapted from the POMONA Partnership.[8]

Table 2. Criteria for assigning levels of evidence

LEVEL	CRITERIA
I	At least 1 properly conducted randomized controlled trial, systematic review, or meta-analysis
II	Other comparison trials, non-randomized, cohort, case control, or epidemiologic studies, and preferably more than 1 study
III	Expert opinion or consensus statements

Practice guidelines

The updated guidelines are presented in their entirety in **Table 3**.[1,2,9-180]

Discussion

Improving clarity. On the whole, there has been substantial elaboration and rewording of most of the 2006 Guidelines, with attention paid to rendering the considerations and recommendations easier to understand and apply.

Compared with the 2006 Guidelines, the focus of the updates is more clearly on health conditions and needs of adults with DD that diverge from those of the general population. Although primary care guidelines that have been found effective for preventing diseases in the general population should normally also be applied to people with DD, the guidelines in **Table 3**[1,2,9-180] provide additional recommendations and appropriate modifications to standard practice that are relevant for adults with DD. However, some recommendations that apply to the general population have been included in the updated guidelines either because they pertain to tests and other interventions from which adults with DD tend to be excluded or because there is inadequate evidence-based guidance specific to adults with DD.

Table 3. Preventive care checklist for adults with developmental disabilities: *The level of evidence is indicated for each recommendation and is based on the cited reference or references.*

CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
GENERAL ISSUES IN PRIMARY CARE OF ADULTS WITH DD		
1. Disparities in primary care exist between adults with DD and the general population. The former often have poorer health, increased morbidity, and earlier mortality.[2] Assessments that attend to the specific health issues of adults with DD can improve their primary care.[9]	a. Apply age- and sex-specific guidelines for preventive health care as for adults in the general population.[10,11] Perform an annual comprehensive preventive care assessment including physical examination and use guidelines and tools adapted for adults with DD.[9]	I
2. Etiology of DD is useful to establish, whenever possible, as it often informs preventive care or treatment.[12-14]	a. Contact a genetics centre for referral criteria and testing protocols concerning etiologic assessment of adults whose DD is of unknown or uncertain origin.[15-17]	III
Advances in genetic knowledge continue to enhance detection of etiology.[13,18]	b. Consider reassessment periodically if a previous assessment was inconclusive, according to the criteria of the genetics centre.[19]	III
3. Adaptive functioning can decline or improve in some adults with DD. A current assessment of intellectual and adaptive functioning helps to determine necessary care and supports, and establishes a baseline for future assessment.[1,20,21]	a. Refer to a psychologist for assessment of functioning if the patient has never been assessed during adolescence or adulthood, or if a considerable life transition is expected (eg, cessation of schooling or transition from middle to old age).	III
	b. Consider reassessment if indicated, comprehensively or in specific areas, to determine contributing factors to problem behaviour (see guideline 22).[22]	III
4. Pain and distress, often unrecognized,[23] might present atypically in adults with DD, particularly those who have difficulty communicating. Nonspecific changes in behaviour might be the only indicator of medical illness or injury.[24,25]	a. Be attentive to atypical physical cues of pain and distress using an assessment tool adapted for adults with DD.[26,27]	III
Evaluation tools are available to assess the presence and intensity of pain in adults with DD.[27-29]	b. Consider medical causes of changes in behaviour (eg, urinary tract infection, dysmenorrhea, constipation, dental disease).[30]	III
5. Multiple or long-term use of some medications by adults with DD can cause harm that is preventable.[31]	a. Review the date of initiation, indications, dosages, and effectiveness of all medications regularly (eg, every 3 mo).[32]	III
	b. Determine patient adherence capacity and recommend dosettes, blister-packs, and other aids if necessary.	III
	c. Watch for both typical and atypical signs of adverse effects.[33] Regularly monitor potentially toxic medications or interactions of medications (eg, liver function tests or serum drug levels) at the recommended interval for each medication.[34]	III
	d. Ensure that patient and staff or caregivers are educated about appropriate use of medications, including over-the-counter, alternative, and as-needed medications.	III
6. Abuse and neglect of adults with DD occur frequently and are often perpetrated by people known to them.[35-39] Behavioural indicators that might signal abuse or neglect include unexplained change in weight, noncompliance, aggression, withdrawal, depression, avoidance, poor self-esteem, inappropriate attachment or sexualized behaviour, sleep or eating disorders, and substance abuse.[35]	a. Screen annually for risk factors (eg, caregiver stress) and possible behavioural indicators of abuse or neglect.[35]	III
	b. When abuse or neglect is suspected, report to the police or other appropriate authority and address any consequent health issues (eg, through appropriate counseling).[35]	III

Continued on page 545

Table 3 *contiued from page 544*

CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
7. Capacity for voluntary and informed consent varies with the complexity and circumstances of decision making. The limited range of life experiences of some adults with DD, level of intellectual functioning, learned helplessness, and some mental health issues might impair capacity to give informed or voluntary consent. An adult with DD assessed as incapable of some aspects of decision making (eg, understanding or judging consequences) might still be able to convey, through verbal or other means, perspectives that can inform the judgment of a substitute decision maker.[40]	a. Always assess capacity for consent when proposing investigations or treatments for which consent is required.[41]	III
Communicating appropriately with adults with DD is necessary for assessing their capacity to consent and for seeking this consent.[42]	b. Adapt the level and means of communicating to the patient's level of intellectual and adaptive functioning.[43]	III
Although some adults with DD might be incapable of giving consent, they might be able to contribute to decision making (eg, understanding information, expressing perspectives, giving assent) with appropriate support from regular caregivers. Caregivers can also contribute to decision making. They may consent to or refuse treatment on behalf of an adult with DD who is assessed to be incapable of providing informed consent, if they are the most appropriate and available substitute decision makers according to the law.[40]	c. Always consider the best interests of the adult with DD, including his or her perspective in pursuing or forgoing any health care intervention. Support whatever decision-making capacity is possible in adults with DD. Involve family or other caregivers to facilitate communication with, and understanding of, the adult with DD, but also be attentive to inappropriate taking over of decision making.[42,44]	III
8. Advance care planning can often make a positive difference to the outcome of difficult life transitions and crises, and for end-of-life care.[40,43,45]	a. Discuss advance care plans with adults with DD and their caregivers, especially to determine their preference of a substitute decision maker.[41]	III
	b. Record advance care plans and review them annually, or sooner in the context of a health crisis, for appropriateness to the adult with DD's present situation and for what needs to be implemented.[43]	III
9. Interdisciplinary health care is effective in addressing the complex needs of adults with DD. Ideally this would involve a family physician, nurse, and other health practitioners as required, with a coordinator, who might be the family physician, to ensure continuity of care.[46,47]	a. Involve other available health professionals as needed.[46] To address complex physical, behavioural or mental health needs, consult available regional service coordination agencies or specialized interdisciplinary teams.[48,49]	III
PHYSICAL HEALTH GUIDELINES FOR ADULTS WITH DD		
10. Physical inactivity and obesity are prevalent among adults with DD and are associated with adverse outcomes, including cardiovascular disease, diabetes, osteoporosis, constipation, and early mortality.[50,51] Being underweight, with its attendant health risks, is also common.[52]	a. Monitor weight and height regularly and assess risk status using body mass index, waist circumference, or waist-hip ratio measurements.[53,54]	II
A health promotion program can improve attitudes toward physical activity and satisfaction with life.[55,56]	b. Counsel patients and their caregivers annually or more frequently, if indicated, regarding guidelines for nutrition and physical fitness and how to incorporate regular physical activity into daily routines. Refer to dietitian if indicated.[56-59]	II
11. Vision and hearing impairments among adults with DD are often underdiagnosed and can result in substantial changes in behaviour and adaptive functioning.[60-64]	a. Perform office-based screening of vision and hearing (eg, Snellen eye chart, whispered voice test) annually as recommended for average-risk adults, and when symptoms or signs of visual or hearing problems are noted, including changes in behaviour and adaptive functioning.[33,65]	III
	b. Refer for vision assessment to detect glaucoma and cataracts every 5 y after age 45.[65]	III
	c. Refer for hearing assessment if indicated by screening and for age-related hearing loss every 5 y after age 45.[65]	III
	d. Screen for and treat cerumen impaction every 6 mo.[66,67]	III
12. Dental disease is among the most common health problems in adults with DD owing to their difficulties in maintaining oral hygiene routines and accessing dental care. Changes in behaviour can be the result of discomfort from dental disease.[33,68]	a. Promote regular oral hygiene practices and other preventive care (eg, fluoride application) by a dental professional.[69-72]	I
13. Cardiac disorders are prevalent among adults with DD. Risk factors for coronary artery disease include physical inactivity, obesity, smoking, and prolonged use of some psychotropic medications.[51,73,74]	a. When any risk factor is present, screen for cardiovascular disease earlier and more regularly than in the general population and promote prevention (eg, increasing physical activity, reducing smoking).[73]	III
Some adults with DD have congenital heart disease and are susceptible to bacterial endocarditis.	b. Refer to a cardiologist or adult congenital heart disease clinic.[75]	III
	c. Follow guidelines for antibiotic prophylaxis for those few patients who meet revised criteria.[76]	II

Continued on page 546

Table 3 *contiued from page 545*

CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
14. Respiratory disorders (eg, aspiration pneumonia) are among the most common causes of death for adults with DD. Swallowing difficulties are prevalent in those patients with neuromuscular dysfunction or taking certain medications with anticholinergic side effects, and they might result in aspiration or asphyxiation.[77-79]	a. Screen at least annually for possible signs of swallowing difficulty and overt or silent aspiration (eg, throat clearing after swallowing, coughing, choking, drooling, long mealtimes, aversion to food, weight loss, frequent chest infections). Refer as appropriate.[80]	III
15. Gastrointestinal and feeding problems are common among adults with DD. Presenting manifestations are often different than in the general population and might include changes in behaviour or weight.[81-83]	a. Screen annually for manifestations of GERD and manage accordingly. If introducing medications that can aggravate GERD, monitor more frequently for related symptoms.[83,84]	III
	b. If there are unexplained gastrointestinal findings or changes in behaviour or weight, investigate for constipation, GERD, peptic ulcer disease, and pica.[82,84]	II
Adults with DD might have an increased risk of *Helicobacter pylori* infection related to factors such as having lived in a group home, rumination, or exposure to saliva or feces due to personal behaviour or environmental contamination.[83,85,86]	c. Screen for *H pylori* infection in symptomatic adults with DD or asymptomatic ones who have lived in institutions or group homes. Consider retesting at regular intervals (eg, 3-5 y).[83]	III
	d. Consider urea breath testing, fecal antigen testing, or serologic testing depending on the indication, availability, and tolerability of the test.[83,85]	III
16. Sexuality is an important issue that is often not considered in the primary care of adolescents and adults with DD.[87,88]	a. Discuss the patient's or caregiver's concerns about sexuality (eg, menstruation, masturbation, fertility and genetic risks, contraception, menopause) and screen for potentially harmful sexual practices or exploitation. Offer education and counseling services adapted for those with DD.[89,90]	III
17. Musculoskeletal disorders (eg, scoliosis, contractures, and spasticity, which are possible sources of unrecognized pain) occur frequently among adults with DD and result in reduced mobility and activity, with associated adverse health outcomes.[51,91]	a. Promote mobility and regular physical activity.[56,92]	III
	b. Consult a physical or occupational therapist regarding adaptations (eg, wheelchair, modified seating, splints, orthotic devices) and safety.[92]	III
Osteoporosis and osteoporotic fractures are more prevalent and tend to occur earlier in adults with DD than in the general population.[93] In addition to aging and menopause, risk factors include severity of DD, low body weight, reduced mobility, increased risk of falls, smoking, hypogonadism, hyperprolactinemia, the presence of particular genetic syndromes (eg, Down and Prader-Willi),[91,94-96] and long-term use of certain drugs (eg, glucocorticoids, anticonvulsants, injectable long-acting progesterone in women).[34,97] Diagnosis and management of osteoporosis related to the side effects of current treatments can be challenging in adults with DD.	c. Periodically assess risk of developing osteoporosis in all age groups of male and female patients with DD. Those at high risk warrant regular screening starting in early adulthood.[94,96]	III
	d. Recommend early and adequate intake or supplementation of calcium and vitamin D unless contraindicated (eg, in Williams syndrome).[94]	III
Osteoarthritis is becoming more common with increasing life expectancy and weight gain, posing diagnostic and treatment difficulties.[51,98]	e. Be aware of osteoarthritis as a possible source of pain.[51]	III
18. Epilepsy is prevalent among adults with DD and increases with the severity of the DD. It is often difficult to recognize, evaluate, and control,[99-101] and has a pervasive effect on the lives of affected adults and their caregivers.[102]	a. Refer to guidelines for management of epilepsy in adults with DD.[101]	III
	b. Review seizure medication regularly (eg, every 3-6 mo). Consider specialist consultation regarding alternative medications when seizures persist, and possible discontinuation of medications for patients who become seizure-free.[101]	III
	c. Educate patients and caregivers about acute management of seizures and safety-related issues.[103]	III
19. Endocrine disorders (eg, thyroid disease, diabetes, and low testosterone) can be challenging to diagnose in adults with DD.[33,104-106] Adults with DD have a higher incidence of thyroid disease compared with the general population.[107]	a. Monitor thyroid function regularly. Consider testing for thyroid disease in patients with symptoms (including changes in behaviour and adaptive functioning) and at regular intervals (eg, 1-5 y) in patients with elevated risk of thyroid disease (eg, Down syndrome).[33]	III
	b. Establish a thyroid baseline and test annually for patients taking lithium or atypical or second-generation antipsychotic drugs.[34]	III
Currently there is no clear evidence of increased prevalence of diabetes in adults with DD, with some exceptions (eg, Down syndrome).[108,109] Diabetes management guidance has been developed for adults with DD and their care providers.[110,111]	c. Consider screening for diabetes in adults with DD who are obese or who have sedentary lifestyles or hyperlipidemia.	III
Limited available data suggest that hypogonadism is common among men with DD.[106] Substantial data are available on hypogonadism associated with specific syndromes (eg, Prader-Willi syndrome).[112]	d. Consider screening for hypogonadism and testosterone level at least once after full puberty is achieved, ideally at around age 18 y, and refer as appropriate if low levels are found.[105,106]	III

Continued on page 547

Table 3 *contiued from page 546*

CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
20. Infectious disease prevention and screening. Even though immunization is a crucial component of preventive care, adults with DD might have limited awareness of immunizations.[9,33,113]	a. Follow guidelines for routine immunization of adults.[114,115] b. Ensure influenza and *Streptococcus pneumoniae* vaccinations are current and offered when appropriate.[116] c. Discuss the human papillomavirus vaccine with female patients with DD between the ages of 9 and 26 y and, if appropriate, their substitute decision makers.[117]	III III III
It is important to screen for infectious diseases (eg, hepatitis B, HIV, and *H pylori*) in adults with DD. Some adults with DD have an increased risk of exposure to infectious diseases (eg, hepatitis A and B).[118,119]	d. Screen for infectious diseases based on the patient's risk factors for exposure (for *H pylori* see 15c, 15d). e. Offer hepatitis A and B screening and immunization to all at-risk adults with DD,[117–119] including those who take potentially hepatotoxic medications or who have ever lived in institutions or group homes.[115]	III III
21. Cancer screening is an essential aspect of preventive care. However, adults with DD are less likely than those in the general population to be included in preventive screening programs such as cervical screening,[113] breast examination, mammography, and digital rectal examination.[2] They are also less likely to do self-examination or to report abnormalities. Colorectal cancer risk is considerably greater for women than for men with DD.[120]	a. Perform regular cervical screening for all women who have been sexually active.[121] b. Perform annual breast screening, including mammography, for female patients with DD aged 50-69 y.[122] c. Perform an annual testicular examination for all male patients with DD.[123] d. Screen for prostate cancer annually using digital rectal examination from age 45 y for all male patients with DD.[124] e. Screen for colon cancer regularly in all adult patients with DD older than 50 y.[120,125]	I III III II I
BEHAVIOURAL AND MENTAL HEALTH GUIDELINES FOR ADULTS WITH DD		
22. Problem behaviour, such as aggression and self-injury, is not a psychiatric disorder but might be a symptom of a health-related disorder or other circumstance (eg, insufficient supports).[25,126,127]	a. Before considering a psychiatric diagnosis, assess and address sequentially possible causes of problem behaviour, including physical (eg, infections, constipation, pain), environmental (eg, changed residence, reduced supports), and emotional factors (eg, stress, trauma, grief).[127]	II
Problem behaviours sometimes occur because environments do not meet the developmental needs of the adult with DD.[128]	b. Facilitate "enabling environments" to meet these unique developmental needs as they will likely diminish or eliminate these problem behaviours.[128]	III
Despite the absence of an evidence base, psychotropic medications are regularly used to manage problem behaviours among adults with DD.[129,130] Antipsychotic drugs should no longer be regarded as an acceptable routine treatment of problem behaviours in adults with DD.[131]	c. Regularly audit the use of prescribed psychotropic medication, including those used as needed.[132] Plan for a functional analysis (typically performed by a behavioural therapist or psychologist) and interdisciplinary understanding of problem behaviours. Review with care providers psychological, behavioural, and other nonmedication interventions to manage problem behaviours. Consider reducing and stopping, at least on a trial basis, medications not prescribed for a specific psychiatric diagnosis.[133]	III
23. Psychiatric disorders and emotional disturbances are substantially more common among adults with DD, but their manifestations might mistakenly be regarded as typical for people with DD (ie, "diagnostic overshadowing"). Consequently, coexisting mental health disturbances might not be recognized or addressed appropriately.[21,134,135]	a. When screening for psychiatric disorder or emotional disturbance, use tools developed for adults with DD according to their functioning level (eg, Aberrant Behaviour Checklist-Community [ABC-C]; Psychiatric Assessment Schedule for Adults with DD [PAS-ADD]).[136–139]	III
Increased risk of particular developmental, neurologic, or behavioural manifestations and emotional disturbances (ie, "behavioural phenotypes") is associated with some DD syndromes.[140,141]	b. Consult available information on behavioural phenotypes in adults with DD due to specific syndromes.[142,143]	III
Establishing a diagnosis of a psychiatric disorder in adults with DD is often complex and difficult, as these disorders might be masked by atypical symptoms and signs.[21,135] In general, mood, anxiety, and adjustment disorders are underdiagnosed[144] and psychotic disorders are overdiagnosed in adults with DD.[145,146]	c. When psychiatric disorder is suspected, seek interdisciplinary consultation from clinicians knowledgeable and experienced in DD.	III
24. Psychotic disorders are very difficult to diagnose when delusions and hallucinations cannot be expressed verbally.[145] Developmentally appropriate fantasies and imaginary friends might be mistaken for delusional ideation, and self-conversation for hallucination.[145,147,148]	a. Seek interdisciplinary input from specialists in psychiatry, psychology, and speech-language pathology with expertise in DD to help clarify diagnoses in patients with limited or unusual use of language.[144,149,150]	III
25. Input and assistance from adults with DD and their caregivers are vital for a shared understanding of the basis of problem behaviours, emotional disturbances, and psychiatric disorders, and for effectively developing and implementing treatment and interventions.[127,151,152]	a. Establish a shared way of working with patients and caregivers. Seek input, agreement, and assistance in identifying target symptoms and behaviours that can be monitored. b. Use tools (eg, sleep charts, antecedent–behaviour-consequence [ABC] charts) to aid in assessing and monitoring behaviour and intervention outcomes.[153,154]	III III

Continued on page 548

Table 3 *contiued from page 547*

CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
26. Interventions other than medication are usually effective for preventing or alleviating problem behaviours.[133,144,155]	a. To reduce stress and anxiety that can underlie some problem behaviours, emotional disturbances, and psychiatric disorders, consider such interventions as addressing sensory issues (eg, underarousal, overarousal, hypersensitivity), environmental modification, education and skill development, communication aids, psychological and behaviour therapies, and caregiver support.[144]	III
	b. Cognitive behavioural therapy can be effective in decreasing anger and treating anxiety and depression in adults with DD.[156,157]	III
	c. There is increasing evidence of the efficacy of psychotherapy for emotional problems (eg, related to grief, abuse, trauma) that might underlie aggression, anxiety, and other such states.[158-162]	III
27. Psychotropic medications (eg, antidepressants) are effective for robust diagnoses of psychiatric disorders in adults with DD[163] as in the general population.[164]	a. When psychiatric diagnosis is confirmed after comprehensive assessment, consider psychotropic medication along with other appropriate interventions as outlined in guideline 26.[165]	III
Psychotropic medications, however, can be problematic for adults with DD and should therefore be used judiciously. Patients might be taking multiple medications and can thus be at increased risk of adverse medication interactions. Some adults with DD might have atypical responses or side effects at low doses. Some cannot describe harmful or distressing effects of the medications that they are taking.[34,166]	b. "Start low, go slow" in initiating, increasing, or decreasing doses of medications.[167]	III
	c. Arrange to receive regular reports from patients and their caregivers during medication trials in order to monitor safety, side effects, and effectiveness.[133]	III
	d. In addition to reviews every 3 mo (see guideline 5), also review the psychiatric diagnosis and the appropriateness of prescribed medications for this diagnosis whenever there is a behavioural change.[34,133]	III
When unable to pinpoint a specific psychiatric diagnosis, behaviours of concern might serve as index behaviours against which to conduct a trial of medications.[133,167]	e. Having excluded physical, emotional, and environmental contributors to the behaviours of concern, a trial of medication appropriate to the patient's symptoms might be considered.	III
28. Antipsychotic medications are often inappropriately prescribed for adults with behaviour problems and DD.[168] In the absence of a robust diagnosis of psychotic illness, antipsychotic medications should not be regarded as routine treatments of problem behaviours in adults with DD.[131]	a. Do not use antipsychotic medication as a first-line treatment of problem behaviours without a confirmed robust diagnosis of schizophrenia or other psychotic disorder.[131]	III
Antipsychotic medications increase risk of metabolic syndrome and can have other serious side effects (eg, akathisia, cardiac conduction problems, swallowing difficulties, bowel dysfunction).[34,166]	b. Carefully monitor for side effects of antipsychotic medication, including metabolic syndrome. Educate patients and caregivers to incorporate a healthy diet and regular exercise into their lifestyle.[34]	III
	c. Reassess the need for ongoing antipsychotic medications at regular intervals and consider dose reduction or discontinuation when appropriate (also see guidelines 5 and 27).[34]	III
29. Behavioural crises can occasionally arise that might need management in an emergency department.[169-173]	a. When psychotropic medications are used to ensure safety during a behavioural crisis, ideally such use should be temporary (no longer than 72 h).	III
	b. Debrief with care providers in order to minimize the likelihood of recurrence. This should include a review of crisis events and responses (eg, medication, de-escalation measures), and identification of the possible triggers and underlying causes of the behavioural crisis.[133,174]	III
	c. If the patient is at risk of recurrent behavioural crises, involve key stakeholders, including local emergency department staff, to develop a proactive, integrated emergency response plan.[174]	III
30. Alcohol or drug abuse is less common among adults with DD than in the general population, but the former might have more difficulty moderating their intake and experience more barriers to specialized rehabilitation services.[175-177]	a. Screen for alcohol and drug abuse as part of the annual health examination.	III
31. Dementia is important to diagnose early, especially in adults with Down syndrome who are at increased risk.[178] Diagnosis might be missed because changes in emotion, social behaviour, or motivation can be gradual and subtle. A baseline of functioning against which to measure changes is needed.	a. For patients at risk of dementia, assess or refer for psychological testing to establish a baseline of cognitive, adaptive, and communicative functioning. Monitor with appropriate tools.[179]	III
Differentiating dementia from depression and delirium can be especially challenging.[180]	b. Educate family and other care providers about early signs of dementia. When signs are present, investigate for potential reversible causes of dementia.	III
	c. Consider referral to the appropriate specialist (ie, psychiatrist, neurologist) if it is unclear whether symptoms and behaviour are due to emotional disturbance, psychiatric disorder, or dementia.[179]	III

DD—developmental disabilities, GERD—gastroesophageal reflux disease.

Promoting ethical practices. Many disparities and challenges encountered by adults with DD in primary care stem not only from the paucity of information available to care providers but also from attitudes and practices that fall short of respecting the dignity of people with DD. The selection of updates was guided by the ethical framework adopted for the 2006 Guidelines, which emphasized respect for the dignity of adults with DD throughout their lives, the importance of their caregiving relationships and communities, and the need to take into account the health issues particular to them, individually and as a group. Thus, the 2006 Guidelines regarding informed and voluntary consent (guideline 7 in **Table 3**)[1,2,9-180] and advanced care planning (guideline 8) were amplified. The value of consulting, educating, and enlisting the support of caregivers underlies many updated recommendations. In making recommendations for management of particular health conditions of adults with DD, consideration was given to what would most likely benefit the overall health and well-being of these adults while involving the least possible risk of restrictions, harmful side effects, distress, and other burdens. This framework was relevant, for example, when considering decreasing the recommended frequency of tests in the 2006 Guidelines, such as those for glaucoma and thyroid disorder (in guidelines 11b and 19a), when it was unlikely to result in any substantial difference in detection rates. In other cases, references to tools that improve communication, adapt standard test procedures, or minimize the distress from interventions experienced by adults with DD were added to specific recommendations.

New guidelines. A new guideline on detecting pain and distress (guideline 4) was added, as pain and distress can manifest in atypical ways in adults with DD (eg, different physical cues or changes in behaviour).

Furthermore, new guidelines were included for screening and prevention of infectious diseases (guideline 20), cancer (guideline 21), and alcohol or drug abuse (guideline 30), because it has been shown that adults with DD are less likely than those in the general population to be included in preventive screening programs, to do self-examinations, or to report abnormalities or difficulties in these areas.[4]

The behavioural and mental health guidelines contain substantially more detail than in the 2006 Guidelines, with new categories added to address nonpharmaceutical interventions (guideline 26) and psychotropic and antipsychotic medications (guidelines 27 and 28). An important new recommendation (guideline 28a) rejects the routine use of antipsychotic medications for problem behaviour, specifically aggressive challenging behaviour, without a confirmed robust diagnosis of schizophrenia or other psychotic disorder.[131]

Limitations and implications for future research. The aim of these guidelines is to inform primary care providers of the most prevalent health issues of adults with DD as a group and of the best approaches to management. However, any such set of guidelines will always be limited in their application by the reality that adults with DD are not a homogeneous group nor do they experience health disorders in the same way. These guidelines are not meant to replace attentive observation and prudent clinical decisions. The most appropriate care for an adult with DD takes into account relevant factors in his or her particular circumstances. Furthermore, although these guidelines are generally applicable to adults with DD, primary care providers will need to address additional specific health issues when there is a known cause of DD.

The division of these guidelines into distinct physical, behavioural, and mental health categories was intended to facilitate their application. Several guidelines, however, address the interaction of physical factors with behavioural and mental health ones, and between these and environmental factors and other determinants of health. More research is needed into such interactions and their implications for the deployment of an interdisciplinary and holistic approach to primary care of adults with DD. A helpful advance for researchers has been the POMONA Project's identification of 18 measurable health indicators and the development of a survey tool for gathering health data for adults with DD across 14 European countries.[181,182]

Some of these updated guidelines recommend the use of resources and specialized services that, while generally available in Canada, might be lacking or inaccessible in some regional health service systems. In such circumstances, it is necessary to adapt these guidelines to allow primary care providers to provide a reasonable standard of care and to develop practical resource-sharing strategies (eg, using clinical videoconferencing).

Further study of the effect of the guidelines on improving primary care of adults with DD and their health outcomes is essential. The extent to which they are applied must be assessed, and when they are not used the reasons need to be determined. It is likely that a comprehensive approach involving the training of primary care providers in the content and use of these guidelines, developing clinical tools to help apply them, and establishing clinical support networks could work in concert to increase the use of these guidelines. Since 2005, the Ontario Ministry of Community and Social Services, the Ministry of Health and Long-Term Care, and Surrey Place Centre have been co-sponsoring the Developmental Disabilities Primary Care Initiative, which aims to integrate these various components. Evaluation of this initiative is being undertaken and should shed light on whether this comprehensive approach promotes the application of these guidelines by primary care providers of adults with DD, changes their practices, and improves health outcomes.

People with disabling conditions, including those with DD, have been aptly described as being at risk of a double disadvantage. Having a debilitating health condition in many studies renders likely study participants ineligible, and research on DD is generally a low priority for researchers.[183] Most of the recommendations specifically concerning adults with DD in the updated guidelines are supported by level III evidence based on expert opinion or published consensus statements. Three are based on randomized controlled trials, systematic reviews, or meta-analysis (level I evidence), and 7 are based on less methodologically rigorous studies (level II). Even when level I or II evidence for recommendations for the general population was found, but no level I or II evidence relating specifically to people with DD, it was thought prudent, in view of differences between these 2 groups, to reject, adapt, or formulate new guidelines based on expert opinion (level III evidence) for these guidelines.

Ethical and practical difficulties in conducting research on people with DD have been discussed in some recent studies.[184,185] Because of the vulnerabilities of adults with DD, the ethical management of research involving their participation requires careful attention to the likelihood of benefit and of risks of substantial harm; issues surrounding consent, privacy, and confidentiality; and access to the benefits of the research findings.

Conclusion

In order to remain relevant and useful clinically, guidelines for the primary care of adults with DD in Canada should be updated regularly in light of new findings in practice and research. As knowledge and experience are gained from primary care providers caring for adults with DD who are living longer and residing in greater numbers in the community, expert opinion and consensus will continue to be helpful in updating the guidelines. Ethical and high-quality research on primary care of adults with DD, however, remains an urgent priority.

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Contributors

Dr Sullivan was the project lead and was responsible for the development of the initial concept as well as all aspects of the guideline development and revision. **Dr Berg** provided expert clinical and scholarly input throughout the development of the guidelines. **Dr Bradley** led the revision process of the behavioural and mental health section. **Dr Cheetham** provided expert clinical and editorial input during the revision process, including extensive review of published evidence. **Dr Denton** led the revision discussions surrounding the general guidelines, contributed to the guideline revision process, and provided input on final editorial decisions. **Mr Heng** played a lead role in all aspects of the project, including the draft and final revision process. **Dr Hennen** played a lead role in all aspects of the project. **Dr Joyce** led the revision discussions surrounding the physical health guidelines, reviewed the full text of all cited references, and provided substantial editorial input throughout the revision process. **Ms Kelly** provided critical coordination of the project and contributed substantially to all aspects of the revision process. **Ms Korossy** searched and screened the published literature, set up and organized the RefWorks database housing published evidence, and participated in all stages of the revision and editorial process. **Dr Lunsky** was co-lead of the revision process on the behavioural and mental health section from a psychology perspective. **Ms McMillan** contributed expert input throughout the revision process from a nursing perspective. All authors approved the final version for publication.

Competing interests

None declared

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CHCS Center for Health Care Strategies, Inc.

Technical Assistance Brief

Quality Measurement in Integrated Care for Medicare-Medicaid Enrollees

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States, with the support of the Centers for Medicare & Medicaid Services (CMS), are working toward improving the integration of care for individuals dually eligible for both Medicare and Medicaid (known as Medicare-Medicaid enrollees or "dual eligibles"). They face several challenges in demonstrating how these new models improve the care provided, including complex methodological issues around appropriate comparison groups and time periods, the need to access data, and the lack of baseline quality measures pertinent to dual eligibles. In addition, many specific challenges exist around choosing the right set of quality and performance measures: many measures are designed for only one system of care, or one subset of dual eligibles, and few standardized measures are available for some of the most important aspects of care, such as the effectiveness of care coordination. These challenges exist whether the state is using a fee-for-service (FFS) or a capitated managed care model to improve care delivery. The Affordable Care Act's new opportunities to integrate care for Medicare-Medicaid beneficiaries heighten state and federal interest in identifying the best approaches to quality measurement.

This brief from the Center for Health Care Strategies (CHCS), created with support from The SCAN Foundation and The Commonwealth Fund, summarizes existing state and federal activities to develop quality of care measures for Medicare-Medicaid enrollees. It is intended to help guide states in developing measurement approaches for proposed integrated programs, whether in capitated or FFS models. It covers how states can assess quality in specific domains of integrated care such as long-term services and supports (LTSS) and behavioral health services, and gather information from beneficiaries on care and services provided by integrated care systems. Finally, it describes how stakeholder input can be used to help define performance measures.

IN BRIEF

States are working to improve the integration of care for individuals dually eligible for both Medicare and Medicaid, but they face several challenges in demonstrating how these new models improve the quality of care. These challenges exist whether the state is using a fee-for-service or a managed care model to improve care delivery. The Affordable Care Act's new opportunities to integrate care for Medicare-Medicaid beneficiaries heighten state and federal interest in identifying the best approaches to quality measurement.

This brief from the Center for Health Care Strategies, created with support from The SCAN Foundation and The Commonwealth Fund, summarizes efforts to develop quality of care measures for Medicare-Medicaid enrollees. It provides guidance to states in developing measurement approaches for proposed integrated programs, including assessment of quality in specific domains of integrated care such as long-term services and supports and behavioral health services. It also describes how performance measures can be shaped by stakeholder input.

Existing State and Federal Approaches to Measurement in Integrated Care in Capitated Arrangements

Pioneering integrated care programs for Medicare-Medicaid enrollees exist at both the national and state level. These programs offer a useful starting point to examine the types of performance measures available to assess the success of integrated care programs. Existing programs have used "standardized measures" developed or endorsed by national organizations such as the National Committee for Quality Assurance (NCQA) or the National Quality Forum (NQF), with technical specifications allowing like comparisons.[1] Some non-standardized, state-specific measures are in use as well. The following section outlines examples of existing performance measurement approaches in select federal and state programs and includes considerations for developing measures for integrated

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care programs. These programs were chosen based on their track record of public reporting of quality measures in integrated care programs.

Medicare Advantage Special Needs Plans

Most integrated care is delivered through state and federal contracts with Medicare Advantage Special Needs Plans, referred to as "Dual Eligible SNPs" or "D-SNPs," that are allowed to limit enrollment to Medicare-Medicaid enrollees. CMS' requirements for Medicare Advantage and D-SNPs offer a starting point for quality of care measures for this population.[2] Because most SNPs are part of larger Medicare Advantage organizations, many of their measures are reported at the larger organizational level, which makes it impossible to detect performance at the SNP level.[3] However, a subset of Medicare Advantage measures must be reported at the SNP population level, and several specific SNP measures are also required. These measures are standardized, reported publicly, and used to encourage performance improvement. Highlighted SNP measures, including select Healthcare Effectiveness Data and Information Set (HEDIS) measures, are listed in Exhibit 1.

A clear advantage to the ongoing use of these measures is the ability to compare plan performance across states and detect change from year to year. However, these measures cannot stand alone for integrated care monitoring, since they do not measure the provision of LTSS, and, with the exception of the few behavioral health measures, are not oriented to the needs of younger Medicare-Medicaid enrollees.

When states consider adding measurement requirements to plan contracts for integrated programs to address LTSS and behavioral health, they weigh the benefit against the burden of the many requirements under Medicare Advantage for SNP, Medicare Advantage-Part C, and Part D measurement.

Minnesota's HEDIS Reports for Medicare-Medicaid Enrollees

Working within a capitated environment, Minnesota's Senior Health Options (MSHO) program illustrates how D-SNP requirements have been used for quality measurement and reporting. SNPs participating in MSHO, which serves Medicare-Medicaid enrollees age 65 and over, are required to report measures for licensing as well as to maintain their contracts with Medicare and Medicaid.[5] Exhibit 2 depicts the complex set of requirements for Minnesota's SNPs.[6] Several of MSHO's measures are reported publicly. The Minnesota Department of Health publishes annual HEDIS reports for each of the state's health plans for all populations enrolled in managed care.[7] In 2011, the health plans' MSHO enrollment sizes ranged from 5,700 member months to over 120,000 member months. All of the plans reported several HEDIS measures, including this subset of Effectiveness of Care, Access, and Use of Services measures:

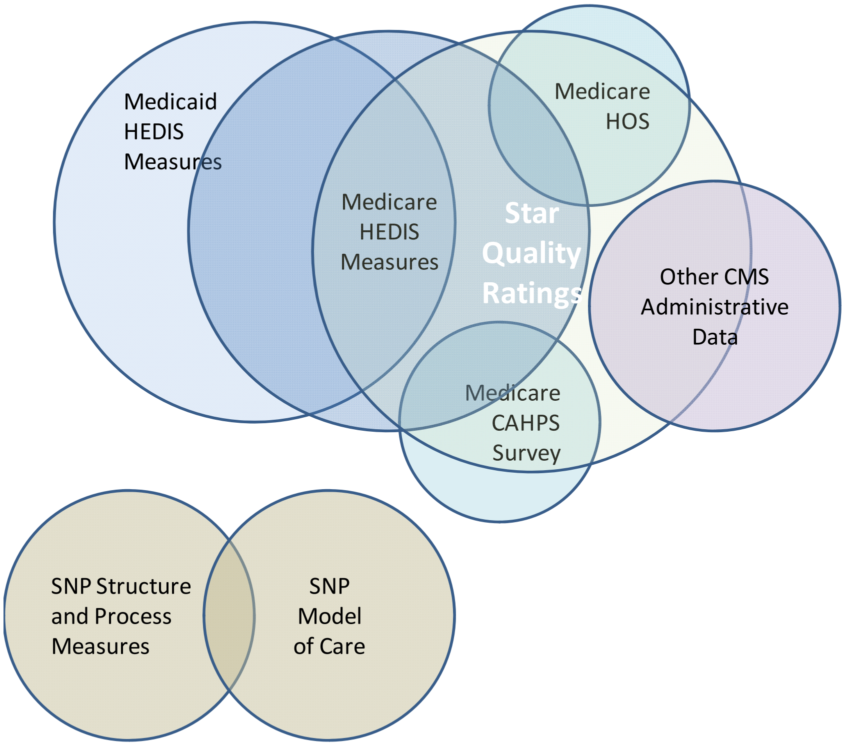
- Use of High-Risk Medications in the Elderly;
- Potentially Harmful Drug-Disease Interactions in the Elderly;
- Annual Monitoring for Patients on Persistent Medications;

Exhibit 1**: Selected Measures Required for Dual Eligible - SNP Reporting**[4]

Source	Domain	Specific Examples
HEDIS	Effectiveness of Care: ▪ Prevention	▪ Colorectal Cancer Screening ▪ Glaucoma Screening in Older Adults
HEDIS	Effectiveness of Care: ▪ Chronic conditions	▪ Controlling High Blood Pressure ▪ Antidepressant Medication Management ▪ Follow-up After Hospitalization for Mental Illness ▪ Medication Reconciliation Post-Discharge
HEDIS	Beneficiary Reported Outcomes of Care	▪ Medicare Health Outcomes Survey
HEDIS	Care for Older Adults	▪ Advance Care Planning ▪ Medication Review
HEDIS	Utilization	▪ Plan All-Cause Readmissions
CAHPS*	Experience of Care Survey	▪ Getting Needed Care ▪ Getting Care Quickly ▪ Health Plan Customer Service ▪ Getting Needed Prescription Drugs
CMS/ NCQA	Structure and Process Measures	▪ Complex Care Management ▪ Coordination of Medicare and Medicaid ▪ Care Transitions

*CAHPS = Consumer Assessment of Healthcare Providers and Systems

***Exhibit 2*: MSHO Performance Measurement Reporting Requirements**



- Comprehensive Diabetes Care;
- Controlling High Blood Pressure;
- Adult's Access to Preventive/Ambulatory Health Services;
- Use of Services measures for Ambulatory Care, Inpatient Utilization, Mental Health, and Identification of Alcohol and Other Drug Services; and
- Care for Older Adults (SNP-only measure).

The Care for Older Adults set is worth special attention (see Exhibit 3).[8] These measures, specifically designed for SNP plans, should be a good fit for the target population of seniors enrolled in MSHO. The measures require data collection on four critical issues for older adults: (1) documented preferences for advance life support (advance care planning); (2) a systematic review of the entire medication list, including non-prescription drugs; (3) an assessment that covers not only acute medical issues, but also cognitive and functional status; and (4) screening or a management plan for pain. High performance rates on these measures should contribute to better health outcomes and quality of life for individuals.

However, Minnesota officials relayed a lack of support for these measures among their key clinician stakeholders. With the exception of medication review, they are concerned that the measures do not capture the ongoing management of chronic conditions and meaningful communications with care coordinators needed for enrollees 85 years and older.

***Exhibit 3*: Care for Older Adults Results for MSHO Plans, 2011**

Minnesota Senior Health Options Plan	Advance Care Planning	Medication Review	Functional Status Assessment	Pain Screening
Blue Plus	45.8%	74.1%	77.8%	36.0%
Medica	66.9%	93.4%	92.9%	80.5%
South Country	68.4%	88.3%	63.0%	75.4%

In addition to the measures reported by health plans, Minnesota's Department of Human Services uses encounter data to calculate and report HEDIS measures for its contracted plans. The combination of these various approaches contributes to a rich environment for performance measurement for integrated care.

Other Uses of Standard Measures for Medicare-Medicaid Enrollees

In the Medicare Advantage and Medicare Prescription Drug Programs, CMS uses HEDIS and CAHPS (Consumer Assessment of Healthcare Providers and Systems) to report plan ratings. The measures are updated annually, and CMS publishes technical notes explaining the changes.[9] The HEDIS and CAHPS results are published annually via the Medicare Plan Finder.[10] The health plans that perform the best on the selected measures receive an indicator called the "high performing icon."

These measures, along with the Health Outcomes Survey (HOS), are also used by CMS to calculate the "Star" ratings that help guide quality bonus payments to health plans. Unlike Minnesota, however, very few states require local reporting on their enrolled Medicare-Medicaid enrollee population. Thus, the ratings typically represent a combination of dual eligibles along with Medicare Advantage enrollees, who tend to be healthier, have higher incomes, and have less need for assistance with activities of daily living compared to those dually eligible for Medicare and Medicaid.[11]

Non-Standardized Measures in Evaluations

States that have previously implemented integrated care models for Medicare-Medicaid enrollees, including Massachusetts, Arizona, and Texas, have conducted a range of ad hoc evaluations to monitor their programs. While the studies were conducted in a managed care context, the approaches of these states can be helpful in thinking how to evaluate care for FFS beneficiaries as well. The examples below offer approaches to measuring specific topics of interest.

- <u>Nursing Facility Use and Avoidance</u>: Massachusetts' Senior Care Options (SCO) program, an integrated program for seniors built on the capitated model, focused on nursing home avoidance and published several reports on its website.[12] An early program evaluation, conducted by JEN Associates noted, "*…descriptive statistics demonstrate that SCO enrollees in comparison to the control population enter nursing facilities at a lower rate. In addition the time to first nursing utilization is greater and the time spent in a nursing facility episode is less than in the control population. For SCO enrollees that do use a nursing facility there is substantially lower frequency of long term residency.*"[13] Using functional Activities of Daily Living data as an outcome indicator, the evaluation identified that those admitted to nursing facilities were a more frail population. A second year evaluation confirmed findings that SCO enrollees were more likely to stay in the community, using nursing facilities more for extended rehabilitation than end-of-life care. A less thorough study might have missed the factors that led to program success.

- <u>Beneficiary Feedback on Program</u>: Massachusetts's SCO gained valuable beneficiary feedback from an interview-based study conducted by UMass' Center for Health Policy and Research.[14] Unlike standard beneficiary surveys, the interviews were conducted in person in Spanish and Portuguese in addition to English. The 92 interviewees, who averaged 79 years of age, may have had difficulties with a telephone or mail survey even if they had received a survey in their own language. The results were generally positive, with the interviewees having a fairly high level of awareness of SCO and most reporting that they received all necessary services, although very few were aware of the 24/7 access to a nurse care manager.

- <u>Risk-Adjusted HEDIS</u>: A recent Avalere study compared four HEDIS measures for individuals enrolled in Mercy Care, an integrated care plan in Arizona, to national Medicare FFS enrollee data.[15] This analysis is unique in applying risk adjustment factors to measures that are not risk-adjusted in the standard HEDIS calculation to account for potential differences in health status between dual eligibles in the Mercy Care plan and other Medicare enrollees. The results are shown in Exhibit 4.

  Avalere's report noted that although Mercy Care's rates of service use were higher than the national average for the Medicare duals population before being risk adjusted, they were actually lower than the national average after risk adjustment. The report stressed the importance of considering differences in case mix when comparing the outcomes of populations. This was particularly

***Exhibit 4*: Avalere Study Mercy Care vs. Medicare FFS**

HEDIS Measure	Medicare FFS (National)	Mercy Care Plan
Adults' Access to Preventive/Ambulatory Health Services	79%	81%
Inpatient Utilization (discharges per 1,000 member months)	33.4%	23.2%
Inpatient Utilization (days per 1,000 member months)	195.2	110.3
Emergency Department Use (visits per 1,000)	48.8	44.5
All-Cause 30-day Readmission Rate (using HEDIS standard risk adjustment)	0.19	0.15

necessary for Mercy Care because a large proportion of their enrollees were at higher risk than the average Medicare-Medicaid enrollee.[16]

- Public Reporting of Performance Measures: Texas' STAR+PLUS program is now reporting a small set of dashboard measures specific to its integrated program. They include the following innovative measures of integration:[17]
  - Percent of STAR+PLUS members with good access to service coordination;
  - Percent increase in STAR+PLUS members who receive personal attendant and/or respite services through the Consumer Directed Services delivery model;
  - Number of STAR+PLUS members entering nursing facilities; and
  - Number of STAR+PLUS 1915 (c) waiver clients returning to community services.

Financial Alignment Demonstrations for Medicare-Medicaid Enrollees

Since CMS created the mechanism through the ACA to implement Financial Alignment Demonstrations of integrated care for Medicare-Medicaid enrollees, half of the states in the country have seized the opportunity to design new integrated programs. Most states chose to develop either a capitated or managed FFS approach, with a few working on both models. CMS' goals include improving quality of care as well as controlling the rate of cost growth for this high-risk population.[18] State-specific goals include getting better information on Medicare-paid medical services (e.g., hospitalization and prescription drugs) that will help states support beneficiaries to live in the community and avoid costly institutional care. All of the demonstrations will offer new approaches to coordinate care, and most of the capitated models will integrate new benefits, such as mental health and LTSS that are used at a higher rate among the dually eligible population. In developing these new models, state program staff and their many stakeholders are interested in developing measurement strategies that help answer the underlying question: ***Did these new models make a difference to the care and services delivered to beneficiaries and beneficiaries' quality of life?***

The performance measures necessary to answer this fundamental concern need to go beyond the traditional preventive and acute medical care quality measures to address the unique needs of the Medicare-Medicaid enrollee population. In addition to assessing overall costs of care, states and CMS staff are seeking to measure the impact of the demonstrations on four domains:

1. Beneficiaries' quality of life and experiences of care;
2. Changes in LTSS use;
3. Changes in behavioral health service use; and
4. Overall coordination of care.

All states participating in the demonstrations will collect data on a combination of "core" and state-defined quality measures. Appendix 1 lists the core quality measures and Appendix 2 lists the state-specific measures contained in the first three Memorandums of Understanding (MOUs) signed between CMS and Massachusetts, Ohio, and Washington State. The next section outlines considerations for measuring demonstration outcomes within each of the four measurement domains listed above to help guide states and other stakeholders interested in assessing the success of integrated care approaches.

1. *Measuring Quality of Life*

Measuring quality of life is especially important and increasingly challenging as beneficiaries become more frail and dependent on services provided by others. Achieving the greatest possible independence, controlling ones' living environment, living pain-free, and engaging with the community as desired are all factors that should be considered in assessing quality of life for this population. Although several tools exist for measuring the quality of life for people with disabilities and those who need LTSS, none are used by states for their existing integrated programs or are required by CMS for SNPs.

Following are potential approaches to assessing quality of life that could be applied to Medicare-Medicaid enrollees. While none cover the many languages spoken by this population, the interview approaches could potentially pair an interviewer with a translator for those whose primary language is other than English.

Behavioral Risk Factor Surveillance System Survey The AARP Scorecard[19] uses two questions from the Behavioral Risk Factor Surveillance System survey to assess quality of life for those living in the community who indicate they have a disability:

- *How often do you get the social and emotional support you need?*
- *In general, how satisfied are you with your life?*[20]

Home- and Community-Based Service (HCBS) Experience Survey This CAHPS-like survey has been supported by CMS: it has gone through cognitive testing, but not field-testing for general use. It includes a set of questions on Community Inclusion and Empowerment.[21] The development of this survey resulted in alternative wording for people who have difficulty using response options about the frequency of a particular event ("always/sometimes/never"), which was found to be an issue for a significant portion of the population. The survey also includes new questions on the quality of HCBS that previously were not collected in a standardized way across states. Sample questions include:

- *When you want to, how often can you get together with these family members who live nearby?*
- *When you want to, how often can you do things in the community that you like, such as shopping or going out to eat?*
- *Do you need more help than you get now from [personal assistance/behavioral health staff] to do things in your community?*
- *Do you take part in deciding what you do each day – for example, what you do for fun at home or in your community?*
- *Do you take part in deciding when you do things each day – for example, deciding when you get up, eat, or go to bed?*

Medicare Health Outcomes Survey This survey includes a set of questions taken from the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System survey that measure "Healthy Days."[22] One question in the Healthy Days Symptoms Module is:

- *During the past 30 days, for about how many days did PAIN make it hard for you to do your usual activities, such as self-care, work, or recreation?*

Other surveys include questions about comfort as a key indicator of quality of life. The Quality of Life Scale for Nursing Homes developed by Rosalie Kane, for example, includes a comfort scale. Questions are specific to the perception of cold, noise, pain, and whether residents get a good night's sleep.[23]

National Core Indicators (NCI) This set of measures was developed for people with intellectual and developmental disabilities through a collaboration of the National Association of State Directors of Developmental Disability Services and the Human Services Research Institute.[24] The NCI include topics linked to quality of life, such as choice and control of caregivers. Examples of questions posed to family members about the individual receiving services include:

- *Does your family member participate in community activities?*
- *Do you feel that services and supports have made a positive difference in the life of your family?*
- *Overall, do you feel that your family member is happy?*

Personal Experience Outcomes iNtegrated Interview and Evaluation System (PEONIES) Wisconsin developed its PEONIES survey to assess quality of life for people using LTSS.[25] This resource-intensive survey tool uses a semi-structured interview to assess quality of life through the following outcomes:

- *I decide where and with whom I live.*
- *I make decisions regarding my supports and services.*
- *I work or do other activities that are important to me.*

- *I have relationships with family and friends I care about.*
- *I decide how I spend my day.*
- *I am involved in my community.*
- *My life is stable.*
- *I am respected and treated fairly.*
- *I have privacy.*
- *I have the best possible health.*
- *I feel safe.*
- *I am free from abuse and neglect.*

The importance of gathering quality of life information directly from beneficiaries and their chosen representatives cannot be overstated. As the NQF Measures Application Partnership report points out, "*The measurement strategy should promote a broad view of health and wellness, encouraging the development of a person-centered plan of care that establishes goals and preferences for each individual. Ideally, that care plan and its goals would form the basis for measurement.*"[26] Documenting progress towards those preferences is best done by gathering information from the beneficiary.

2. *Measuring Long-Term Services and Supports*

As mentioned above, states have not collected and reported information on HCBS quality in standardized ways, which poses a challenge for adding such measures to the evaluation of the Financial Alignment Demonstrations. Institutional measures of long-term care, such as those reported for nursing facilities in the CMS Nursing Home Compare website,[27] only apply to individuals living in institutional settings. Others are limited to certain providers, such as measures used in the Home Health Compare website.[28] Absent standard measures, the demonstrations may look to the states' unique measures. Examples of state-developed measures described in a recent report by Truven Health Analytics on managed LTSS include: (1) timeliness of initiating community-based LTSS; (2) timeliness of completing level of care assessments; (3) nursing facility or other institutional admissions; (4) maintenance of community transition; (5) receipt of services authorized in the care plan; and (6) member-centeredness of care plan.[29] A recent report from Mathematica Policy Research and the AARP Public Policy Institute offers a summary of state-established performance measures for managed LTSS programs. LTSS measures cited include: (1) changes in functional status; (2) percent of beneficiaries who receive a timely assessment and care plan; and (3) number of beneficiaries who have received home safety evaluations.[30]

States' HCBS programs operated under CMS waiver authority include "assurances" that provide a common platform for states to develop LTSS measures. The assurances require states to collect and report on the structural aspects of the program, such as timeliness of service, provider qualifications, and financial accountability, but also include monitoring of the health and welfare of beneficiaries. Many of these are appropriate to track for individuals dually eligible for Medicare-Medicaid who use LTSS.

Massachusetts' CMS-approved MOU for its Financial Alignment Demonstration offers an example of how a state can incorporate LTSS considerations into an integrated care performance measurement approach. The state included the following LTSS measures in the core set of measures required for its capitated plans:[31]

- Percent of High Risk Residents with Pressure Ulcers (Long Stay);
- Risk Stratification Based on LTSS or Other Factors; and
- Self-Direction (measures training for care coordinators on self-direction).

Care transitions, included in Massachusetts' core set of measures, represent a critical opportunity to identify and avoid gaps in care that often occur during shifts from one setting of care to another. The NQF's Measure Application Partnership (MAP) Dual Eligibles Workgroup recommended the Three-Item Care Transition Measure (CTM3), which was endorsed by NQF.[32] This measure of preparation for hospital discharge is a helpful tool for assessing coordination of care. The Structure and Process measures also include care transitions measures (see discussion of Measuring Coordination of Care below).

Additionally, as part of the demonstration, states are required to track a utilization measure of institutional versus community-based care for beneficiaries who qualify for institutional level of care. Finding the right approach to that measure may prove challenging, as again, state approaches to measuring "rebalancing" are not standardized. The AARP Scorecard[33] uses a spending measure to assess the provision of community-based care: *Percent of Medicaid and state-funded LTSS spending going to HCBS for older people and adults with physical disabilities*. The scorecard, however, notes the limitations in using a single measure and suggests three supplemental "choice of setting" indicators:

- The proportion of Medicaid LTSS spending that pays for HCBS;
- The proportion of new Medicaid LTSS beneficiaries who receive HCBS; and
- The percentage of HCBS users in publicly funded programs who direct their own services.[34]

These LTSS-sensitive measures are equally important in the evaluation of both capitated and managed FFS models. As more Financial Alignment Demonstration MOUs are posted publicly, a consensus on a state and federal measurement approach to LTSS integration may emerge as later-signing states adopt and refine the measures proposed by early-signers. States may also look to the state-specific measures included in approved state MOUs to inform their own state-specific LTSS measures.[35]

3. *Measuring Behavioral Health*

Medicare-Medicaid enrollees have a disproportionate need for both mental health and substance use treatment compared to Medicare-only enrollees.[36] Many health plans and providers that have traditionally served Medicare and commercial enrollees do not have experience with screening, assessment, and referral for these behavioral health services. As a result, many Medicare-Medicaid enrollees go without needed services. Thus, measures that reflect appropriate screening and referral are important, as well as measures of improved overall quality of mental health and chemical dependency services.

Whether states use a capitated or managed FFS approach in their demonstrations, measures of behavioral health can be applied. For example, the NQF MAP Dual Eligibles Workgroup considered appropriate measures for Medicare-Medicaid enrollees with behavioral health needs, and recommended two measures as ready for implementation:[37]

- Screening for Clinical Depression and Follow-Up Plan; and
- Initiation and Engagement of Alcohol and Other Drug Dependence Treatment.

In developing its MOU, Massachusetts chose to include these NQF MAP recommendations, as well as these three additional measures pertinent to behavioral health that states might also consider:[39]

- Follow-up After Hospitalization for Mental Illness;
- Antidepressant Medication Management; and
- Unhealthy Alcohol Use: Screening and Brief Counseling.

California's Financial Alignment Demonstration, which will not include behavioral health in the service package, has nonetheless sought input from stakeholders on the best measurement approach for shared accountability for behavioral health service delivery. Among the measures proposed by California for stakeholder input are these placeholders signaling the state's openness to new approaches to behavioral health:[40]

- Behavioral Health Shared Accountability Process Measure (Year 1);
- Behavioral Health Shared Accountability Enhanced Process Measure for Evidence of Data Sharing and Joint Care Planning (Year 2); and
- Reduction in Emergency Department Use for Seriously Mentally Ill and Substance Use Disorder Enrollees (Year 3).

As officials in states using managed FFS and capitated models begin to develop performance measures for carved-out approaches to behavioral health, it may be helpful to review the evaluation of the Serious Mental Illness (SMI) Innovations Project in Pennsylvania.[41] The evaluators found improvements in utilization, and also measured whether the projects met pilot goals,

***Exhibit 5*: Physical and Behavioral Health Measures for Pennsylvania's SMI Innovations Project**

Outcomes Measures	Performance Measures
▪ Emergency visits (rate per 1,000 members per month) ▪ Mental health re-hospitalizations (rate per 1,000 members per month) ▪ Readmissions within 30 days	▪ Stratification of at least 90 percent of members into risk groups and annual re-stratification ▪ Patient-centered care plans ▪ Notification of at least 85 or 90 percent of admissions within one business day of responsible entity learning of admission ▪ Prescriber notification of at least 85 or 90 percent of medication refill gaps for atypical antipsychotics leading to a medication possession ratio of < 0.8[38]

reported as certain performance metrics (Exhibit 5).

4. *Measuring Coordination of Care in Capitated Arrangements*

CMS requires that SNPs undergo an evaluation of their care management systems via an NCQA review of required Structure and Process measures. The three categories of Structure and Process measures most pertinent to evaluating whether health plans deliver integrated care to Medicare-Medicaid enrollees are shown in Exhibit 6.

NCQA has begun sharing its plans to test new Structure and Process measures for the Medicare-Medicaid enrollee population. This will help to address the gap in the appropriate measurement of care coordination that has been a source of frustration for both state and federal officials.

In addition to the collection and reporting of the above types of measures, health plans participating in capitated model Financial Alignment Demonstrations will be required to submit their Model of Care documents to CMS. These Model of Care documents will be evaluated by NCQA, and may be reviewed by state staff involved in the demonstration. These models of care are generally hundreds of pages long, including detailed descriptions of assessment and care planning processes for enrollees, as well as provider and staff training and the health plans' monitoring of the models' success in improving the delivery of services.

Of note, the Government Accountability Office (GAO) released a report in September 2012 that examined the models of care submitted by several D-SNPs in 2012.[43] The GAO noted that CMS does not require D-SNPs to use or report on standardized measures in the models of care, which would make it possible for CMS to compare D-SNPs' effectiveness and evaluate how well they have done in meeting

***Exhibit 6:* Structure and Process Measures Relevant to Integrated Care**[42]

Measure Name	Measure Content
SNP 1: Complex Case Management	The organization coordinates services for members with complex conditions and helps them access needed resources. Elements include: ▪ Identifying Members for Case Management ▪ Access to Case Management ▪ Case Management Systems ▪ Frequency of Member Identification ▪ Providing Members with Information ▪ Case Management Assessment Process ▪ Individualized Care Plan ▪ Informing and Educating Practitioners ▪ Satisfaction with Case Management ▪ Analyzing Effectiveness/Identifying Opportunities ▪ Implementing Interventions and Follow-up Evaluation
SNP 4: Care Transitions	The organization manages the process of care transitions, identifies problems that could cause transitions and, where possible, prevents unplanned transitions. Elements include: ▪ Managing Transitions ▪ Supporting Members through Transitions ▪ Analyzing Performance ▪ Identifying Unplanned Transitions ▪ Analyzing Transitions ▪ Reducing Transitions
SNP 6: Coordination of Medicare and Medicaid Benefits	The organization coordinates Medicare and Medicaid benefits and services for members. Elements include: ▪ Coordination of Benefits for Dual Eligible Members ▪ Administrative Coordination of D-SNPs ▪ Administrative Coordination for Chronic Condition and Institutional Benefit Packages (May not be applicable for demos) ▪ Service Coordination ▪ Network Adequacy Assessment

their goals across plans. The report recommended that CMS systematically evaluate D-SNP performance to hold plans accountable and compare performance across plans and to inform the implementation and reporting requirements of the Financial Alignment Demonstrations. In addition, the GAO also stated that moving to a standard set of performance and outcome measures should pose minimal administrative burden to the plans and might, in some cases, be less burdensome and no more costly than what some D-SNPs currently collect.

Health plans will undergo readiness review prior to entering into three-way contracts with CMS and the states. Areas to be evaluated include the plans' processes and procedures for beneficiary assessment, care coordination, enrollment, and enrollee and provider communications among others.[44] The readiness review will include system testing, provider network review, and desk and on-site review of their capacity to serve the beneficiaries enrolled.

Data-gathering efforts across these critical domains will contribute to the overall evaluation of the demonstrations. CMS has contracted for a national evaluation that will synthesize information across states (see Exhibit 7 for more information about demonstration evaluation activities). The national evaluation team, led by Research Triangle Institute, will also be responsible for measuring changes in utilization and cost-savings, in addition to quality of care and services.

Stakeholder Input on Quality Measures in the Demonstrations

States and CMS have aggressively sought stakeholder feedback to help shape the Financial Alignment Demonstrations, but most of the input states have received has been on program design, beneficiary protections, and benefits, rather than on quality measures. Now that three states have published their MOUs with a core set of quality measures, stakeholders in other states can evaluate these three states' measurement approaches and consider whether the measures cover all the important aspects of performance under the demonstrations.

California has directly requested stakeholder input on its proposed quality measures. The state held a series of public meetings on quality and evaluation that culminated in a proposed measure set published for comment on its website.[45] Exhibit 8 includes examples of feedback from California stakeholders including both general and specific comments, many of which could be helpful for FFS programs as well.[46]

The comments in Exhibit 8 reflect stakeholders' concerns and hopes for the demonstration. California also held an LTSS Summit in which stakeholders were given the opportunity to brainstorm quality measurement priorities.[47] In Washington, focus groups were held with stakeholders that also proved useful for state officials' thinking about which approaches resonated with people not enmeshed in policy work. Other states may look to these states' examples and encourage their own stakeholders to comment on performance measures for their new programs.

***Exhibit 7*: Evaluation of the Financial Alignment Demonstrations**

Independent Evaluation by Research Triangle Institute

Separate from the performance measurement activities undertaken by states, the Financial Alignment Demonstrations will include an evaluation led by Research Triangle Institute (RTI). Both state-specific analyses and a meta-analysis across states are planned. Evaluation topics will include:

- Beneficiary health status and outcomes;
- Quality of care provided across care settings;
- Beneficiary access to and utilization of care across care settings, satisfaction and experience;
- Administrative and systems changes and efficiencies; and
- Overall costs or savings for Medicare and Medicaid.

The RTI evaluation team will have access to plan-reported measures and will use encounter data to calculate additional measures. The evaluation will use both qualitative and quantitative approaches such as:

- Conducting site visits; qualitative analysis of program data; focus group and key informant interviews;
- Tracking changes in utilization, cost, and quality measures;
- Evaluating the impact of the demonstration on cost, quality, and utilization measures; and
- Calculating savings attributable to the demonstration.

Exhibit 8: **Stakeholder Feedback on California's Proposed Quality Measures**

Examples of Stakeholders' General Comments

- Suggestions for Year 1:
  - Use more process-oriented measures;
  - Measure whether beneficiaries have lost any services they had received before, and if so, why and for how long; and
  - Measure establishment of care plans and hospitalization notification.
- Suggestions for Years 2 and 3:
  - Transition to outcome measures;
  - Apply customer satisfaction tools;
  - Measure timeliness of referrals and appointments;
  - Reflect social model values and priorities (e.g., consumer control, social participation, caregiver support) in measures; and
  - Measure changes in emergency department and inpatient utilization.
- Suggestions for consumer survey questions:
  - Do consumers understand their rights and benefits?
  - Do consumers know who to contact if they have questions/concerns/need to appeal a care decision?
  - Are consumers involved as much as they would like in treatment/service plan decisions?

Examples of Stakeholders' Comments about LTSS Measures

- Consider the Agency for Healthcare Research and Quality's HCBS measures, especially see those related to consumer choice about provider and services.[48]
- Use process measures for beneficiaries determined at risk for LTSS: (1) proportion who received comprehensive assessment (including cognitive); (2) reassessment; and (3) care plan in place.
- For the frail seniors in community settings (those with mobility limitation, incontinence, dementia, etc.), measure the incidence of skin ulcers, falls, abuse, significant weight loss, dehydration, and medication errors.
- Examples of specific suggestions for LTSS measures:
  - Degree to which consumers experience an increased level of functioning;
  - Unmet need in ADLs/IADLs;
  - Participants reporting unmet need for community involvement;
  - Degree to which health status is maintained and improved;
  - Degree to which consumers report that staff are sensitive to their cultural, ethnic, or linguistic backgrounds;
  - Degree to which consumers felt they were respected by staff;
  - Percent of caregivers usually or always getting needed support; and
  - Proportion of people with disabilities receiving preventive health care visits.
- Examples of specific suggestions for nursing facility measures:
  - Care Transition Record Transmitted to Health Care Professional;
  - Percent of High Risk Residents with Pressure Ulcers (Long Stay);
  - Pneumococcal vaccination for long-stay residents;
  - Percent of long-stay residents whose need for help with daily activities has increased;
  - Percent of residents (short-stay and long-stay) who have moderate to severe pain;
  - Percent of long-stay residents who were physically restrained; and
  - Percent of long-stay residents who are more depressed or anxious.

Examples of Stakeholders' Comments about Measures of Mental Health and Substance Use Treatment

- Implement positive measures of mental health recovery:
  - Dimensions: Health, Home, Purpose (meaningful activity) and Community (relationships and social networks). Example: Mental Health America's Milestones of Recovery Scale.
- Tailor traditional D-SNP measures to the subset of the population with serious and persistent mental illness, e.g.:
  - Medication adherence for beneficiaries with depression tailored for individuals with bipolar disorder;
  - Weight gain and obesity applied to individuals taking atypical medications for psychotic disorders.
- Use recovery based outcomes:
  - Increased independence in housing;
  - Increased income/employment and avoiding institutions (jails, nursing homes and hospitals);
  - Engagement in meaningful activity;
  - Adequate social support.
- Measure utilization of services:
  - Psychiatric hospitalizations (reflects unmet needs);
  - Outpatient mental health care (including those who are only receiving psychotropic medications but do not require continued therapy).
- Year 1 measures:
  - Percentage of behavioral health/substance use members with integrated (medical/behavioral) care plan;
  - Percentage of behavioral health/substance use members under Care Management;
  - Percentage of behavioral health/substance use members completing a health risk assessment.
- Years 2 and 3 measures:
  - Psychiatric bed days;
  - Emergency department utilization rates;
  - Readmission rates;
  - Medication adherence.

Promising Work Underway

Several promising efforts are underway nationally that support the work of state and federal officials in developing performance measures for programs integrating care for Medicare-Medicaid enrollees. In addition to the NQF MAP Dual Eligibles Workgroup, the AARP Scorecard is revisiting the measure set for its next edition. Both efforts rely on the contribution of scores of volunteers, who provide their expertise to consider best practices and available measures. NCQA is also beginning to explore specific measurement approaches for dual eligibles enrolled in managed care, which may result in an improved set of Structure and Process measures.

Another project that may contribute to the development of performance measures for Medicare-Medicaid enrollees includes "Promoting Integrated Care for Dual Eligibles" supported by The Commonwealth Fund.[49] In this project, a small number of high-performing health plans that serve individuals who are dually eligible will be engaged in a consortium, with the goal of identifying best practices and thinking about how to better expand such models.

Finally, CMS recently published a solicitation for researchers to test new measures in three areas: (1) continuity of information and care from hospital discharge to the outpatient setting; (2) continuity between mental health provider and primary care provider (PCP); and (3) items that may be added to the CAHPS survey addressing language-centered care, cultural competence, physical activity, healthy eating, and caregiver strain.[50] Enhanced focus on these areas of measurement offers great promise for improving integrated care programs not only in capitated models but in all delivery systems, including emerging FFS models.

Conclusion

The good and bad news about the heightened attention to Medicare-Medicaid enrollees in the Affordable Care Act is that many eyes are now on state and federal officials as they design new programs and develop methods to evaluate those programs. It can be a bit uncomfortable to have so much attention when a program is still in the design phase because there are many unanswered questions about the collection and sharing of data needed to measure success. The promising news is that funding is being dedicated to evaluation both within states and at the national level, as well as helping states to think about how to improve care and services for the beneficiaries they care about.

For example, in the GAO report mentioned above, the authors observed that CMS has neither formally evaluated the sufficiency and appropriateness of the care that D-SNPs provide nor assessed their effectiveness in integrating benefits and coordinating care for dual-eligible beneficiaries. GAO provided several recommendations to CMS, including that CMS require D-SNPs to explicitly describe in their Models of Care how they will evaluate services and increase accountability, and collect and report standard performance and outcome measures to CMS that are relevant to the enrolled population.[51] In addition, GAO suggested that this performance information should be made available to the public and that CMS should evaluate D-SNPs' ability to provide sufficient, appropriate care to Medicare-Medicaid plan enrollees.

These recommendations for the use of standard measures, which would support state-to-state comparison regardless of demonstration design, are already being incorporated in the MOUs between states and CMS and in the planned evaluation. CMS has made it clear to states that stakeholder involvement does not end with input into the design, and that transparency and sharing of information will be required throughout the demonstration. California and its prospective contractors took the unusual step of making the heath plan Models of Care available publicly, along with health plan responses to questions about the use of quality measures for improving care and services. This is a good starting place for engaging stakeholders in the critical dialogue about performance measurement for integrated care.

About the Center for Health Care Strategies

The Center for Health Care Strategies (CHCS) is a nonprofit health policy resource center dedicated to improving health care access and quality for low-income Americans. CHCS works with state and federal agencies, health plans, providers, and consumer groups to develop innovative programs that better serve people with complex and high-cost health care needs. For more information, visit www.chcs.org.

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Endnotes

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Integrated Care for People with Medicare and Medicaid:

A Roadmap for Quality

White Paper

National Committee for Quality Assurance

March 2013

NCQA
Measuring quality.
Improving health care.

Integrated Care for People with Medicare and Medicaid

White Paper

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Executive Summary

The lack of coordination between Medicare and Medicaid for people who have coverage in both programs is well documented. This group incurs high levels of spending in both programs. Because of the complexities of different coverage and program administration requirements, states have found it challenging to work with plans and providers to create programs that provide the full range of services that people with Medicare and Medicaid need. And although a few states have moved forward, to date, program enrollment has been small.

As a result of fiscal pressure faced by most state Medicaid programs and new opportunities generated by the *Patient Protection and Affordable Care Act* (ACA), many states are actively pursuing initiatives to provide integrated care for the Medicare-Medicaid population, often through managed care arrangements. Managed care (including plans covering both general health care and long-term services and supports [LTSS]) and coordinated fee-for-service delivery systems are candidates for arranging and furnishing integrated care. However, there are few methods for assessing the quality of care through these arrangements.

Good integrated care holds the promise of eliminating the fragmented, medically-oriented care that often wastes state and federal dollars and leaves beneficiaries with substantial needs and their families feeling confused and overwhelmed without needed support for daily functioning. To achieve this promise, however, entities responsible for integrated care must be accountable across the full range of services (from medical and behavioral care to LTSS); must be flexible enough to design care that addresses the needs and preferences of individuals and their families; and must have a quality measurement, improvement and monitoring program.

This paper describes a strategy for evaluating the quality and person-centeredness of integrated care, using a roadmap of structure and process assessments of functions and capabilities needed by the entities responsible for integration of care and services and combining this with outcomes and other types of performance measures. In the paper, we use the word "framework" to describe the key concepts underlying the structure and process measures; it can be expanded to include the content of performance measures as companions to the structure and process measures. By "roadmap," we mean that the structure and process measures provide a roadmap around which entities can organize their model of care.

Over time, we envision adding more person-centered performance measures that provide robust information about the process and eventually the outcomes of the people served — that include their experience of care, functional status, quality of life and health outcomes — and that speak to the varied populations that have Medicare and Medicaid coverage.

With federal and state efforts moving rapidly to implementation, many stakeholders are concerned about the risks stemming from lack of experience among new entities taking on integrated care, and a paucity of evaluation approaches in this area. Our quality strategy, developed with consumer and other stakeholder input, offers a way to demonstrate and monitor efforts to improve care for this vulnerable population.

Introduction

More than 9 million Americans are enrolled in both the Medicare and Medicaid programs. Often, the care provided to these beneficiaries is fragmented and there is misalignment of administrative, regulatory, statutory and financing systems. Health care costs for people with Medicare and Medicaid are twice as high as for people with Medicare alone.[1] In the Medicaid system, these costs also are greater than for the average Medicaid beneficiary, primarily because of spending for long-term services and supports.[2] Better care for people who have Medicare and Medicaid has the potential to improve outcomes and to lower health-care spending.

The overarching goals of the National Committee for Quality Assurance (NCQA) are to:

- Improve the quality of care, the experience of care for beneficiaries and families, and their ability to realize their own goals, and
- Improve the value of care by eliminating unnecessary utilization and costs.

To achieve these goals, we have developed an approach for evaluating care provided in integrated models to people with Medicare and Medicaid. Our intention is to go beyond the existing capabilities of the types of entities likely to participate in state integration programs. We want to set expectations for capabilities that entities may not yet have but can aspire to achieve. Entities will need to do well in arranging for and coordinating across the full range of care that beneficiaries need, including medical, behavioral and long-term services and supports.

In this paper, we briefly discuss the Medicare-Medicaid eligible population and prior integration efforts; introduce a model for integrated entities and a framework for assessing and promoting quality of integrated care; and discuss the challenges to implementing and achieving the goals of person-centered, integrated care for this population. We use the word "framework" to describe the key concepts underlying the structure and process measures; it can be expanded to include the content of performance measures as companions to the structure and process measures. By "roadmap," we mean that the structure and process measures provide a roadmap around which entities can organize their model of care.

Problem: Vulnerable Population, Fragmented Care

Higher rates of poverty and disability contribute to higher costs of the population with Medicare and Medicaid

In general, people with Medicare and Medicaid differ from the general Medicare population in that they are poorer and more likely to have disabilities and be in ill health. They differ from the general Medicaid population in that they are older and sicker. Within the Medicare-Medicaid population, there are diverse subpopulations; for example, the frail elderly; younger people who have physical or mental health disabilities; and relatively healthy people who are poor enough to qualify for Medicaid and old enough to qualify for Medicare.

Of the 9.1 million adults with Medicare and Medicaid benefits, about 60 percent are 65 or older. More than 90 percent of these beneficiaries fall below 200 percent of the poverty line.[1] The eligibility criteria and level of Medicaid benefits vary by state. Medicaid also provides varying degrees of coverage: beneficiaries who qualify because of very low income or high medical spending (often for long-term services and supports [LTSS]), as well as being over age 65 or having disabilities, can obtain full coverage of all Medicaid services not covered by Medicare, often including Medicare premiums and cost sharing. Beneficiaries with higher incomes are entitled to Medicare coverage of premiums (and sometimes cost-sharing) only.*

People with Medicare and Medicaid are typically sicker and have higher medical spending and use of medical services than other Medicare or Medicaid beneficiaries. (Refer to Table A in the Appendix.) The high disease burden among these beneficiaries partially explains the higher spending; in many cases, higher spending is the result of using LTSS, including nursing home and other institutional care that qualified them for Medicaid coverage. People with Medicare and Medicaid account for a disproportionate share of both Medicare and Medicaid spending relative to their population size (Figure 1).

Still, there is wide variation in spending in the Medicare-Medicaid population, with a small portion of people accounting for 40 percent of program expenditures (Figure 2). Approximately 60 percent of Medicaid spending is for care (mostly institutional care) of the top 10 percent of people, and LTSS accounts for 69 percent of Medicaid spending on people with Medicare and Medicaid. Combined Medicare and Medicaid spending for this population varies across settings and conditions.[2] (Refer to Table B in the Appendix.)

Program benefits and design lead to fragmented care

One challenge of providing high-quality, coordinated care for people with Medicare and Medicaid is that each program offers different benefits, which can lead to a lack of coordination — and even to incentives that work, perversely, against good, person-centered care. Medicare covers most acute, preventive and post-acute services (e.g., home health and rehabilitation services) and tends to pay more than Medicaid. For beneficiaries with full Medicaid and Medicare benefits (and depending on the optional benefits offered

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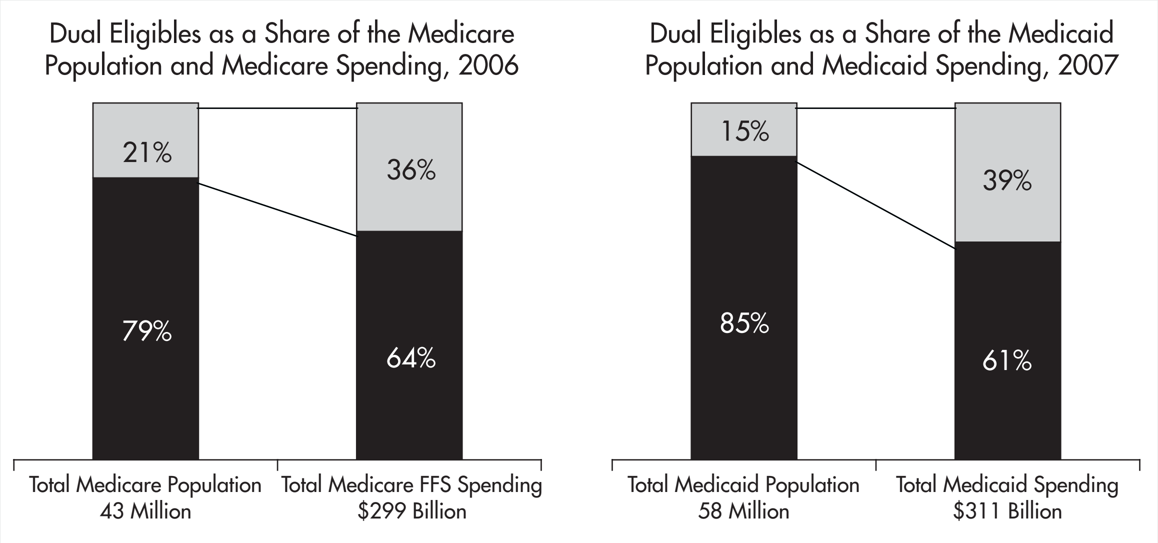
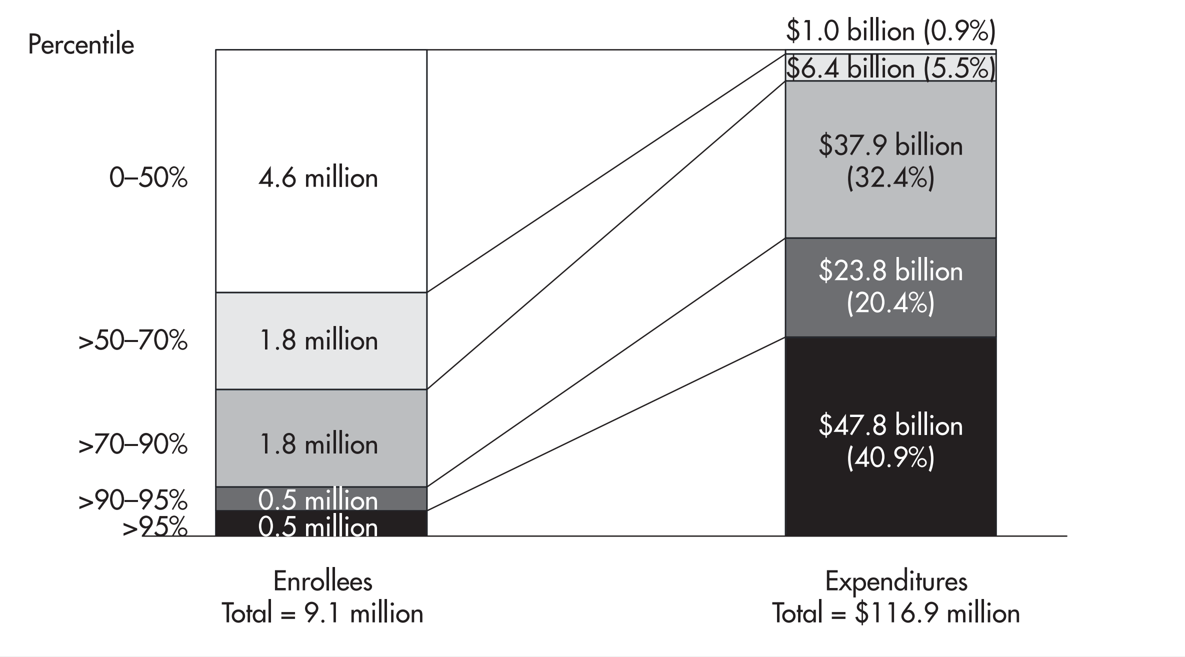
*In cases where beneficiaries qualify for Medicaid coverage of Medicare cost sharing, beneficiaries do not need to pay cost sharing amounts. However, states may not have to pay providers for these amounts if the Medicaid payment amount for the service is sufficiently lower than the Medicare rate.

FIGURE 1. Medicare-Medicaid Beneficiaries Account for Disproportionate Shares of Medicare and Medicaid Spending



Source: Kaiser Family Foundation

FIGURE 2. Concentration of Medicaid Spending for People With Medicare and Medicaid



Source: Kaiser Commission on Medicaid and the Uninsured and Urban Institute estimates based on data from FY 2008 MSIS and CMS-64 reports, 2012.

Note: Does not include Medicare premiums. Totals and percentages may not match other tables and figures that include premium data.

by the state), Medicaid covers vision, dental and hearing care; behavioral health care not already covered by Medicare; LTSS (i.e., nursing home, home and community-based care); Medicare premiums; and, often, Medicare cost sharing.

For some beneficiaries, there is overlap in the post-acute care services that Medicare covers and the LTSS that Medicaid covers (although these are theoretically discrete). Sometimes, Medicaid covers items or services that Medicare does not (e.g., drugs not covered in a Medicare Part D formulary).[3]

Ideally, entities responsible for integrated care for the Medicare-Medicaid population would have systems in place to ensure that beneficiaries are treated in the setting that best fits their needs and preferences, and that the care team has the flexibility to develop care plans and services that consider the full array of beneficiary needs. However, the few entities attempting to do so in the current environment struggle to streamline care because there are different benefits and payers and separate payments for services.

Perverse incentives come into play when care is more profitable in a particular setting or payment system; for example, transferring a person with Medicare and Medicaid from a nursing home (paid for by Medicaid) to hospital care (paid for by Medicare). In this example, the nursing home avoids the cost of providing care and may benefit from state "bed-hold" policies, in which the state continues to pay the nursing home for a short time while a beneficiary is in the hospital.

Discharging the member from the hospital back to the nursing home may qualify the facility to receive a higher payment under Medicare through the

BOX 1. Profiles of People With Medicare and Medicaid

Mr. C. is a 78-year-old man with multiple chronic illnesses (congestive heart failure, peripheral vascular disease, atrial fibrillation, schizophrenia). He lives alone and has limited family support. Before joining an integrated program, he did not take medications regularly or see a primary care provider. In 2008, he had seven inpatient hospital admissions. Once he joined an integrated program, his care manager, supported by an interdisciplinary care team that included a psychiatrist and a social worker, worked with the primary care provider to increase one medication. The team monitored Mr. C's conditions and his adherence to his medication regime and diet requirements. With the care team's help, the number of Mr. C's admissions per year has declined over time. In 2009, Mr. C. had four inpatient hospital admissions. In 2010 he was admitted twice, and since November 2011, he has had no admissions.

Mrs. L. is a Hispanic woman with diabetes. Before joining an integrated program she knew she had vision problems, but avoided seeing an eye doctor. Once joining a program, her care manager identified the overdue preventive service and arranged to visit Mrs. L. at home, along with a Spanish-speaking primary care physician who encouraged Mrs. L. to see an ophthalmologist. Early retinal disease was detected and was treated by laser surgery, preventing the loss of her sight. The care manager also arranged for better lighting in the hallway of her building to help prevent a fall.

Mrs. K., a 92-year-old woman with severe functional impairment and Alzheimer's disease, lived with her elderly and frail spouse. Before joining an integrated program, she had significant risk factors for wandering because of disorientation to time and place, agitation and restlessness, and she experienced frequent falls and injuries. Once joining a program, the care manager developed a plan of care, based on the initial comprehensive assessment that involved a home health aide and a chair and bed alarm. Whenever the alarm sounded, the home health aide responded immediately to assist Mrs. K. with mobility and activities of daily living. Her wandering and falls decreased, and she was able to remain in her own home and avoid being placed in a nursing home. Additionally, the care manager instructed the family and aide in behavioral interventions to decrease agitation, and implemented a regimen of regular activity and exercise. The care manager

continued on page 7

continued from page 6

also worked with Mrs. K.'s primary care physician to monitor and modify her medication regimen.

Mr. P. is a 30 year old man who was in a very serious automobile accident and was left with paralysis in both legs. Before joining a program, Mr. P had three surgeries and was deeply depressed. While his condition stabilized, he still must see a number of specialists, including a neurologist and urologist. Mr. P enrolled in a plan for people with Medicare and Medicaid; the plan covers acute care, physician services, drugs, long term services and supports and behavioral health, and helped Mr. P. get a motorized wheelchair. He is determined to pursue graduate studies and has been accepted into a program. He has worked with his care manager to arrange for his aide to help him prepare for classes. Another aide comes in the evening to help him with dinner, to work on his computer and get into bed. The care manager touches base with Mr. P. regularly and helped him prevent two emerging infections and inpatient stays that would have resulted. Mr. P. is happy that these services allow him to remain out of a nursing home and in his home and community pursuing his career. His depression has lifted and he has expressed satisfaction with his health plan despite the difficult circumstances.

Ms. M. is a 34-year-old woman who has battled severe and persistent mental illness since she was a teenager. Before joining an integrated program, at her family's urging, she had several inpatient stays and institutionalizations at crisis moments in the course of her illness. She is now in an integrated health plan for people with Medicare and Medicaid that includes coverage for behavioral health. Consequently, a behavioral health expert is part of her care team. This professional visited Ms. M. in her home upon enrollment in the plan. She reviewed medication and compliance extensively and consulted with Ms. M's primary care physician about a change in one medication and in the dosage of another medication. Ms. M.'s care manager has been calling her weekly to check on the medication regimen. She has expressed an interest in work. Her care manager explored resources in her community and reviewed the options with her for vocational training in a computer support program since she has technical aptitude. As a result of these efforts, Ms. M. is in a one-year program. After six months, her attendance has been excellent. Her engagement in this training has motivated her to comply with her medication regimen and she has been able to avoid any inpatient or institutional stays during this period.

skilled nursing facility benefit. This reduces the state's costs, but raises Medicare spending and increases beneficiary risk. Persons who are transferred from the nursing home to hospital are at risk of infection, delirium and decline in function, are susceptible to medical errors that often occur during transition and have higher overall costs than persons who remain in a nursing home.[4]

Disjointed funding and benefit design can result in a pattern of shifting beneficiaries from setting to setting for financial rather than clinical reasons, and offer little incentive to coordinate care or improve efficiency.[1] Although there has been dramatic growth in the use of Medicaid waivers to shift long-term care from institutions to home- and community-based services, many people who would prefer to stay in their homes still cannot get the needed long term supports and services and so get long-term services and supports from a nursing home. In 2007, an estimated 5 percent to 12 percent of nursing home residents could be cared for at home if they had appropriate services, though this number appears to be dropping.[5] There is no entity responsible both for organizing the care around the beneficiaries' needs and for making most effective use of available resources.

Opportunity: New Initiatives, Lessons Learned

Federal Integration Initiatives Seek Broader Implementation and Benefits

With enactment of the Patient Protection and Affordable Care Act (ACA), the Centers for Medicare & Medicaid Services (CMS) made a new commitment to improving integration of care for people with Medicare and Medicaid, by establishing the Medicare-Medicaid Coordination Office.* CMS has supported programs to promote greater coordination and streamlined management of care. It announced demonstration initiatives for states to integrate primary, acute, behavioral health and LTSS for full-benefit, Medicare-Medicaid beneficiaries (Box 2).

The federal government, state Medicaid programs and the broader policy community have long been aware of the large concentration of spending, poor coordination of care and perverse incentives associated with traditional financing and delivery of care for people with Medicare and Medicaid.[6,7] Over the years, federal and state initiatives have tried different approaches to integration, including the Program of All-Inclusive Care for the Elderly (PACE) and state-based initiatives in Wisconsin, Minnesota and Massachusetts. These have shown benefits in quality and beneficiary and caregiver satisfaction; findings are mixed on costs. All programs have low enrollment, relative to the potential Medicare-Medicaid population where they are offered. Medicare also has offered Special Needs Plans (SNP), including those that target people with Medicare and Medicaid. To promote integration, Congress required all SNPs for the Medicare-Medicaid population to establish agreements with state Medicaid programs by 2013; most duals SNPs have put these in place but this is a very recent change.

Several states have contracted with organizations to furnish Medicaid coverage of LTSS through capitated arrangements.[8] Some of these have integrated Medicaid acute care services with LTSS, but blended payment with Medicare is rare, due in part to rules that preserve beneficiary choice in Medicare. CMS cannot require people to use a managed care plan for Medicare (indeed, people with Medicare have the option to stay in the fee-for-service system), even if they are already enrolled in a plan for Medicaid services.

These efforts have demonstrated key challenges:

- **Integration is hard.** Medicare and Medicaid have their own benefits and cultures, and working with federal and state policymakers who may have different goals and priorities can be challenging. The two programs also have different administrative rules (e.g., marketing, grievance and appeal processes, development of payment rates, and quality improvement and reporting) that further inhibit integration.

- **Medicare advocates are wary of mandatory managed care.** Although Medicaid programs often require enrollment into managed care by people who are generally healthy (e.g., children and their mothers), more states have been moving to mandate that the elderly and those with disabilities enroll in managed care, but for Medicare-covered services, beneficiaries must be able to choose between traditional Medicare and managed care. Advocates often resist mandatory enrollment and assignment if beneficiaries do not actively choose and they are especially concerned about how older people with many chronic conditions will fare in a new model of care. This is so even though many will acknowledge that the status quo is not optimal — for example, it relies too much on institutional care.

- **Integration requires new relationships and complementary skills.** Integrating care for people with Medicare and Medicaid requires working closely with providers who have long experience with specific types of beneficiaries (e.g., home- and community-based providers for people with disabilities; providers that serve people with severe and persistent mental illness or substance use). Many successful integration models serve few enrollees and are strongly embedded with the local providers and community. They often lack the analytic capacity and resources that traditional health plans have developed *for managing large datasets and provider networks*. Conversely, most traditional managed care plans do not have experience paying for or managing use of LTSS and may not be even familiar with the various non-medical providers in the community. Stakeholders are concerned about managed care's potential for reducing access to care in general, about too much focus and spending directed towards medical care over LTSS, "medicalizing" the delivery of social and personal supports, and about safety net providers and community resources specifically.

BOX 2. Recent Federal Initiatives to Support Integrated Care for Medicare-Medicaid Enrollees

State demonstrations to integrate care for people with Medicare and Medicaid. In this demonstration, CMS is supporting 15 states to develop new models for delivering integrated services to people with Medicare and Medicaid. (Support is for design, not necessarily for full implementation of new models.) The models are intended to coordinate care across primary, acute, behavioral health and long-term care. State design proposals indicate wide variation in the target populations and approaches to integration. Most states participating in this demonstration are also participating in the financial alignment demonstration.

Financial alignment demonstration. The goal of this demonstration is to test two models for aligning Medicare and Medicaid financing and integrating primary, acute, behavioral health and long term services and supports:

- **Capitated model.** CMS and states enter into a Memorandum of Understanding, and then CMS, the state and health plans enter into a three-way contract. In return for a prospective payment combining Medicare and Medicaid funds, plans provide comprehensive coverage. CMS and the state set the rate actuarially to return savings over what would have been spent in the absence of the demonstration, and a portion of plans' payment will be withheld contingent upon meeting quality thresholds.
- **Managed fee-for-service model.** Under this approach, CMS and the State also enter into a Memorandum of Understanding, but there is no three-way contract. The state manages its delivery systems directly. The Memorandum of Understanding allows shared savings between the two programs from initiatives that successfully reduce cost and improve quality for both programs. States invest in care coordination and, if they achieve savings for Medicare that equal or exceed a target, they receive payment from Medicare. States receive payments only if they meet or exceed pre-set quality goals for people in the program.

*_Section 2602 of the Beneficiary Protection and Affordable Care Act_ (Pub. L. 111-148) created the Federal Coordinated Health Care Office ("Medicare-Medicaid Coordination Office").

- **Quality measures are lacking.** Existing measures do not fully address the complex characteristics of people with Medicare and Medicaid (i.e., use of LTSS, functional decline, frailty, multiple coexisting conditions) nor do they address critical indicators of quality improvement through the provision of integrated care. Some existing measures are relevant (including those specifically designed for SNPs): for example, measures of transitions and readmissions are included for these plans and are equally useful in a managed fee-for-service environment. But we do not have measures that capture coordination of care across medical and long-term services and supports or that capture outcomes when enrollees may have different goals. Existing measures are necessary as a starting point, but are insufficient to provide the desired full picture of care.

Model of Integrated Care Entity and Quality Framework Needed

There is great promise to improve quality within integrated care models. Integrated care ultimately means person-centered care such that the care provided meets the specific needs of each individual to help them attain their goals. A well-defined vision that is translated into concrete statements of expectations — combined with performance measures — can influence entities to provide care in new ways or for new populations. In the following section, we describe this vision and the specific elements we have found are needed to be in place to deliver on the promise of integrated care.

Defining the entity that is accountable for integrated care

As states work with the federal government to develop new programs for providing integrated care, they are turning to a variety of organizations (both new and existing) to take financial responsibility and accountability for results (Box 3). States are building from existing relationships with managed care plans, managed long-term care plans, accountable care organizations, beneficiary-centered medical homes, health homes, care managers and Medicare SNPs. Any state's choice will reflect its existing health care system, politics and resources. Whatever the choice, three components are needed for success:

1. **Entities should be responsible for a comprehensive range of services that include medical care, behavioral health care and LTSS.** Entities must demonstrate that they can work across Medicare and Medicaid to present an integrated product, with benefits managed together and not carved out or administered as either "Medicaid" or "Medicare," and attempt to ensure that individuals get the right service, in the right setting, at the right time in a way that is organized around the person and his or her needs and preferences rather than around the facility or provider furnishing care.

2. **In the capitated model, financing must support integration, allowing for the streamlined provision of a mix of medical, behavioral and LTSS services, based on the individual's needs and preferences.** Flexibility is critical to "rebalance" use of home- and community-based LTSS against reliance on institutional care. Financial risk mitigation is also an important consideration to reduce any incentives for selection bias and to help enable entities to better manage caring for high-cost beneficiaries. Entities that manage care cannot use a "one size fits all" approach; they must target resources to individuals at

greatest risk. Financial incentives should support care decisions that avoid institutional care (hospital or nursing home).

3. **Entities must participate in a quality strategy with a quality measurement program tied to improved outcomes and program design.** At the outset, entities should be able to demonstrate key capabilities and functions critical to serving the Medicare-Medicaid population. They should develop additional capacity and demonstrate quality improvement as they grow and mature as organizations and as better measures become available. Quality indicators should provide continuous feedback to program improvement efforts.

BOX 3. Existing Models That Already Support Integration

Program for All-Inclusive Care for the Elderly (PACE). PACE was authorized as a permanent program in Medicare and as a state option in Medicaid by the 1997 Balanced Budget Act. As of April 2012, there were 23,000 enrollees.[9] Providers furnish comprehensive medical, LTSS and social services to frail, nursing home-eligible elderly, using a model of care that relies heavily on adult day health facilities that provide respite care and health care services. The goal of PACE is that members maintain their independence in their own homes.[10] PACE uses a model of pooled capitation funding to a fully at-risk health provider. Evaluations found that PACE had positive effects on functional status and patterns of care. Cost findings are mixed: there are Medicare savings, higher Medicaid costs and somewhat higher costs overall.[11,12]

State programs for people with Medicare and Medicaid. Wisconsin, Minnesota and Massachusetts have used health plans as the entities receiving pooled capitation payments from Medicare and Medicaid under federal waivers.[13] Evaluations conducted in 2000 and 2005 found mixed results in terms of quality, utilization and overall cost to Medicare.[13] Enrollment has grown from the initial enrollment of 3,000 in 2005.

Special Needs Plans (SNPs). These plans are a specific offering under Medicare Advantage, where a fully capitated health plan provides services to a targeted group of Medicare beneficiaries as an alternative to traditional fee-for-service Medicare. SNPs enroll three types of special needs beneficiaries: institutionalized, people with Medicare and Medicaid and people with severe or disabling chronic conditions. The law requires SNPs that focus on the Medicare-Medicaid population to establish relationships with states to coordinate Medicare and Medicaid services by 2013. This has been challenging because states do not have strong incentives to work through the complex issues associated with developing programs for people with Medicare and Medicaid, when Medicare is responsible for making most of the payments.[14] However, most of these SNPs have secured needed contracts. Some SNPs have delivered promising results, for example the Commonwealth Care Alliance in Massachusetts.

Managed long-term care. Some states have moved to managed long-term care for their Medicaid beneficiaries at high risk of needing nursing home care. For example, New York has a Medicaid managed long-term care program (to date, mainly in New York City) that relies on local provider-based entities (as opposed to traditional health plans) to assume full financial risk for providing the full array of LTSS, together with care management.[15] Arizona has the longest track record in providing all long-term care through capitated arrangements with private health plans; neither Arizona nor Tennessee offer traditional fee-for-service coverage of long-term care. In most state initiatives, entities are home grown and provider based, but some companies (UnitedHealthcare and Amerigroup) have developed long-term-care plans.[16]

Other models. Other care delivery models include Geriatric Resources for Assessment of Care and Resources for Elders (GRACE), and *Summa Health/Area Agency on Aging 10B/Geriatric Evaluation Project (SAGE). Descriptions are available at* http://www.thescanfoundation.org/sites/thescanfoundation.org/files/TSF_Policy_Brief_6_Model_Successes_3.pdf.

Quality Framework for Integrated Care

This section establishes a framework for evaluating the quality of entities that integrate care for people with Medicare and Medicaid. It was informed by a scan of existing research evidence and promising models of care; priorities set by a panel of consumers representing different subpopulations of the Medicare-Medicaid population; and guidance from a panel of experts and other stakeholders. It provides a common approach for measuring quality that can be applied across the diverse models of integration being considered in different states. This framework is unique among approaches to measurement in that it is built around care coordination — centered around individualized assessment of needs and preferences — occurring across providers and settings in a way that is flexible and meaningful and that most of the time does not happen for these beneficiaries today.

Our specific quality framework builds from several key assumptions.

First, we focused on issues common across subgroups of people with Medicare and Medicaid. Historically, most quality measures focus on specific clinical conditions or settings. These types of measures are unsatisfying because few of them can be applied universally to people with Medicare and Medicaid. In addition, many people with Medicare and Medicaid are specifically excluded from these measures because of comorbidities or upper age limits that are a part of the specific elements of the measure.

Instead, our framework focuses on components common across many subgroups and illuminates processes and outcomes of general interest to individuals with chronic or disabling conditions. As noted in the Institute of Medicine's 2001 report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, processes are critical for avoiding quality failures.[17] Processes can be both systematic and flexible enough to allow them to adapt to the needs of special subgroups (e.g., people with serious and persistent mental illness).

Second, we focused on services across care settings and disciplines — medical, behavioral, institutional, home- and community-based services, and other supportive social services. Most existing measure activities look within a care setting such as a nursing home, a medical practice or a hospital. This framework focuses on integration and coordination across all settings and providers serving the beneficiary and family, and includes the social and community services sectors that are critical for people with complex health care and social needs.

Third, we aimed to prioritize measures that address the beneficiary/family perspective. This priority is important, given the diversity of people represented and the lack of attention to beneficiary/family perspectives in existing systems. With diverse, vulnerable subgroups in this population and the need to customize and adapt care to individual needs, it is critical to gain input about care from beneficiaries and families.

Fourth, we recognized the need to balance the achievable with the aspirational. This framework is intended to be practical and achievable in the short term, with the recognition that expanding integrated care beyond the few existing programs will require substantial effort and provide experiences to learn from. The framework articulates a vision for what integrated care should look like in the future, where person-centered, collaborative care is a widespread.

Fifth, our model combines a roadmap of "structures and processes" with performance measures that address use of effective care, costs of care and beneficiary experiences. Our experience implementing quality measurement and improvement in other settings (Box 4) has shown that it is critical to talk about the capabilities and infrastructure that providers or other entities must build as they learn how to care for beneficiaries in new ways. Our approach is consistent with that of the National Quality Forum's Dual Eligible Beneficiaries Workgroup of the Measure Applications Partnership, which recommends structural measures to support high-quality care, along with existing performance measures.[18] Table 1 illustrates the difference between structure and process measures which articulate expectations for and assess an entity's capacity and demonstrated ability to provide integrated care; performance measures assess the receipt of services, outcomes or perceptions among specific populations. Future work will develop performance measures that capture the essential outcomes of care, but that depend upon data that is not currently available. The structure and process roadmap calls for a plan of care that includes understanding, documenting and monitoring progress towards meeting beneficiaries' goals. Building these care processes and the information infrastructure needed to support them will enable measurement of outcomes such as how well beneficiary goals were met — whether functioning improved, care at home or more personal goals.

BOX 4. Beneficiary-Centered Medical Home: Establish Expectations, Raise Expectations Over Time

With its Beneficiary-Centered Medical Home program, NCQA showed how to articulate a model of care and increase expectations over time, to both reflect and spur improvements in primary care practice. We turned broad principles for excellent team-based, coordinated primary care into concrete, challenging structure and process measures. The beneficiary-centered medical home is used across the country and many payers rely on it even if they use different approaches to payment. The program's standards articulate specific investments providers must make and what must be in place to support good results. Together with a detailed scoring system, the standards allow consistent and fair evaluation. Pilot-test results have shown that, on balance, beneficiary-centered medical homes improve quality and reduce cost.[19] With each update of the program, we have learned from the leading edge practices what is possible and set that as a new expectation.

We have added standardized measurement of beneficiary experience, recognizing that this is the foundation for capturing beneficiary-centeredness. We hope to incorporate results from clinical quality measures into the program, as well; many states that support beneficiary-centered medical homes require reporting on quality results.

Key Domains of Quality for Integrated Care

This quality framework model distills the key functions of integrated care into three steps, the content of which depend on the person's level of need for coordination. These concepts go well beyond what is expected of health care entities today — the new contribution of this research is that our concept of screening and assessment is person-centered and encompasses elements beyond what is usually contained in the assessments that take place in a particular setting:

1. Screening and assessment.
2. Care planning.
3. Coordinated service delivery.

Person-centered care begins with respect, championship of rights and full participation of individuals in decisions about their care. Data systems with population health-management tools that can support these steps are crucial, as well as a dedicated approach to routine quality measurement and improvement. This model is necessary for achieving (and for demonstrating achievement of) the goals of improving or slowing decline in health and well-being; reducing the overall costs of care; and improving the quality of care and — in particular — beneficiary and family experiences with care.

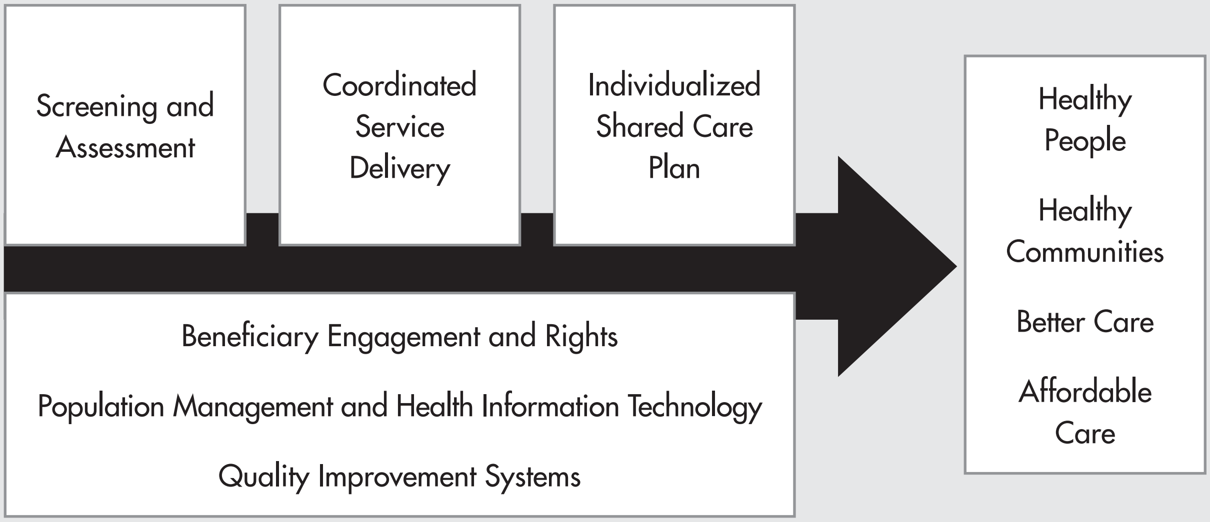
Figure 3 presents the overall framework for measuring quality of integrated care for people with Medicare and Medicaid. Organizations must put in place structures and processes for all three steps — both design and implementation are important. The structure and process measures follow the framework for quality in integrated care and array the key capabilities and functions for an entity to effectively integrate care.

For the beneficiary, these three steps are how organizations will personalize their care. Initial screening is done for everyone, to learn which beneficiaries need more comprehensive, in-person assessment. Screening and — if needed — comprehensive assessment — can identify the beneficiary's risk level, care needs and whether close monitoring is called for. These activities also can be the way for organizations to learn the beneficiary's preferences. All beneficiaries will have some kind of a care plan, whether a preventive care plan for those who are relatively healthy and stable, or a more active care plan, for those who need ongoing medical or behavioral care or long term supports and services. The care plan, built on the screening/assessment, guides not only the provision of care but also the frequency of reassessment. Unplanned transitions such as hospitalizations and other events, such as Emergency Department visits, health events or changes in support systems, will trigger reassessment of risk and if warranted, changes in the care plan.

Structure and Process Roadmap

Building on the quality framework and the measures NCQA developed for SNPs (on behalf of CMS), we identified the structures and processes needed to address the full range of Medicare and Medicaid benefits,

FIGURE 3. Framework for Quality in Integrated Care



as well as concerns about person-centered care. These structures and processes are statements of what program components must be in place. One way to evaluate performance of integrated care entities is to review evidence that the entity has implemented the required structures and follows the essential processes. Independent reviewers can provide an assessment of how well the entity satisfies the requirements on a point scale. Alternatively, regulators could conduct readiness reviews that take place before beneficiaries enroll or articulate expectations about structures and processes in a contract. Regardless of the timing and vehicle, it will be important to assess these capabilities and enforce their use. The structures and processes included in this framework provide a roadmap to establishing the infrastructure, including the data systems and care processes, needed to be able to measure performance.

Performance measures are expressed as a ratio — for example for a target population that should receive a type of treatment, what share actually received it. Performance measures are useful for evaluating performance in specific areas and domains, while evaluation of structures and processes can fill the gap in areas when performance measures are lacking. (See Table 1 for examples.)

These structures and processes address some of the measurement gap areas identified by the National Quality Forum (NQF) workgroup, including goal-directed, person-centered care planning and implementation and system structures to ensure connection between the health system and LTSS.

- **Screening and — if warranted — assessment.** Screening should occur at entry for all beneficiaries, more comprehensive assessment should occur for those found to be higher risk based on the screening. Screening and assessment should be holistic (i.e., include medical, behavioral, functional and psychosocial needs) and address individual preferences, and reassessment should take place in response to triggering events.

- **Individualized, shared care plan.** The shared care plan transforms the results of the screening and assessment into an individualized, person-centered, integrated care plan. The individual and family members or caregivers (as appropriate) collaborate with providers to develop a coordinated, comprehensive care plan that encompasses all care needed, across all settings. The plan should be accessible to the beneficiary, to the designated family/caregivers and to providers, and updated based on routine periodic assessment (depending on need) and on trigger events.

- **Coordinated service delivery.** The shared care plan supports and includes accountability for managing care transitions and for tracking and follow-up of services and referrals. In particular, coordination between Medicare and Medicaid benefits and services is included. For individuals with multiple chronic conditions, the plan would plan for and be the basis of coordination among multiple specialties.

- **Quality improvement.** Standardized approaches to measuring quality and implementing targeted quality improvement are needed to develop the data sources and capacity for measuring key indicators that are of greatest interest for people with Medicare and Medicaid, but are now lacking. Approaches include attention to beneficiary experiences with the care-planning process, transitions and overall care, in addition to other performance measures, such as those recommended by the NQF or currently reported by a variety of entities. (Refer to Tables D and E in the Appendix.)

TABLE 1. Comparison of Structure/Process Measures and Performance Measures

In this document, we follow a convention developed for earlier work with CMS that distinguishes "structure and process measures" (also called "standards" in other NCQA programs) from "performance measures." Structure and process measures articulate expectations for and assess an entity's capacity and demonstrated ability to provide person-centered, integrated care and can serve as a roadmap to implementing integrated care systems; performance measures assess the receipt of specific services, outcomes or perceptions among specific populations. This table gives examples of these types of measures.

Structure and Process Measures	Performance Measures
Periodic Reassessment Process The organization's assessment procedures address: • Frequency of routine comprehensive reassessment based on risk. • Triggering events for off-schedule comprehensive reassessment. • Methods and sources of information to monitor individuals' risks and needs.	*Medication Reconciliation Post-Discharge* The percentage of discharges from January 1 — December 1 of the measurement year for members 66 years of age and older for whom medications were reconciled on or within 30 days of discharge. *Diabetes Screening for People With Schizophrenia or Bipolar Disorder* The percentage of members 25 years and older with a schizophrenia diagnosis or bipolar disorder diagnosis who were prescribed any antipsychotic medication and received a diabetes screening during the measurement year.
Individualized Care Plan The organization, with each beneficiary, develops a coordinated, comprehensive, integrated care plan that encompasses all care needed across all settings and includes the following: • Development of an individualized care plan by, or representing the care provided by, the full care team, including prioritized goals that consider the beneficiary's and caregivers' goals, preferences and desired level of involvement in the care plan. • Identification of barriers to meeting goals or complying with the plan. • Development and communication of self-management plans. • A process to assess beneficiary progress against care plans. • Contact information for all care providers. • Identification of and contact information for the individual who is the first point of contact and who is responsible for managing the care plan.	*Three-Item Care Transition Measure* One-dimensional, self-reported survey that measures the quality of preparation for care transitions: understanding the self-care role in the post-hospital setting, medication management and having one's preferences incorporated into the care plan. *Comfortable Dying* The percentage of beneficiaries who were uncomfortable because of pain on admission to hospice, whose pain was brought under control within 48 hours. *Care for Older Adults* The percentage of adults 66 years of age and older who had each of the following during the measurement year: • Advance care planning. • Medication review. • Functional status assessment. • Pain screening.

- **Beneficiary engagement and rights.** These processes enhance the role of individuals as partners in their care, communicating about their rights and responsibilities, and for handling and resolving beneficiary grievances.

- **Health information technology and population health management.** The data and infrastructure available for supporting the care process must capture and integrate information from multiple sources and support systems for sharing and using information to identify high-need participants. This information can help identify and track populations at different levels of risk and facilitate and integrate care, and is shared among members of the care team across settings.

Performance Measures

The evaluation framework envisions the use of new and existing performance measures to assess key goals related to population health, cost and quality of care and beneficiary experience. While some existing performance measures address issues of relevance for people with Medicare and Medicaid, adaptation is needed. New measures are needed to address critical topics including beneficiary experiences and preferences for care as well as quality of life and functional outcomes. The structures and processes described above complement performance measures and also support the development of new measures in key areas.

Existing measures addressing cross-cutting issues such as medication reconciliation, screening for depression and readmissions are reported by SNPs; other measures are reported by nursing homes and are used for assessing quality in LTSS. Some of these measures could be readily used for evaluating integrated care but may require adaptation. Tables D and E in the Appendix provide lists of measures that are currently used or have been recommended for evaluating quality both for general medical care and for LTSS. In the short term, some of these measures could be adapted for reporting by integrated care entities (such as those shown in Table 2), but new measures will be needed to address high-priority topics that reflect the needs of a diverse Medicare-Medicaid population, including (but not limited to):

- Appropriate prescribing and medication management.
- Autonomy.
- Sense of control/self-determination.
- Pain and symptom management.
- Effectiveness of supports for people with functional limitations.

Measures addressing these areas present challenges for implementation; for example, among the most commonly noted gaps are measures of beneficiary/family experience of care and measures evaluating beneficiary functioning. Existing standardized tools to measure physical and mental health functioning are not always appropriate in a frail population or in a population with multiple chronic conditions or significant cognitive impairment; nor do measures address self-determination and autonomy — often most important to people with Medicare and Medicaid.

We must develop new outcome measures of health-related quality of life and functioning that address the complex and unique needs and views of the Medicare-Medicaid population. To make beneficiary/family reported information valid, reliable and useful, a number of issues need to be considered:

- Do existing tools adequately account for health literacy and cognitive issues in people with Medicare and Medicaid?
- When are proxy reports from family members or caregivers acceptable or appropriate?
- What methods of data collection are feasible and replicable in different settings?
- What type of risk stratification or adjustment is needed for comparison over time or across organizations?

The answers to these questions may differ for the type of beneficiary-reported information and the measure purposes.

Alignment of Structure and Process Roadmap With Performance Measures

The structure and process roadmap lays the foundation for performance measures that measure aspects of a process and eventually outcomes of care. Table 2 shows the relationship between structures and processes, and existing performance measures. For example, in the area of screening and assessment where we have expectations for the two-part evaluation of beneficiaries' needs, we have identified three existing performance measures — depression screening, care for older adults and falls risk assessment. We

TABLE 2. Alignment of Existing and New Performance Measures With Structures and Processes

Structure and Process Domain	Screening and Assessment	Care Planning	Coordinated Service Delivery
Existing Performance Measures	• Depression screening • Care for older adults (pain assessment, functional status assessment, advanced care planning) • Falls risk assessment	• Depression follow-up • Care for older adults (medication review) • Falls risk plan of care • Diabetes screening • Cholesterol screening • Cancer screening	• Care transition record transmitted • Follow-up after hospitalization for mental health • Medication reconciliation
Potential New Performance Measures	• % of beneficiaries with risk assessment within X days of enrollment • Assessment of quality of life • Screening for low health literacy • Daily activity function	• % of beneficiaries with care plan within X days of enrollment • Shared decision making • Assessment of goals and preferences	• % of beneficiaries with discharge follow-up • Potentially avoidable hospitalization

also have begun to identify new opportunities for measures to assess the effectiveness of the screening and assessment process; for example, new measures could be developed to capture the timeliness of this process as well as whether important content areas such as quality of life, health literacy and daily activity function are addressed. In time, as the performance of assessments and documentation of their results become routine, it may be possible to measure the person-centered outcome at the heart of this process: progress towards achieving goals.

The structure and process roadmap described above could help both the development and the implementation of new measures. The structures and processes related to screening and assessment give organizations experience with defining populations that need specific kinds of screening or assessment. Information systems for population health management make it possible to capture key data about screening and assessment processes that are needed to construct a measure. Quality measurement and improvement processes allow organizations to understand patterns of care and to work to improve.

Implementation Challenges

A number of challenges face entities, states and the federal government as they move towards implementing programs to integrate care for people with Medicare and Medicaid.

Use of good measures of quality — whether structure and process or outcomes — is particularly important to assure stakeholders that efforts to integrate care — whether through managed care or managed fee-for-service — improve care even as care models and financial incentives change. Ideally, these measures will allow us to learn which of the diverse approaches to person-centered care management yield the best results.

Traditionally, it has been unusual for providers to coordinate care across long-term services and supports, medical care and behavioral health. Some people refer to this problem as that of "silos," where each type of provider thinks only about the beneficiary in terms of the services that provider furnishes. This is true of the U.S. health care system in general; it relies on specialized services for different health care problems, which is reinforced by benefit design and payment systems. Quality measures have tended to follow the silos, being collected within a particular setting and for particular diseases. Measuring HbA1c for diabetes, for example, is more straightforward than measuring "good, person-centered" care, and the quality of the communication and collaboration among the separate providers that provide that care for a person with diabetes, congestive heart failure, hypertension and depression.

The shift in the LTSS world from funding specific programs (e.g., adult day health care) to funding services based on an individualized assessment (e.g., personal care, home modifications and medical management) will be challenging for LTSS providers. This idea will be even more foreign to providers of Medicare services who are used to providing care within the definitions and payment incentives of Medicare post-acute care, including the 100-day skilled nursing facility benefit.

For the managed care models, one would expect that capitated payments to entities would create the incentive for the entities themselves to consider more broadly a beneficiary's needs under a single budget. For managed fee-for-service models with shared savings opportunities, incentives may also encourage more person-centered approaches. For both managed care and managed fee-for-service models, developing new payment systems, focusing providers on new goals and improving the flow of information across providers will be challenging.

As noted above, the Medicare and Medicaid programs themselves have vastly different cultures. Medicare operated federally, with uniform rules, participation requirements and consumer protections. Medicaid varies a great deal across the states, reflecting the political priorities, budget and local delivery system. These different cultures could result in challenges from the perspective of entities that will need to respond to both purchasers.

Also challenging are the shortages of many types of providers — starting with primary care providers but going on to include providers with specialized expertise. Providers will need to use electronic health information to support this work, but it is not clear that the technology has all the needed functions yet. While more hospitals and clinician offices are using electronic health information, health information exchange among medical providers is still in its infancy, and providers of long-term services and supports have rarely been considered in the construction of health information exchange programs. Even providers with health information technology will need support from analytical staff to use the systems to target services and monitor care.

Finally, integrated models need to take into account the different configuration and capabilities and historic role that providers have, which will vary enormously across the country. Entities will need to play a clear and direct role in assuring provider network adequacy for both Medicare and Medicaid services. Adequacy encompasses the appropriate mix of services; geographic distribution to meet the needs of beneficiaries in the entire service area; and physical accessibility. Entities will need to select, credential and monitor providers who can serve a complex population, are willing to collaborate across professions and settings and can work with multiple stakeholders from the aging, behavioral health and disability communities. This is an especially critical issue in LTSS as personal care providers in self-directed programs allow beneficiaries to use non-certified family and friends as providers.

Use of Quality Framework for Integrated Care

A quality framework that combines structure and process measures with performance measures offers a way to demonstrate and monitor quality for a vulnerable population. State and federal government agencies can refer to the PCMH program evolution as a way to build programs serving people with Medicare and Medicaid. Over time, standardized measurement of beneficiary experience and outcomes (clinical, functional and quality of life) can be added and performance expectations can be raised.

Here are three potential approaches for incorporating this quality framework into integrated care evaluation:

- **For state-based programs, states can build evaluation metrics into integrated programs.** Many states and private purchasers/sponsors have formal or informal partnerships with private evaluation entities that review contracting entities (e.g., managed care organizations, beneficiary-centered medical homes) and furnish the results to program sponsors. Sponsors are free to develop payment, reimbursement and incentive structures, but can rely on the independent results to identify the entities most ready to take on the challenge of managing the population.

  States can use other strategies, such as an accreditation program, to satisfy some program elements. Some state governments require accreditation; others use accreditation results to satisfy some state requirements. For example, state insurance departments deem NCQA-Accredited health plans to meet state requirements for a robust approach to verifying provider credentials.

- **Direct federal funding.** For example, CMS has funded (a) the SNP measure development and mandated that the measures be used in a program, paying for a contractor to do training, collection of measures and evaluation of models of care; (b) development of measures and measure resporting systems for Medicaid and CHIP; and (c) support for assessing quality in demonstrations.

Finally, while this paper is focused on the Medicare-Medicaid population, the quality framework and measures have the potential to be relevant to other groups that share the same characteristics; for example, people who have only Medicare, Medicaid or private insurance, yet also experience chronic physical and behavioral problems, along with functional impairment.[20]

Conclusion

Designing new models for providing person-centered, integrated care for beneficiaries with Medicaid and Medicare coverage is a critical policy challenge. Good integrated care holds the promise of eliminating the fragmented, medically-oriented care that often wastes state and federal dollars and leaves beneficiaries and their families feeling confused and overwhelmed. This paper offers an approach to evaluating the quality of integrated care, starting with structures and processes measures that set expectations for key functions and capabilities and create the foundation for the development and application of outcome measures. It also identifies existing performance measures that could be adapted for evaluating entities in the short run. Over time, as the structures and processes become fully embedded in integrated care programs, we envision adding measures to capture outcomes for diverse groups of people with Medicare and Medicaid.

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Appendix

TABLE A. Demographics, Health Characteristics and Utilization for People With Medicare and Medicaid versus Medicare Only

	Medicare and Medicaid		Medicare Only
Demographics[1]			
Below 200% of poverty line	91%		33%
Female	63%		54%
Under 65 (disabled)	41%		12%
African-American	18%		8%
Hispanic	14%		7%
No high school education	53%		22%
Rural residence (vs. urban)	30%		22%
Lives in institution	20%		2%
Lives alone	27%		26%
Lives with spouse	15%		46%
Lives with others (e.g., child)	30%		13%
Physical Impairment			
No activities of daily living impaired[1]	46%		72%
1-2 activities of daily living impaired[1]	24%		19%
3-6 activities of daily living impaired[1]	30%		9%
	Nursing Home	**Community**	
Any activities of daily living impaired[2]	88%	43%	
Cognitive/mental health			
Any impairment[2]	58%		25%
	Aged	**Disabled**	
Dementia[3]	30%	5%	
Depression[3]	18%	28%	
Schizophrenia[4]	4%	12%	
Other serious disorder[4]	18%	27%	
	Nursing Home	**Community**	
Any impairment[2]	92%	52%	
Chronic conditions			
3+ chronic conditions[2]	55%		44%

	Medicare and Medicaid		Medicare Only
	Aged	**Disabled**	
Ischemic heart disease[3]	43%	17%	
Diabetes[3]	36%	23%	
Heart failure[3]	33%	11%	
Rheumatoid arthritis/osteoarthritis[3]	31%	13%	
COPD[3]	18%	10%	
Annual Utilization	**Aged**	**Disabled**	
1+ inpatient visit[2]	29%	22%	18%
1+ ER visit[2]	13%	22%	12%
1+ home health visit[2]	15%	7%	8%
1+ skilled nursing facility stay[2]	13%	4%	4%
	Nursing Home	**Community**	
1+ inpatient visit[2]	42%	23%	
1+ ER visit[2]	3%	20%	
1+ home health visit[2]	8%	12%	
1+ skilled nursing facility stay[2]	37%	4%	

[1] MedPac. A Data Book: Health Care Spending and the Medicare Program (June 2011), Section 3: Dual-eligible-beneficiaries. http://www.medpac.gov/document_TOC.cfm?id=6172

[2] Kaiser Family Foundation. Issue Brief: Medicare's role for dual eligible beneficiaries (April 2012). http://www.kff.org/medicare/8138.cfm

[3] MedPac. Report to the Congress: Improving Incentives in the Medicare Program (June 2009), Chapter 5: Coordinating the care of dual-eligible beneficiaries. http://www.medpac.gov/document_TOC.cfm?id=576

[4] Kaiser Family Foundation Chronic Disease and co-morbidity among people with dual eligibility: implications for patterns of Medicaid and Medicare Service Use and Spending (July 2010). http://www.kff.org/medicaid/upload/8081.pdf

TABLE B. Total Medicare and Medicaid per Capita Spending for People With Medicare and Medicaid[1]

	All	Spending Relative to Average
All Beneficiaries	$26,185	
No nursing home spending	$19,171	0.72
Top nursing home spending[2]	$75,496	2.88
Aged	$26,841	1.03
No nursing home spending	$16,916	0.65
Top nursing home spending	$74,439	2.84
Disabled (<65)	$24,924	0.95
No nursing home spending	$22,530	0.86
Top nursing home spending	$84,339	3.22
Dementia	$46,578	1.78
COPD	$40,645	1.55
Depression	$38,829	1.48
Diabetes	$32,188	1.23
Heart failure	$40,632	1.55
Ischemic heart disease	$34,568	1.32
Rheumatoid arthritis/Osteoarthritis	$31,864	1.22
4+ chronic conditions	$43,989	1.68
5+ chronic conditions	$50,278	1.92

[1] MedPac. June 2009. Report to the Congress: Improving Incentives in the Medicare Program, Chapter 5: Coordinating the care of dual-eligible beneficiaries. http://www.medpac.gov/document_TOC.cfm?id=576

[2] Top nursing home spending includes the top 20th percentile of spending for beneficiaries who used nursing home services.

TABLE C. Structure and Process Measures for Integrated Care

Domains	Measures
Comprehensive Assessment	*CA 1: Screening and Assessment Process* Element A: Screening Process Element B: Comprehensive, Individualized Assessment Process Element C: Comprehensive Assessment Content Element D: Risk Stratification Element E: Periodic Re-Screening and Re-Assessment Process Element F: Providing Screening and Comprehensive Assessment
Individualized Care Plan	*ICP 1: Individualized Care Plan* Element A: Individualized Care Plan Element B:Using the Care Plan Element C: Care Plan Performance Element D: Informing and Educating Providers
Coordinated Care Delivery	*CCD 1: Care Transitions* Element A: Reducing Transitions Element B: Managing Transitions Element C: Supporting Beneficiaries Through Transitions Element D: Identifying Unplanned Transitions *CCD 2: Coordination of Medicare and Medicaid* Element A: Administrative Coordination Element B: Service Coordination Element C: Network Adequacy Assessment
Population Health Management and Health Information Technology	*HITP 1: Population Health* Element A: Process for Data Collection and Integration Element B: Using Data for Risk Stratification Element C: Information Systems Element D: Coordinating Information Exchange
Quality Measurement and Improvement	*QI 1: Measure and Improve Performance* Element A: Measure Performance Element B: Measure Beneficiary Experience Element C: Implement Continuous Quality Improvement Element D: Demonstrate Continuous Quality Improvement
Beneficiary Engagement and Rights (BER)	*BER 1: Engaging and Informing Beneficiaries* Element A: Beneficiary Rights Information Element B: Information about Benefits Element C: Beneficiary Expectations Element D: Handling Beneficiary Grievances Element E: Resolving Grievances

TABLE D. Existing Performance Measures Used/Recommended for Evaluating General Medical Care in National Programs in Medicare or Medicaid

Measures in the table were identified through the multiple sources: (1) The Special Needs Plan (SNP) reporting requirements; (2) The initial core set of health care quality measures for Medicaid-eligible adults; (3) The National Quality Forum (NQF) Measurement Applications Partnership (MAP) recommended measures (C-core set; E-expansion set) for beneficiaries with dual eligibility for Medicare and Medicaid; (4) The Medicare Advantage (MA) Plan Rating measure reporting requirements; (5) Specific measures identified in state proposal to CMS for the integrated care demonstration project; and (6) Measures for adults included in the final rule for Medicare and Medicaid electronic health record incentive program for eligible providers stage 2 (Meaningful Use — MU). These measures address the aspects of care related to general medical care (ambulatory care and acute care).

National Quality Strategy Measurement Domains Performance Measures	SNP	Medicaid Core	NQF MAP	MA	State Demo	MU	NQF #	Data Source	Owner
Health and Well-Being Outcomes									
Assessment of health related quality of life in adults with ESRD			E				260	Survey	RAND
Change in daily activity function as measured by the AM-PAC			E				430	Survey	CREcare
Improving or maintaining physical health				✓			NA	Survey	NCQA/ HOS
Improving or maintaining mental health				✓			NA	Survey	NCQA/ HOS
Prevention and Screening									
Adult BMI assessment		✓		✓	✓		NA	Admin/ Paper	NCQA
Adult weight screening and follow-up			E		✓	✓	0421	Admin/ EHR	CMS/QIP
Counseling on physical activity in older adults				✓	✓		0029	Survey	NCQA/ HOS
Care for older adults: Functional status assessment	✓			✓	✓		NA	Admin/ Paper	NCQA
Care for older adults: Pain screening	✓			✓	✓		NA	Admin/ Paper	NCQA
Flu shots for adults		✓		✓	✓		0039	Survey	NCQA/ CAHPS®
Influenza immunization					✓	✓	0041	Admin/ EHR	AMA/PCPI

National Quality Strategy Measurement Domains Performance Measures	SNP	Medicaid Core	NQF MAP	MA	State Demo	MU	NQF #	Data Source	Owner
Pneumococcal vaccination in older adults					✓	✓	0043	Survey/EHR	NCQA/CAHPS®
Breast cancer screening		✓		✓	✓	✓	0031	Admin/EHR	NCQA
Colorectal cancer screening	✓				✓	✓	0034	Admin/Paper/EHR	NCQA
Cervical cancer screening		✓			✓	✓	0032	Admin/Paper/EHR	NCQA
Chlamydia screening in women		✓				✓	0033	Admin/EHR	NCQA
Glaucoma screening in older adults	✓			✓			NA	Admin	NCQA
Screening for falls risk			C		✓	✓	0101	Admin/EHR	NCQA/AMA/PCPI
Falls risk management				✓	✓		0035	Survey	NCQA/HOS
Depression screening and follow up		✓	C		✓	✓	0418	Admin/EHR	CMS/QIP
Tobacco use: Screening and cessation intervention					✓	✓	0028	Admin/ERH	AMA/PCPI
Medical assistance with smoking and tobacco use cessation		✓			✓		0027	Survey	NCQA
Pregnant women that had HBsAg testing						✓	0608	Admin/EHR	Ingenix
Fasting LDL-C test has been performed						✓	NA	EHR	CMS/QIP
Aspirin use and discussion					✓		NA	Survey	NCQA
Screening for high blood pressure and follow-up documented						✓	NA	EHR	CMS/QIP
Effective Treatment of Chronic Conditions									
HIV/AIDS: Annual medical visit		✓				✓	0403	Admin/EHR	AMA/PCPI/NCQA
HIV/AIDS: PCP prophylaxis						✓	0405	Admin/EHR	NCQA

National Quality Strategy Measurement Domains Performance Measures	SNP	Medicaid Core	NQF MAP	MA	State Demo	MU	NQF #	Data Source	Owner
HIV/AIDS: RNA control for beneficiaries with HIV						✓	0407	Admin/ EHR	NCQA
Diabetes: Eye exam				✓	✓	✓	0055	Admin/ Paper/EHR	NCQA
Diabetes: Foot exam				✓	✓	✓	0056	Admin/ Paper/EHR	NCQA
Diabetes: Hemoglobin A1c testing		✓			✓		0057	Admin/ Paper	NCQA
Diabetes: Hemoglobin A1c poor control				✓	✓	✓	0059	Admin/ Paper/EHR	NCQA
Diabetes: Hemoglobin A1c control				✓	✓		0575	Admin/ Paper	NCQA
Diabetes: LDL-C screening		✓		✓	✓		0063	Admin/ Paper	NCQA
Diabetes: LDL-C control				✓	✓	✓	0064	Admin/ Paper/EHR	NCQA
Diabetes: Urine protein screening					✓	✓	0062	Admin/ Paper/EHR	NCQA
Diabetes: Blood pressure management					✓		0061	Admin/ Paper	NCQA
Diabetes: Diabetes treatment (Part D)				✓	✓		NA	Admin	PQA
Diabetes: Medication adherence for oral diabetes medications (Part D)				✓	✓		0541	Admin	PQA
Diabetes: Optimal diabetes care			E				0729	Paper/EHR	MN Community
Diabetic retinopathy: Documentation of macular edema and severity						✓	0088	Admin/ EHR	AMA/PCPI
Respiratory: Pharmacotherapy management of COPD exacerbation	✓				✓		0549	Admin	NCQA
Respiratory: Use of spirometry test in assessment and diagnosis of COPD	✓				✓		0577	Admin	NCQA

National Quality Strategy Measurement Domains Performance Measures	SNP	Medicaid Core	NQF MAP	MA	State Demo	MU	NQF #	Data Source	Owner
Respiratory: Management of poorly controlled COPD			C				1825	Admin	ActiveHealth
Respiratory: Use of appropriate medications for asthma					✓	✓	0036	Admin/ EHR	NCQA
Cardiovascular: Medication adherence for cholesterol (Part D)				✓	✓		0541	Admin	PQA
Cardiovascular: Cholesterol management for beneficiaries with cardiovascular cond.				✓	✓		NA	Admin/ Paper	NCQA
Cardiovascular: Medication adherence for hypertension (Part D)				✓	✓		0541	Admin	PQA
Cardiovascular: Controlling high blood pressure	✓	✓		✓	✓	✓	0018	Admin/ Paper/EHR	NCQA
Cardiovascular/ Hypertension: Improvement in blood pressure						✓	N/A	EHR	CMS
Cardiovascular: Persistence of beta-blocker treatment after a heart attack	✓				✓		0071	Admin	NCQA
Cardiovascular/ Coronary artery disease: Beta-blocker therapy						✓	0070	Admin/ EHR	AMA/PCPI
Cardiovascular/ Ischemic vascular disease: Complete lipid panel and LDL control						✓	0075	Admin/ EHR	NCQA
Cardiovascular/Ischemic vascular disease: Use of aspirin or another antithrombotic						✓	0068	Admin/ EHR	NCQA
Cardiovascular/Heart failure: ACE inhibitor or ARB therapy					✓	✓	0081	Admin/ EHR	AMA/PCPI

National Quality Strategy Measurement Domains Performance Measures	SNP	Medicaid Core	NQF MAP	MA	State Demo	MU	NQF #	Data Source	Owner
Cardiovascular/ Heart failure: Beta-blocker therapy						✓	0083	Admin/ EHR	AMA/PCPI
Primary open angle glaucoma: Optic nerve evaluation						✓	0086	Admin/ EHR	AMA/PCPI
Colon cancer: Chemotherapy						✓	0385	Admin/ EHR	AMA/ PCPI/ ASCO
Breast cancer: Hormonal therapy						✓	0387	Admin/ EHR	AMA/PCPI
Cataracts: 20/40 or better visual acuity within 90 days following cataract surgery						✓	0565	Admin/ EHR	AMA/ PCPI/ NCQA
Rheumatoid arthritis: Use of disease modifying anti-rheumatic drug (DMARD) Therapy				✓	✓		0054	Admin	NCQA
Management of urinary incontinence				✓			0030	Survey	NCQA/ HOS
Osteoporosis management in women who had a fracture	✓			✓	✓		0053	Admin	NCQA
Dementia: Cognitive assessment						✓	NA	Admin/ EHR	AMA/PCPI
Mental Health and Substance Abuse									
Adherence to antipsychotics in individuals with schizophrenia		✓			✓		1879	Admin	CMS-QIP
Antidepressant medication management	✓	✓			✓	✓	0105	Admin/ EHR	NCQA
Initiation and engagement of alcohol and other drug dependence treatment		✓	C		✓	✓	0004	Admin/ EHR	NCQA
Unhealthy alcohol use: Screening and brief counseling			E				N/A	Admin	AMA/PCPI
Major depressive disorder: Suicide risk assessment						✓	0104	Admin/ EHR	AMA/PCPI

National Quality Strategy Measurement Domains Performance Measures	SNP	Medicaid Core	NQF MAP	MA	State Demo	MU	NQF #	Data Source	Owner
Bipolar disorder and major depression: Appraisal for alcohol or chemical substance use						✓	0110	Admin/ EHR	CQAIMH
Depression remission at 12 months						✓	0710	EHR	MNCM
Depression utilization of the PHQ-9 tool						✓	0712	EHR	MNCM
Safety									
Annual monitoring for beneficiaries on persistent medications	✓	✓			✓		NA	Admin	NCQA
Potentially harmful drug-disease interactions in the elderly	✓						NA	Admin	NCQA
Use of high-risk medication in the elderly	✓		E		✓	✓	0022	Admin/ EHR	NCQA
High-risk medication use in the elderly (Part D)				✓	✓		NA	Admin	PQA
Plan all-cause readmission	✓	✓	C	✓	✓		1768	Admin	NCQA
Hospital-wide readmission			C				1780	Admin	CMS/Yale
PQI 01: Admission for diabetes, short-term complication		✓			✓		0272	Admin	AHRQ
PQI 05: Admission for COPD		✓			✓		0275	Admin	AHRQ
PQI 08: Admission for CHF		✓			✓		0277	Admin	AHRQ
PQI 15: Admission for adult asthma		✓			✓		0283	Admin	AHRQ
Cataracts: Complications within 30 days following cataract surgery						✓	0564	Admin/ EHR	AMA/ PCPI/ NCQA
Adverse drug event prevention and monitoring: Warfarin time in therapeutic range						✓	NA	EHR	CMS

National Quality Strategy Measurement Domains Performance Measures	SNP	Medicaid Core	NQF MAP	MA	State Demo	MU	NQF #	Data Source	Owner
Effective Communication and Care Coordination									
Care for older adults: Advance care planning	✓		E		✓		0326	Admin/ Paper	NCQA
Care for older adults: Medication review	✓			✓	✓		0553	Admin/ Paper	NCQA
Documentation of current medication in the medical record						✓	0419	Admin/ EHR	CMS/QIP
Follow-up after hospitalization for mental illness	✓	✓			✓		0576	Admin	NCQA
Medication reconciliation post-discharge	✓			✓	✓		0554	Admin/ Paper	NCQA
Three-item care transition measure			C		✓		0228	Survey	University of CO
Medical home system survey			E				0494	Survey	NCQA
Transition record received by discharged beneficiary			E				0647	Admin/ EHR	AMA-PCPI
Care transition record transmitted to health care professional		✓			✓		0648	Admin/ EHR	AMA-PCPI
Post-discharge continuing care plan created			E				0557	Admin/ Paper	Joint Commission
Post-discharge continuing care plan transmitted to next level of care provider upon discharge			E		✓		0558	Admin/ Paper	Joint Commission
Diabetic retinopathy: Communication with physician managing diabetes care						✓	0089	Admin/ EHR	AMA/PCPI
Closing the referral loop: Receipt of specialist report						✓	NA	EHR	CMS
SNP 6: Coordination of Medicare and Medicaid coverage			E				NA	Documented praocesses	NCQA/ CMS
Affordable Care and Appropriate Resource Use									
Prostate cancer: Avoidance of overuse of bone scan						✓	0389	Admin/ EHR	AMA/PCPI

National Quality Strategy Measurement Domains Performance Measures	SNP	Medicaid Core	NQF MAP	MA	State Demo	MU	NQF #	Data Source	Owner
Use of imaging studies for low back pain						✓	0052	Admin/ EHR	NCQA
Avoidance of antibiotic treatment in adults with acute bronchitis					✓		0058	Admin	NCQA
Total cost of care PMPM					✓		NA	Admin	NCQA
Emergency department visits per 1,000 enrollees					✓		NA	Admin	NCQA
General hospital inpatient utilization admissions					✓		NA	Admin	NCQA
Mental health services utilization per 1,000 enrollees					✓		NA	Admin	NCQA
Beneficiary- and Family-Centered Care									
Functional status assessment for knee replacement						✓	N/A	EHR	CMS
Functional status assessment for hip replacement						✓	N/A	EHR	CMS
Functional status assessment for complex chronic conditions (heart failure)						✓	N/A	EHR	CMS
CAHPS® health plan survey of beneficiary experience		✓	C	✓	✓		0006	Survey	NCQA/ AHRQ
Cultural competency implementation measure			E				1919	Survey	RAND
CARE — Consumer assessment and reports of end of life			E				1632	Survey	Center for Gerontology
Comfortable dying: Pain brought to a comfortable level within 48 hours of initial assessment			E				0209	Survey	National Hospice and Palliative Org
Beneficiaries admitted to the ICU who have care preferences documented			E				1626	Paper/EHR	RAND

National Quality Strategy Measurement Domains Performance Measures	SNP	Medicaid Core	NQF MAP	MA	State Demo	MU	NQF #	Data Source	Owner
Hospice and palliative care — Treatment preferences documented			E				1641	EHR	UNC Chapel Hill
Oncology: Medical and radiation — Pain intensity quantified						✓	0384	Admin/ EHR	AMA/PCPI
Adults' access to preventive/ambulatory health services				✓	✓		NA	Admin	NCQA
Beneficiary access and performance problems				✓	✓		NA	Admin	CMS
Members choosing to leave the plan				✓	✓		NA	Admin	CMS
Plan makes timely decisions about appeals				✓	✓		NA	Admin	CMS
Review appeals decisions				✓	✓		NA	Admin	CMS
Call center — Foreign language interpreter and TTY/TDD avail.				✓	✓		NA	Admin	CMS
Call center — Pharmacy hold time				✓	✓		NA	Admin	CMS
Appeals auto-forward				✓	✓		NA	Admin	CMS
Appeals upheld				✓	✓		NA	Admin	CMS
Enrollment timeliness				✓	✓		NA	Admin	CMS
Complaints about the drug plan				✓	✓		NA	Admin	CMS
Members choosing to leave the drug plan				✓	✓		NA	Admin	CMS
Getting information from drug plan				✓	✓		NA	Admin	CMS

SNP: Required HEDIS reporting for all Special Needs Plans (SNP)

Medicaid Core: Department of Health and Human Services Initial Core Set of Health Care Quality Measures for Medicaid-Eligible Adults

NQF MAP: Measure recommended by the NQF Measurement Application Partnership for Beneficiaries Dually Eligible for Medicare and Medicaid (MAP); C — Core set recommended measure; E — Expansion set recommended measure

MA: Medicare Advantage Plan Rating Program (also known as Star rating system)

State Demos: States which have proposed the use of specific measures to evaluate care for beneficiaries enrolled integrated care plans (MA,CO, CT, HI, IA, OH, MO, OK, IL, NM). Note, CT did not list specific measures but the measure domains matched closely to existing measures.

MU: Measures for adults included in the final rule for Medicare and Medicaid electronic health record incentive program for eligible providers stage 2 (Meaningful Use — MU)

NQF#: NQF Endorsed Measure Number

TABLE E. Existing Performance Measures for Long Term Services and Supports Measures Used in National Programs

Measures in this table were identified through two sources: (1) The National Quality Forum Measurement Application Partnership (NQF-MAP) recommendations for post-acute care and long-term care and (2) The NQF MAP recommendations for Home and Community Based Services (HCBS) measures applicable to beneficiaries with dual eligibility for Medicare and Medicaid. These measures address aspects of care related to post-acute care and long-term services and supports (nursing home, home and community-based care, skilled-nursing facility, rehabilitation facility).

Measurement Domains/ Performance Measures	Nursing Home Compare	Home Health Compare Measures	AARP LTSS Score-card	National Balancing Indicators	NQF HCBS Limited Set	NQF #	Source
Falls Measures							
Percentage of residents experiencing one or more falls with major injury (long stay)	✓					0674	MDS
Multi-factorial fall risk assessment conducted for beneficiaries 65 and over		✓				0537	OASIS-C
Percentage of residents who self-report moderate to severe pain (short-stay)	✓					0676-0677	MDS
Pain Measures							
The percentage of residents on a scheduled pain medication regimen on admission who self-report a decrease in pain intensity or frequency (short-stay)	✓					0675	MDS
Pain assessment conducted		✓				0523	OASIS-C
Pain intervention implemented during short-term episode of care		✓				0524	OASIS-C
Improvement in pain interfering with activity		✓				0177	OASIS-C
Pressure Ulcers Measures							
Percentage of residents with pressure ulcers that are new or worsened (short stay)	✓					0678	MDS
Percentage of high-risk residents with pressure ulcers (long stay)	✓					0679	MDS

Measurement Domains/ Performance Measures	Nursing Home Compare	Home Health Compare Measures	AARP LTSS Score-card	National Balancing Indicators	NQF HCBS Limited Set	NQF #	Source
Pressure ulcer prevention in plan of care		✓				0538	OASIS-C
Pressure ulcer prevention plans implemented		✓				0539	OASIS-C
Pressure ulcer risk assessment conducted		✓				0540	OASIS-C
Vaccination Measures							
Percentage of nursing home residents who were assessed and appropriately given the seasonal influenza vaccine (short stay)	✓					0680-0681	MDS
Influenza immunization received for current flu season		✓				0522	OASIS-C
Percentage of residents who were assessed and appropriately given the pneumococcal vaccine	✓					0682-0683	MDS
Pneumococcal polysaccharide vaccine (PPV) ever received		✓				0525	OASIS-C
ADL/Functioning Measures							
Percentage of residents whose need for help with activities of daily living has increased	✓					0688	MDS
Improvement in bathing		✓				0174	OASIS-C
Improvement in bed transferring		✓				0175	OASIS-C
Improvement in management of oral medications		✓				0176	OASIS-C
Improvement in ambulation/locomotion		✓				0167	OASIS-C
Degree to which beneficiaries experience an increased level of functioning					✓		Commission on Accreditation of Rehabilitation Facilities

Measurement Domains/ Performance Measures	Nursing Home Compare	Home Health Compare Measures	AARP LTSS Score-card	National Balancing Indicators	NQF HCBS Limited Set	NQF #	Source
Unmet need in ADLs/ IADLs (11 measures total)					✓		Senior Center Performance Outcome Measures Project Participant Experience Survey
Other Clinical Measures							
Improvement in status of surgical wounds		✓				0178	OASIS-C
Improvement in dyspnea		✓				0179	OASIS-C
Diabetic food care and beneficiary/caregiver education implemented during short-term episode of care		✓				0519	OASIS-C
Drug education on all medications provided to beneficiary/caregiver during short-term episodes of care		✓				0520	OASIS-C
Heart failure symptoms addressed during short-term episodes of care		✓				0521	OASIS-C
Acute care hospitalization		✓				0171	OASIS-C
Percentage of residents with urinary tract infection	✓					0684-0685	MDS
Percentage of residents who have/had a catheter inserted and left in their bladder	✓					0686	MDS
Percentage of residents who were physically restrained	✓					0687	MDS
Percentage of residents who lose too much weight	✓					0689	MDS
Mental Health Measures							
Percentage of residents who have depressive symptoms	✓					0690	MDS
Depression assessment conducted		✓				0518	OASIS-C

Measurement Domains/ Performance Measures	Nursing Home Compare	Home Health Compare Measures	AARP LTSS Score-card	National Balancing Indicators	NQF HCBS Limited Set	NQF #	Source
Beneficiary Experience							
Degree to which beneficiaries report that staff are sensitive to their cultural, ethnic, or linguistic backgrounds and degree to which beneficiaries felt they were respected by staff					✓		Commission on Accreditation of Rehabilitation Facilities
Degree of active beneficiary treatment decision participation					✓		Commission on Accreditation of Rehabilitation Facilities
Case manager helpfulness					✓		Senior Center Performance Outcome Measures Project Participant Experience Survey
Degree to which beneficiaries were satisfied with overall services					✓		Commission on Accreditation of Rehabilitation Facilities
Service satisfaction scales: home worker; personal care; home-delivered meals					✓		Service Adequacy and Satisfaction Instrument
Home health CAHPS®		✓				0517	OASIS-C
Beneficiary Quality of Life							
Degree to which people express satisfaction with relationships					✓		Commission on Accreditation of Rehabilitation Facilities
Satisfaction with close friends					✓		Quality of Life Scale (modified by Burkhardt)
Satisfaction with parents, siblings, other relatives relationships					✓		Quality of Life Scale (Burkhardt version for chronic illness)
Percentage of adults age 18+ with disabilities in the community satisfied or very satisfied with life			✓				Data from 2009 BRFSS (NCCDPHP, BRFSS 2009)

Measurement Domains/ Performance Measures	Nursing Home Compare	Home Health Compare Measures	AARP LTSS Score-card	National Balancing Indicators	NQF HCBS Limited Set	NQF #	Source
Participants reporting unmet need for community involvement					✓		Senior Center Performance Outcome Measures Project Participant Experience Survey
Access Measures							
Emergency department use without hospitalization		✓				NA	OASIS-C
Timely initiation of care		✓				0526	OASIS-C
Percentage of caregivers usually or always getting needed support			✓		✓		Institute analysis of 2009 BRFSS (NCCDPHP, BRFSS 2009)
Ability to identify case manager					✓		Senior Center Performance Outcome Measures Project Participant Experience Survey
Ability to contact case manager					✓		Senior Center Performance Outcome Measures Project Participant Experience Survey
Degree to which people with identified physical health problems obtain appropriate services and degree to which health status is maintained and improved					✓		Commission on Accreditation of Rehabilitation Facilities
Percentage of adults age 18+ with disabilities in the community usually or always getting needed support			✓		✓		Data from 2009 BRFSS (NCCDPHP, BRFSS 2009)
Waiver waitlist				✓	✓		NBIC using CMS Medicaid Waiver Database, and State Self-Assessment

Measurement Domains/ Performance Measures	Nursing Home Compare	Home Health Compare Measures	AARP LTSS Score-card	National Balancing Indicators	NQF HCBS Limited Set	NQF #	Source
Proportion of people with disabilities reporting recent preventive health care visits (individual-level)				✓	✓		NBIC calculations using the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System (BRFSS) data
Proportion of people reporting that service coordinators help them get what they need (individual-level)				✓	✓		NBIC using National Core Indicators (NCI) Data
Availability of self-direction options				✓	✓		NBIC using CMS Medicaid Waiver Database, and State Self-Assessment
Tools and programs to facilitate beneficiary choice (composite indicator, scale 0-4)			✓		✓		AARP conducted a state survey to collect information about states' single entry point systems and various functions that facilitate beneficiary choice. Data from State LTSS Scorecard Survey (AARP PPI, Scorecard 2010).
Other Measures							
Nurse staffing hours — 4 parts	✓					0190	MDS
Proportion of Medicaid HCBS spending of the total Medicaid LTC spending				✓	✓		NBIC using Thomson Reuters
Coordination between HCBS and institutional services				✓	✓		State Self-Assessment

Data Sources: NQF Long-Term Care/Post-Acute Care MAP; NQF Duals MAP review of Home and Community Based Waiver Measures

MDS (Minimum Data Set Nursing home survey); OASIS (Medicare Home and Community Based Care Survey); NBIC (National Balancing Indicators Contract); BRFSS (Behavioral Risk Factor Surveillance System);

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Assessing Measure Readiness for Application in the Dual Eligible Beneficiary Population

Family of Measures

A "family of measures" is a set of measures that relate to one another. Measure families are designed to offer the best available measures that address an important quality issue so that stakeholders across the continuum of care can select the subset that fits their needs. Consider the following characteristics highlighted by MAP when selecting measures for inclusion.

- **NQF Endorsement:** NQF-endorsed® measures are preferred for inclusion because they have met criteria for importance, scientific rigor, feasibility, and usability.
- **Potential impact:** Include measures with the most power to produce improved health, such as outcome measures, composite measures, and cross-cutting measures broadly defined to include a large denominator population.
- **Improvability:** Include measures where quality improvement would be expected to have a substantial effect or address health risks and conditions known to have disparities in care.
- **Relevance:** Include measures that address health risks and conditions that are highly prevalent, severe, costly, or otherwise particularly burdensome for dual eligible beneficiary population.
- **Person-centeredness:** Include measures that are meaningful and important to consumers, such as those that focus on patient engagement, experience, or other patient-reported outcomes.
- **Alignment:** Include measures already reported for existing measurement programs to minimize participants' data collection and reporting burden. Consistent use of measures helps to synchronize public and private sector programs around the National Quality Strategy and amplify the quality signal.
- **Reach:** Include measures relevant to a range of care settings, provider types, and levels of analysis.

Starter Set

Within the Family of Measures for Dual Eligible Beneficiaries, MAP will identify a Starter Set of measures comprised of those that are appropriate for immediate use. Measures in the Starter Set should work well within the dual eligible population *as they are currently designed*. Consider the following characteristics, in addition to those above, when selecting measures for inclusion.

- **Readiness:** Include measures that are ready to be used as-is, without modifications that may have been previously suggested by MAP. Use of measures should not lead to negative unintended consequences.
- **Feasibility:** Include measures where data required to calculate them is readily available or retrievable without undue burden.
- **Comprehensiveness:** Once compiled, the Starter Set should include measures relevant to each of the five high-leverage opportunity areas identified by the MAP Dual Eligible Beneficiaries Workgroup.

NATIONAL
QUALITY FORUM

Memo

July 12, 2013

Family of Measures for Dual Eligible Beneficiaries: Preliminary Findings from MAP Dual Eligible Beneficiaries Workgroup

Purpose and Approach

[insert text]

Family of Measures for Dual Eligible Beneficiaries

A "family of measures is a set of measures that relate to one another, designed to identify the best available measures that address an important quality issue across the continuum of care.

Considerations for Measure Selection

- NQF Endorsement
- Potential Impact
- Improvability
- Relevance
- Person-Centeredness
- Alignment
- Reach

Table 1: Family of Measures for Dual Eligible Beneficiaries

Measure Name, NQF Measure Number, and Status	Measure Description	High-Leverage Opportunity Area	Rationale and Alignment Opportunities

Starter Set for Short-Term Implementation

The "Starter Set" is comprised of the measures from the Family of Measures, above, that are appropriate for use within the dual eligible population as they are currently designed.

Considerations for Measure Selection

- Readiness
- Feasibility
- Comprehensiveness

PAGE 2

Table 2: Starter Set of Measures within the Family for Dual Eligible Beneficiaries

Measure Name and NQF Measure Number	Comments on Potential Application

Measure Gaps and Future Measure Development

The Workgroup has identified high-priority gaps in measurement throughout its work. Gap areas of particular focus included:

[insert text]

Alignment Between "XYZ Program" and the Family of Measures

A family of measures is multi-purpose; it is a starting point for choosing measures that fit the needs of a particular program. A direct comparison between measures in the family and an established program's set of measures builds and understanding of current alignment and highlights opportunities to improve it.

[insert analysis]

Key Themes for Measuring Healthcare Quality in Populations with Behavioral and Cognitive Needs

The Workgroup discussed performance measurement issues that are unique to the population of individuals with disabling behavioral and/or cognitive conditions. High-need subgroups included individuals with one or more of the following conditions: 1) serious mental illness, 2) substance use disorders, 3) acquired cognitive impairment (e.g., dementia), and 4) intellectual/developmental disability. Many quality issues were found to overlap one or more of these high-need subgroups.

In discussion, Workgroup members emphasized:

[insert text]

Potential Measures for High-Need Beneficiaries with Disabling Behavioral/Cognitive Conditions

PAGE 3

Table 3: Measures Applicable to Individuals with Behavioral/Cognitive Conditions

Measure Name, NQF Measure Number, and Status	All High-Need Subgroups	SMI	SUD	Acquired Cognitive Impairment	ID/DD

Next Steps for Stakeholders

National and Federal Efforts

[insert text]

State and Local Efforts

[insert text]

Appendix A: Roster for MAP Dual Eligible Beneficiaries Workgroup

Appendix B: Details of Selected Measures

Table will include fields for measure title, measure description, numerator, denominator, exclusions, level(s) of analysis, care setting(s), data source(s), measure steward, mapping to National Quality Strategy priorities, known uses in public and private programs, and the Workgroup's suggested modifications or other notes.

Meeting Summary

MAP Dual Eligible Beneficiaries Workgroup Web Meeting

April 30, 2013

The National Quality Forum (NQF) convened a web meeting of the Measure Applications Partnership (MAP) Dual Eligible Beneficiaries Workgroup on Tuesday, April 30, 2013. In addition to members listed below, 43 members of the public attended this meeting. An online archive of the meeting is available.

Workgroup Members in Attendance:

Alice Lind (Chair)	
Richard Bringewatt, SNP Alliance	Joan Levy Zlotnik, National Association of Social Workers
Gwendolen Buhr, American Medical Directors Association	Laura Linebach, L.A. Care Health Plan
Adam Burrows, National PACE Association	Samantha Meklir, Health Resources and Services Administration
Mady Chalk, [subject matter expert: Substance Abuse]	Tina Nuttall, Humana, Inc. (substitute for George Andrews)
Alfred Chiplin, Center for Medicare Advocacy	D.E.B. Potter, Agency for Healthcare Research and Quality
Anne Cohen, [subject matter expert: Disability]	Cheryl Powell, CMS Medicare-Medicaid Coordination Office
Steven Counsell, National Association of Public Hospitals and Health Systems	Juliana Preston, [subject matter expert: Measure Methodologist]
Leonardo Cuello, National Health Law Program	Clarke Ross, Consortium for Citizens with Disabilities
James Dunford, [subject matter expert: Emergency Medical Services]	Marisa Scala-Foley, Administration for Community Living

Welcome and Review of Meeting Objectives

Session led by Alice Lind, MAP Dual Eligible Beneficiaries Workgroup Chair, with an additional presentation from Cheryl Powell, Centers for Medicare & Medicaid Services (CMS).

Ms. Lind welcomed the group to the web meeting, introduced new organizational representatives and workgroup members, and reviewed the meeting objectives:

- Begin work on measures for dual eligible beneficiaries with disabling behavioral or cognitive conditions;
- Prepare for in-person meeting by introducing the approach for creating a family of measures;
- Review public comments received on December 2012 Interim Report and discuss how to address them going forward;

- Develop understanding of the quality issues facing beneficiaries with behavioral or cognitive health needs and the opportunities for improvement through measurement.

Ms. Powell shared her thoughts on the past and present efforts of this workgroup, highlighting how useful the MAP reports have been to the ongoing work of the Medicare-Medicaid Coordination Office and their efforts to improve the quality of care. MAP has helped to set the framework for the field and advance thinking about quality measurement among vulnerable individuals. She encouraged the workgroup to continue gathering multiple perspectives, including that of the beneficiary.

How Will the Pieces Fit Together?

Session led by Ms. Lind.

Ms. Lind reviewed the Evolving Core Set of Measures for Dual Eligible Beneficiaries and measures for high-need subgroups as inputs for a family of measures. A *family of measures* is a term the workgroup will use to describe a set of measures that relate to one another; address the highest priorities for measurement; and include the best available measures for a particular topic and prioritized gaps. It provides end-users with a pre-screened group of measures carefully selected to work together for a given topic and transcends any specific healthcare service location to evaluate an individual's experience across healthcare settings over time.

One member asked if the workgroup should give preference to selecting measures that are more general and versatile to facilitate alignment. Ms. Lind shared that the workgroup had previously selected measures both for their specificity and versatility; the workgroup should consider the factors that make dual eligible beneficiaries unique. Another member raised the importance of considering application of measures within integrated health systems. The workgroup will continue to consider a balanced approach to measure selection at the upcoming in-person meeting.

Ms. Lind reviewed public comments received on MAP's December 2012 Interim Report. Workgroup member Clarke Ross, representing the Consortium for Citizens with Disabilities, asked for clarification of public comments on "accessibility." He highlighted that accessibility has multiple meanings, one being compliance with legal requirements of the Americans with Disabilities Act, another being the ability to engage with the health system. Anne Cohen, the disability subject matter expert for the workgroup, commented on the importance of reporting quality measures in a simple and meaningful way so that they are actionable by healthcare organizations and can also inform consumers.

State of Performance Measurement in Behavioral Health

Session led by Ms. Lind, with additional presentations by Lisa Patton, SAMHSA; NQF Behavioral Health Steering Committee co-chair, Harold Pincus; and Behavioral Health Steering Committee member, Mady Chalk.

Ms. Lind presented an overview of the Draft SAMHSA National Framework for Quality Improvement in Behavioral Health Care. The purpose of the framework and its six priorities, goals, and opportunities for successes were reviewed to further the workgroup's synchronization with other national efforts. Following Ms. Lind's presentation, Dr. Patton provided an update on SAHMSA's ongoing refinements to the framework and corresponding measure nomination and review process. She notified participants that the next iteration is expected to be made available for public comment in four to six weeks.

Dr. Pincus and Dr. Chalk provided an overview on the progress of the NQF Behavioral Health Consensus Development Project. The project includes three phases: phase one recommended 10 measures for endorsement, phase two is currently underway with the review of 25 measures, and a third phase is expected. The Steering Committee has recognized many gaps in measurement and experts noted some of the issues complicating the development of measures in this field:

- Need for measures to fit person-centered models of care, specifically for recovery;
- Inadequate screening for alcohol and drug use, including prescription drug interactions;
- Lack of appropriate follow-up for mental health and substance use disorders following a positive screen; and,
- Widespread delay in implementation and use of quality measures, especially the availability of health information technology (HIT).

The MAP Dual Eligible Beneficiaries Workgroup will consider these factors when selecting measures and noting gaps at the upcoming meeting.

What Is Known about Quality Issues for Dual Eligible Beneficiaries with Disabling Behavioral and Cognitive Conditions?

Session led by Megan Duevel Anderson, Project Analyst, NQF and Amaru Sanchez, Project Analyst, NQF.

Ms. Duevel Anderson and Mr. Sanchez presented demographic data regarding high-need beneficiaries with disabling behavioral and cognitive conditions, drawn from a staff-conducted literature review. High-need dual eligible beneficiaries consume a disproportionate amount of Medicare and Medicaid resources, often have multiple diagnoses, and have complex social and health care needs. The service needs of high-need beneficiaries present opportunities to reduce cost and improve quality.

Key Issues for Measurement

Session led by Sarah Lash, Senior Program Director, NQF.

Ms. Lash discussed a list of proposed key issues for measurement for high-need dual eligible beneficiaries with disabling behavioral health and cognitive conditions. The key issues arose from the staff-conducted literature review and are organized by high-leverage opportunities for improvement. Workgroup members were invited to submit feedback on the quality issues list to NQF staff. The key issues will be the foundation for the scan of available measures to be reviewed at the May in-person meeting on the best measures.

Public Comment, Wrap Up, and Summary

The public was given an opportunity to comment. One public commenter questioned if a single measure might apply to multiple categories within a family of measures. NQF staff clarified that any measure selected may fit more than one opportunity area (e.g., both quality of life and mental health). Additionally, a single measure can be included in more than one of MAP's families of measures on different topics.

The meeting concluded with a discussion of next steps. The next meeting of the MAP Dual Eligible Beneficiaries Workgroup will be held on May 21-22, 2013, in Washington, DC. Please see the NQF website for details.

BIOS OF THE MAP DUAL ELIGIBLE BENEFICIARIES WORKGROUP

CHAIR (VOTING)

Alice Lind, MPH, BSN

Alice R. Lind is Director of Long Term Supports and Services and Senior Clinical Officer at the Center for Health Care Strategies (CHCS). She plays an integral role in the organization's efforts to improve care for Medicaid's high-need, high-cost populations, providing technical assistance through a variety of national initiatives. She is also involved in ongoing efforts to improve provider practices and child health quality. Ms. Lind has extensive clinical and Medicaid program development expertise through her 15 years of work in Washington State. She was previously Chief of the Office of Quality and Care Management in the Division of Healthcare Services, Health and Recovery Services Administration for Washington State, where she was responsible for the development and implementation of care coordination programs for Medicaid beneficiaries with chronic conditions and disabilities. She led the start up of a disease management program for 20,000 fee-for-service clients with asthma, congestive heart failure, diabetes, and end-stage renal disease. Under her direction, Washington implemented managed care programs that integrate health care, behavioral health and long-term care for Medicaid and Medicare dual eligible beneficiaries. In prior positions, Ms. Lind managed Washington's Quality Management section, which was responsible for conducting research and evaluation on the quality of care provided to Medicaid managed care clients. She has held clinical positions in occupational health, hospice home care, managing a long-term care facility for terminally ill persons with AIDS, and intensive care. Ms. Lind received a master's degree in public health from the University of North Carolina-Chapel Hill, and a bachelor's degree in nursing from Texas Christian University.

ORGANIZATIONAL MEMBERS (VOTING)

AMERICAN ASSOCIATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Margaret Nygren, EdD

Dr. Nygren has 20 years of experience in the field of intellectual and developmental disabilities in a variety of capacities, including administrator, researcher, policy analyst, and consultant. As Executive Director of AAIDD, she has the honor of leading the oldest Association of professionals concerned with the promotion of progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities. In her most recent previous position as Associate Executive Director for Program Development at the Association of University Centers on Disabilities (AUCD), Dr. Nygren was responsible for the management of national datasets and programs funded by the US Administration on Developmental Disabilities (ADD), Maternal and Child Health Bureau (MCHB), US Department of Education (ED), and US Department of Labor (DOL). Within the Disabled and Elderly Health Programs Group at the Centers for Medicare and Medicaid Services (CMS), Dr. Nygren completed a Fellowship where she provided and technical assistance in program policy areas that supported the President's New Freedom Initiative, including the development of Money Follows the Person initiative. Other previous positions include Director of the Center on Aging and Disabilities at the Lieutenant Joseph P. Kennedy Institute in Washington, DC, and Director of Family Support Services and Director of Mental Retardation Services at Kit Clark Senior Services in Boston. Dr. Nygren earned a

Doctorate of Education in Organizational Leadership from Nova Southeastern University, a MA in Clinical Psychology from West Virginia University, and a BA in Psychology from Beloit College.

AMERICAN FEDERATION OF STATE, COUNTY AND MUNICIPAL EMPLOYEES

Sally Tyler, MPA

Sally Tyler is the senior health policy analyst for the American Federation of State, County and Municipal Employees (AFSCME), based in Washington, DC. She reviews both federal and state health policy for potential impact on the union's members. Areas of specialization include Medicaid, health care delivery systems, health care information technology and quality standards reporting. She recently served as co-chair of the steering committee for the National Quality Forum's patient safety project on serious reportable events. She was a consumer member of the Health Care Information Technology Standards Panel (HITSP) as it made recommendations for interoperability regarding adoption of electronic health records. She is on the advisory board of the American Academy of Developmental Medicine. Tyler has an undergraduate degree from Emory University and a graduate degree from Harvard's Kennedy School of Government.

AMERICAN GERIATRICS SOCIETY

Jennie Chin Hansen, RN, MS, FAAN

Jennie Chin Hansen is CEO of the American Geriatrics Society and immediate past President of AARP. The AGS is the nation's leading membership organization of geriatrics healthcare professionals, whose shared mission is to improve the health, independence and quality of life of older people. As a pivotal force in shaping practices, policies and perspectives in the field, the Society focuses on: advancing eldercare research; enhancing clinical practice in eldercare; raising public awareness of the healthcare needs of older people; and advocating for public policy that ensures older adults access to quality, appropriate, cost-effective care. In 2005, Hansen transitioned after nearly 25 years with On Lok, Inc., a nonprofit family of organizations providing integrated, globally financed and comprehensive primary, acute and long-term care community based services in San Francisco. The On Lok prototype became the 1997 federal Program of All Inclusive Care to the Elderly (PACE) Program into law for Medicare and Medicaid. PACE now has programs in 30 states. In May 2010, she completed her two year term as President of AARP during the national debate over health care reform, in addition to, the other six years she was on AARP's national board of directors. Since 2005, she has served as federal commissioner of the Medicare Payment Advisory Commission (MedPAC). In 2010 she served as an IOM member on the RWJ Initiative on the Future of Nursing. She currently serves as a board member of the SCAN Foundation and a board officer of the National Academy of Social Insurance. In 2011 she begins as a board member of the Institute for Healthcare Improvement (IHI). Jennie has received multiple awards over the years including the 2003 Gerontological Society of America Maxwell Pollack Award for Productive Living, a 2005 Administrator's Achievement Award from the Centers for Medicare and Medicaid Services, and an honorary doctorate from Boston College in 2008.

AMERICAN MEDICAL DIRECTORS ASSOCIATION

Gwendolen Buhr, MD, MHS, Med, CMD

Dr. Gwen Buhr is an Associate in Medicine in the Division of Geriatrics and has served as the Medical Director at The Forest at Duke Retirement Community. Dr. Buhr completed her medical training at the University of Texas Health Science Center at San Antonio, an internal medicine residency at Moses H. Cone Memorial Hospital in Greensboro, North Carolina, and a fellowship in geriatric medicine at Duke University. Following her fellowship, Dr. Buhr was Medical Director and Attending Physician with Physicians Eldercare in Winston Salem, North Carolina (2004). Dr. Buhr is a member of The American

Medical Directors Association (AMDA) and was the recipient of its Quality Improvement Award in 2003. She now serves as the Secretary/ Treasurer for the North Carolina Division of AMDA. Dr. Buhr also is a member of other medical societies including the American Geriatrics Society, the American College of Physicians, and the Christian Medical and Dental Association. Dr. Buhr is licensed by the North Carolina Board of Medical Examiners.

CENTER FOR MEDICARE ADVOCACY

Alfred Chiplin, JD, M.Div.

Alfred J. Chiplin, Jr., Esq. is a Senior Policy Attorney with the Center for Medicare Advocacy, Inc. in its Washington, DC office. His practice is devoted primarily to health care matters, with a concentration on Medicare and managed care coverage and appeal issues. He is also a specialist in legal assistance development and services under the Older Americans Act. Mr. Chiplin served as a consulting attorney with the Consumer Coalition for Quality Health Care and, for over 10 years, as a staff attorney for the National Senior Citizens Law Center, where he focused on the Medicare program and on developments in managed care. He also coordinated Older Americans Act programs for the National Senior Citizens Law Center, including planning and developing the annual Joint Conference on Law and Aging (JCLA). He currently serves on the planning committee for the annual National Aging and Law Conference. Mr. Chiplin is the immediate past chair of the Public Advisory Group (PAG) of the Joint Commission on Accreditation of health care Organizations (JCAHO). Along with Judith A. Stein, Mr. Chiplin is co-editor-in-chief of the Medicare Handbook (Aspen Publishers, Inc., updated annually). Mr. Chiplin received his J.D. degree from the George Washington University and his M. Div. from Harvard University. He is a Fellow of the National Academy of Elder Law Attorneys and a former member of its board of directors, including its executive committee. He is also a member of the National Academy of Social Insurance (NASI), and served on its "Medicare and Markets" study panel.

CONSORTIUM FOR CITIZENS WITH DISABILITIES

E. Clarke Ross, DPA

Clarke has worked 40 years with six national mental health and disability organizations. He currently is the policy associate for the American Association on Health and Disability (AAHD) and is the 2011-2012 Chair of the “Friends of NCBDDD” (National Center on Birth Defects and Developmental Disabilities) at CDC (Centers for Disease Control and Prevention) Advocacy Coalition, having previously served as the Friends chair. He is a member of the SAMHSA Wellness Campaign Steering Committee. Clarke represents the Consortium for Citizens with Disabilities (CCD) on the NQF MAP work group on persons dually eligible for Medicare and Medicaid. His work history includes Chief Executive Officer of CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder; Deputy Executive Director for Public Policy, NAMI – National Alliance on Mental Illness; Executive Director, American Managed Behavioral Healthcare Association (AMBHA); Assistant Executive Director for Federal Relations and then Deputy Executive Director, National Association of State Mental Health Program Directors (NASMHPD); and Director of Governmental Activities, UCPA – United Cerebral Palsy Associations (UCPA). His doctorate is in public administration (D.P.A.) from The George Washington University, class of 1981. He is the father of a 21-year-old son with special challenges.

HUMANA, INC.

George Andrews, MD, MBA, CPE

Dr. George A. Andrews serves as Humana's Corporate Chief of Quality. He oversees Clinical Quality strategy development, Quality Improvement Activities and Patient Safety initiatives. He works closely with the National Network Operations to engage the provider community and enhance provider collaboration with Humana's clinical programs that would lead to improvements in member health outcomes and well-being. Andrews, a former Fulbright scholar, is a diplomat with the National Board of Medical Examiners. He is board certified in the areas of internal medicine and cardiovascular disease and is a fellow of the American College of Physicians, American College of Cardiology and the American College of Chest Physicians. He also is a certified physician executive of the American College of Physician Executives. Before joining Humana in 2008 as the Mid-South Region's Chief Medical Officer, Andrews served as the SVP/Chief Medical Officer at Cariten Healthcare, a Covenant Health Affiliate for 5 years. Prior to that Andrews served as the medical director of health services for CIGNA HealthCare's Florida and North Carolina territories. He began working with CIGNA HealthCare in September 1998. Trained as a cardiologist, Andrews was medical director of cardiology and had a consultative cardiology / internal medicine clinical practice with Coral Springs Cardiology Associates in Coral Springs, Fla., for more than 15 years. Andrews received a master's degree in business administration from the University of South Florida. His medical training includes a cardiology fellowship at Jackson Memorial Hospital at the University Of Miami School Of Medicine in Florida and an internal medicine residency at Columbia Presbyterian Hospital in New York. He earned his doctor of medicine degree from Mount Sinai School of Medicine in New York and completed his undergraduate studies with a magna cum laude bachelor's degree at Columbia University in New York.

L.A. CARE HEALTH PLAN

Laura Linebach, RN, BSN, MBA

Laura Linebach, RN, MBA is the Quality Improvement Director for L.A. Care Health Plan, the largest public entity health plan in the country with over 800,000 members. She directs the company-wide quality improvement programs as well as the disease management program for several product lines including Medicaid and Medicare HMO Special Needs Plan. Before L.A. Care, she was the Quality improvement Director in the commercial HMO area. She has more than 30 years of experience as a healthcare quality professional and leader and has taught numerous classes on nursing history and Quality Improvement throughout her career. Ms. Linebach has had extensive experience in quality management in the military, managed care organizations, community mental health centers and the state mental health hospital setting. She has led organizations through multiple successful NCQA accreditation reviews as well as several of The Joint Committee visits. She founded the Nursing Heritage Foundation in Kansas City Missouri to collect and preserve nursing history and has written several articles related to nursing history. Ms Linebach also served as a flight nurse in the Air Force Reserves and later as Officer-in-Charge of the Immunization Clinic for the 442nd Medical Squadron. She is a member of the National Association for Healthcare Quality and the California Association for Healthcare Quality. Ms. Linebach has a Bachelor of Science degree in nursing from Avila College, Kansas City, Missouri and a master's in history as well as business administration from the University of Missouri-Kansas City.

NATIONAL ASSOCIATION OF PUBLIC HOSPITALS AND HEALTH SYSTEMS

Steven Counsell, MD

Steven R. Counsell, MD is the Mary Elizabeth Mitchell Professor and Chair in Geriatrics at Indiana University (IU) School of Medicine and Founding Director of IU Geriatrics, a John A. Hartford Foundation Center of Excellence in Geriatric Medicine. He serves as Chief of Geriatrics and Medical Director for Senior Care at Wishard Health Services, a public safety net health system in Indianapolis, Indiana. Dr. Counsell recently returned from Australia where as an Australian American Health Policy Fellow he studied "Innovative Models of Coordinating Care for Older Adults." Prior to his sabbatical, he served as Geriatrician Consultant to the Indiana Medicaid Office of Policy and Planning. Dr. Counsell is a fellow of the American Geriatrics Society (AGS), immediate past Chair of the AGS Public Policy Committee, and current member of the AGS Board of Directors. Dr. Counsell has conducted large-scale clinical trials testing system level interventions aimed at improving quality, outcomes, and cost-effectiveness of healthcare for older adults. He was the PI for the NIH funded trial of the Geriatric Resources for Assessment and Care of Elders (GRACE) care management intervention shown to improve quality and outcomes of care in low-income seniors, and reduce hospital utilization in a high risk group. Dr. Counsell was a 2009-2010 Health and Aging Policy Fellow and is currently working to influence health policy to improve integration of medical and social care for vulnerable elders.

NATIONAL ASSOCIATION OF SOCIAL WORKERS

Joan Levy Zlotnik, PhD, ACSW

Dr. Zlotnik has more than 20 years of experience working in leadership positions within national social work organizations. Her pioneering work has focused on forging academic/agency partnerships and on strengthening the bridges between research, practice, policy and education. She currently serves as the director of the Social Work Policy Institute (SWPI), a think tank established in the NASW Foundation. Its mission is to strengthen social work's voice in public policy deliberations. SWPI creates a forum to examine current and future issues in health care and social service delivery by convening together researchers, practitioners, educators and policy makers to develop agendas for action. Dr. Zlotnik served as the director of the Strengthening Aging and Gerontology Education for Social Work (SAGE-SW), the first project supported by the John A. Hartford Foundation as part of its Geriatric Social Work Initiative (GSWI) and has undertaken several projects to better meet psychosocial needs in long term care. Dr. Zlotnik's work in aging, family caregiving and long term care has been recognized through her election as a Fellow of the Gerontological Society of America and as a recipient of the Leadership Award of the Association for Gerontology Education in Social Work (AGE-SW). Prior to being appointed as director of SWPI, Dr. Zlotnik served for nine years as the Executive Director of the Institute for the Advancement of Social Work Research (IASWR), working closely with the National Institutes of Health (NIH), other behavioral and social science disciplines and social work researchers. Under her leadership the growth in social work research was documented and training and technical assistance was offered to doctoral students, early career researchers and deans and directors on building social work research infrastructure and capacity. Previous to IASWR she served as Director of Special Projects at the Council on Social Work Education (CSWE) and as a lobbyist and Staff Director of the Commission on Families for the National Association of Social Workers. Dr. Zlotnik is an internationally recognized expert on workforce issues for the social work profession, and is the author of numerous publications covering the lifespan including developing partnerships, enhancing social work's attention to aging, providing psychosocial services in long term care, and evidence-based practice. She holds a PhD in Social Work from the University of Maryland, an MSSW from the University of Wisconsin-Madison, and a BA from the University of Rochester. Dr. Zlotnik is an NASW Social Work Pioneer© was recognized by the National Institute of Health's (NIH) Social Work Research Working Group for her efforts on behalf of social work research at NIH, and is a recipient of the Association of Baccalaureate Social Work Program Director's (BPD) Presidential Medal of Honor.

NATIONAL HEALTH LAW PROGRAM

Leonardo Cuello, JD

Leonardo Cuello joined the National Health Law Program in December 2009 as a Staff Attorney in the D.C. office. Leonardo works on health care for older adults, reproductive health, and health reform implementation. Prior to joining NHeLP, Leonardo worked at the Pennsylvania Health Law Project (PHLP) for six years focusing on a wide range of health care issues dealing with eligibility and access to services in Medicaid and Medicare. From 2003 to 2005, Leonardo was an Independence Foundation Fellow at

PHLP and conducted a project focused on immigrant and Latino health care, including direct representation of low-income immigrants and Latinos. From 2006 to 2009, Leonardo worked on numerous Medicaid eligibility and services issues though direct representation and policy work, and served briefly as PHLP's Acting Executive Director. During that time, he also worked on Medicare Part D implementation issues, PHLP's Hospital Accountability Project, and also served as legal counsel to the Consumer Subcommittee of Pennsylvania's Medical Care Advisory Committee. Leonardo graduated with a B.A. from Swarthmore College and a J.D. from The University of Pennsylvania Law School.

NATIONAL PACE ASSOCIATION

Adam Burrows, MD

Dr. Adam Burrows has been the Medical Director of the Upham's Elder Service Plan, the PACE program operated by the Upham's Corner Health Center in Boston, since the program's inception in 1996. Dr. Burrows is a member of the Boston University Geriatrics faculty and Assistant Professor of Medicine at the Boston University School of Medicine, where he has twice received the Department of Medicine's annual Excellence in Teaching Award for community-based faculty. Dr. Burrows has been active nationally in promoting and supporting the PACE model of care, serving as chair of the National PACE Association's Primary Care Committee, health services consultant for the Rural PACE Project, editor of the PACE Medical Director's Handbook, and member of the National PACE Association Board of Directors. Dr. Burrows is also the statewide Medical Director for the Senior Care Options program of Commonwealth Care Alliance, a Medicare Advantage Special Needs Plan and one of the four Massachusetts Senior Care Organizations. He has developed ethics committees for Commonwealth Care Alliance and for a consortium of rural PACE organizations, where he serves as chair. Dr. Burrows lectures frequently on dementia, depression, care delivery, ethical issues, and other topics in geriatrics, and since 1997 has led a monthly evidence-based geriatrics case conference at Boston Medical Center. He is a graduate of the Mount Sinai School of Medicine and completed his medical residency at Boston City Hospital, chief residency at the Boston VA Medical Center, and geriatric fellowship at the Harvard Division on Aging. He is board-certified in Internal Medicine and Geriatric Medicine.

SNP ALLIANCE

Richard Bringewatt

Richard J. Bringewatt is President of the National Health Policy Group and Chair of the Special Needs Plan Alliance, an initiative of the NHPG. The SNP Alliance is an invitation-only national leadership group developed to advance specialized managed care programs for high-risk/high-need persons, particularly for persons dually eligible for Medicare and Medicaid. Founding membership of the SNP Alliance included plans involved in national integration demonstrations prior to transitioning to SNP status. Prior to his current position, Mr. Bringewatt was co-founder and President and CEO of the National Chronic Care Consortium. The NCCC was an invitation-only national leadership organization established to design and implement new methods for integrating primary, acute and long-term care among leading health and long-term care systems. During that time, Mr. Bringewatt also provided consultation to many of the early state integration programs, including the Minnesota Senior Health Options program. Over the years, Mr. Bringewatt also has developed and lead national leadership groups, workshops and conferences; developed and advanced legislation; provided legislative testimony to state and federal governments; worked with state and local governments; published articles on a wide range of issues related to integration and specialized managed care; developed materials, tools, models, and products for integration and specialized managed care; crafted and managed new programs, and provided consultation to a broad spectrum of organizations on improving care for high-risk/high-need persons.

Mr. Bringewatt has a Master Degree in Social Work with certification in gerontology from the University of Michigan.

INDIVIDUAL SUBJECT MATTER EXPERT MEMBERS (VOTING)

SUBSTANCE ABUSE

Mady Chalk, MSW, PhD

Mady Chalk, Ph.D. is the Director of the Center for Policy Analysis and Research at the Treatment Research Institute (TRI) in Philadelphia, PA. The Center focuses on translation of research into policy, particularly focused on quality improvement and standards of care, new purchasing strategies for treatment services, implementation and evaluation of performance-based contracting, and integrated financing for treatment in healthcare settings. The Center also supports the Mutual Assistance Program for States (MAPS) which provides an arena in which States and local policy makers, purchasers, elected officials, and treatment providers meet with clinical and policy researchers to exchange ideas and develop testable strategies to improve the delivery of addiction treatment. Prior to becoming a member of the staff of TRI, for many years Dr. Chalk was the Director of the Division of Services Improvement in the Federal Center for Substance Abuse Treatment (CSAT)/Substance Abuse and Mental Health Services Administration (SAMHSA). For 15 years before coming to the Washington area, Dr. Chalk was a faculty member in the Yale University School of Medicine, Department of Psychiatry and the Director of the Outpatient /Community Services Division of Yale Psychiatric Institute. She received her Ph.D. in Health and Social Policy from the Heller School at Brandeis University.

DISABILITY

Anne Cohen, MPH

Anne Cohen, has over fifteen years experience in the disability field. She has served on state and federal advisory committees that address disability issues including the Agency for Healthcare Research and Quality (AHRQ)’s technical panel for the development of CAHPS for People with Mobility Impairments and the California Health Care Foundation's (CHCF) development of Medicaid Health Plan Performance Standards and Measures for People with Disabilities and Chronic Conditions. She founded Disability Health Access, LLC, in 2005, advising healthcare organizations on how to improve services for seniors and people with disabilities. Among her projects she collaborated with Dr. Sue Palsbo, on the development of disability targeted health plan quality measures. In 2012, Anne also began collaborating with Harbage Consulting, a health policy-consulting firm, with expertise in public programs and delivery system reform. Through her work with Harbage she has advised the State of California on implementing integration of Dual eligible individuals. Before forming Disability Health Access, Ms. Cohen was a disability manager at Inland Empire Health Plan, a non-profit Medicaid Health Plan in Southern California. At IEHP, she developed community outreach strategies and coordinated service delivery enhancements to improve care. Her accomplishments included implementing a national model health education curriculum and facilitating strategic research partnerships aimed at utilizing available data to better understand and manage members’ care. Ms. Cohen has a Master of Public Health degree in Health Policy and Administration, and a Bachelor of Science degree in Social Science from Portland State University, Portland, Oregon.

EMERGENCY MEDICAL SERVICES

James Dunford, MD

Dr. Dunford has served as Medical Director of San Diego Fire-Rescue since 1986 and became City Medical Director in 1997. Jim is Professor Emeritus at the UC, San Diego School of Medicine where he has practiced emergency medicine since 1980. Dr. Dunford attended Syracuse University and Columbia University College of Physicians & Surgeons and is board-certified in Emergency Medicine and Internal Medicine. He previously served as flight physician and medical director of the San Diego Life Flight program and founded the UCSD Emergency Medicine Training Program. Dr. Dunford's interests include translating research in heart attack, trauma and stroke care to the community. He investigates the interface between public health and emergency medical services (EMS). For his work with the San Diego Police Department Serial Inebriate Program (SIP) he received the 2007 United States Interagency Council on Homelessness Pursuit of Solutions Award. Dr. Dunford collaborates with the SDPD Homeless Outreach Team (HOT) and directs the EMS Resource Access Program (RAP) to case-manage frequent users of acute care services. He is a Co-investigator in the Resuscitation Outcomes Consortium (ROC), a US-Canadian effort responsible for conducting the largest out-of-hospital cardiac arrest and trauma resuscitation trials in North America.

MEASURE METHODOLOGIST

Juliana Preston, MPA

Juliana Preston is the Vice President of Utah Operations for HealthInsight. Ms. Preston is responsible for leading the organization's quality improvement division in Utah. As the leader of the quality improvement initiatives, she oversees the management of the Medicare quality improvement contract work and other quality improvement related contracts in Utah. Ms. Preston has extensive experience working with nursing homes. She has developed numerous workshops and seminars including root cause analysis, healthcare quality improvement, human factors science, and resident-centered care. In addition to her experience at HealthInsight, she has held various positions during her career in long-term care including Certified Nursing Assistant, Admissions & Marketing Coordinator. Ms. Preston graduated from Oregon State University in 1998 with a Bachelor's of Science degree with an emphasis in Long Term Care and minor in Business Administration. In 2003, she obtained her Master's degree in Public Administration from the University of Utah with an emphasis in Health Policy.

HOME & COMMUNITY-BASED SERVICES

Susan Reinhard, RN, PhD, FAAN

Susan C. Reinhard is a Senior Vice President at AARP, directing its Public Policy Institute, the focal point or public policy research and analysis at the federal, state and international levels. She also serves as the Chief Strategist for the Center to Champion Nursing in America at AARP, a national resource and technical assistance center created to ensure that America has the nurses it needs to care for all of us now and in the future. Dr. Reinhard is a nationally recognized expert in nursing and health policy, with extensive experience in translating research to promote policy change. Before coming to AARP, Dr. Reinhard served as a Professor and Co-Director of Rutgers Center for State Health Policy where she directed several national initiatives to work with states to help people with disabilities of all ages live in their homes and communities. In previous work, she served three governors as Deputy Commissioner of the New Jersey Department of Health and Senior Services, where she led the development of health policies and nationally recognized programs for family caregiving, consumer choice and control in health and supportive care, assisted living and other community-based care options, quality improvement, state pharmacy assistance, and medication safety. She also co-founded the Institute for the Future of Aging Services in Washington, DC and served as its Executive Director of the Center for Medicare

Education. Dr. Reinhard is a former faculty member at the Rutgers College of Nursing and is a fellow in the American Academy of Nursing. She holds a master's degree in nursing from the University of Cincinnati, and a PhD in Sociology from Rutgers, The State University of New Jersey.

MENTAL HEALTH

Rhonda Robinson-Beale, MD

Rhonda Robinson Beale, MD, has more than 30 years' experience in the fields of managed behavioral healthcare and quality management. She is the chief medical officer of OptumHealth Behavioral Solutions (formerly United Behavioral Health). Before joining United, she served as the senior vice president and chief medical officer of two prominent organizations, PacifiCare Behavioral Health (PBH) and CIGNA Behavioral Health. As a highly respected member of the behavioral health community, Dr. Robinson Beale has been involved extensively with the National Committee for Quality Assurance (NCQA), National Quality Forum, and the Institute of Medicine. Dr. Robinson Beale was a member of the committee that produced To Err is Human: Building a Safer Health System and Crossing the Quality Chasm: A New Health System for the 21st Century. Dr. Beale served over 8 years on Institute of Medicine's (IOM) Neuroscience and Behavioral Health and Health Care Services Boards. She serves as a committee member and consultant to various national organizations such as NQF, NCQA, NBGH, NIMH, SAMHSA, and is a past Board Chair of the Association for Behavioral Health and Wellness.

NURSING

Gail Stuart, PhD, RN

Dr. Gail Stuart is dean and a tenured Distinguished University Professor in the College of Nursing and a professor in the College of Medicine in the Department of Psychiatry and Behavioral Sciences at the Medical University of South Carolina. She has been at MUSC since 1985 and has served as Dean of the College of Nursing since 2002. Prior to her appointment as Dean, she was the director of Doctoral Studies and coordinator of the Psychiatric-Mental Health Nursing Graduate Program in the College of Nursing. She was also the Associate Director of the Center for Health Care Research at MUSC and the administrator and Chief Executive Officer of the Institute of Psychiatry at the Medical University where she was responsible for all clinical, fiscal, and human operations across the continuum of psychiatric care. She received her Bachelor of Science degree in nursing from Georgetown University, her Master of Science degree in psychiatric nursing from the University of Maryland, and her doctorate in behavioral sciences from Johns Hopkins University, School of Hygiene and Public Health. Dr. Stuart has taught in undergraduate, graduate, and doctoral programs in nursing. She serves on numerous academic, corporate, and government boards and represents nursing on a variety of National Institute of Mental Health policy and research panels, currently serving on the NINR Advisory Council. She is a prolific writer and has published numerous articles, chapters, textbooks, and media productions. Most notable among these is her textbook, *Principles and Practice of Psychiatric Nursing,* now in its 9th edition, which has been honored with four Book of the Year Awards from the *American Journal of Nursing* and has been translated into 5 languages. She has received many awards, including the American Nurses Association Distinguished Contribution to Psychiatric Nursing Award, the Psychiatric Nurse of the Year Award from the American Psychiatric Nurses Association, and the Hildegard Peplau Award from the American Nurses Association.

MEMBERS PENDING APPROVAL OF NQF BOARD (VOTING)

MEDICAID ACO

Ruth Perry, MD

Ruth E. Perry, M.D. is Executive Director of the Trenton Health Team, a collaborative, community based health improvement organization in Trenton, NJ. Prior to this position, she was the Director of Health and Product Stewardship for the Rohm and Haas Company. She began her career as Attending Physician, Department of Emergency Medicine, Albert Einstein Medical Center in Philadelphia and Associate Professor of Medicine at Temple University Hospital. Dr. Perry received a BA in Biology from Swarthmore College, and a MD degree from Temple University School of Medicine. She is board certified in Internal Medicine.

CARE COORDINATION

Nancy Hanrahan, PhD, RN, FAAN

Dr. Nancy Hanrahan is an associate professor and faculty member of the Center for Health Outcomes and Policy Research at the University of Pennsylvania School of Nursing. As a health systems researcher, she studies innovative models that promote an integrated mind/body approach to mental and physical health care. In her current research, she studies the effectiveness a transitional care model for hospitalized individuals with a primary or secondary mental illness to improve post-hospital outcomes and lower 30-day readmission rates. Her clinical expertise is with individuals who have serious and persistent mental illness.

FEDERAL GOVERNMENT MEMBERS (NON-VOTING, EX OFFICIO)

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

D.E.B. Potter, MS

D.E.B. Potter is a Senior Survey Statistician, in the Center for Financing, Access and Cost Trends (CFACT), Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services (HHS). Her work focuses on improving the measurement of the long-term care (LTC) and disabled populations at the national level. Efforts include data collection and instrument design; measuring use, financing and quality of health care; and estimation issues involving people with disabilities that use institutional, sub-acute and home and community-based services (HCBS). In 2002, she (with others) received HHS Secretary's Award "for developing and implementing a strategy to provide information the Department needs to improve long-term care." She currently serves as Co-Lead, AHRQ's LTC Program, and is responsible for AHRQ's Assisted Living Initiative and the Medicaid HCBS quality measures project.

CMS FEDERAL COORDINATED HEALTHCARE OFFICE

Cheryl Powell

Cheryl Powell has recently been appointed the Deputy Director of the Medicare-Medicaid Coordination Office at the Centers for Medicare & Medicaid Services (CMS). As the Deputy Director, Ms. Powell will assist the Director in leading the work of this office charged with more effectively integrating benefits to create seamless care for individuals' eligible for both Medicare and Medicaid and improving coordination between the federal government and states for such dual eligible beneficiaries. Ms. Powell has extensive experience in both Medicare and Medicaid policy development and operations. She is an expert on Medicaid reform activities and policy development. During her tenure at CMS, she designed and oversaw the implementation of Medicaid program and financial policy as well as national Medicaid managed care, benefits and eligibility operations. While working at Hilltop Institute, Ms. Powell evaluated Medicaid programs and worked with state and local officials to improve quality and health care delivery. Ms. Powell also has extensive knowledge of Medicare operations which will assist in the management of the new office. As Director of Medicare Policy at Coventry Health Care, she worked to improve compliance processes and business operations for Medicare Advantage plans. Ms. Powell previously managed Medicare beneficiary services at the CMS Chicago regional office and played a key role in the implementation and outreach of the Medicare Modernization Act. Ms. Powell earned a master's degree in public policy from The John F. Kennedy School of Government at Harvard University and graduated *summa cum laude* from the University of Virginia a bachelor's degree in psychology.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

Samantha Meklir, MPP

Samantha Meklir, MPP, is an Analyst in the Office of Health Information Technology and Quality (OHITQ) of the Health Resources and Services Administration, U.S. Department of Health and Human Services, where she supports planning and implementing policies and programs related to quality and to health information technology across HRSA and with external stakeholders. As such, some of her activities include (but are not limited to) serving as the Federal Government Task Leader on a Report to Congress on quality incentive payments currently underway and helping to prepare HRSA grantees for meaningful use stage two measures. Samantha began her federal career as a Presidential Management Intern (PMI) and worked at both HRSA and CMS in various positions focusing on Medicaid legislation and programs, health information technology and quality, and the safety net. She served as Legislative Fellow for the late U.S. Senator Paul Wellstone (D-MN) and later as a Social Science Research Analyst in the CMS Office of Legislation Medicaid Analysis Group. Samantha worked for CMS not only in their OL but also in their Chicago Regional Office where she focused on home and community based waivers and later in the Baltimore Center for Medicaid and State Operations Children's Health Program Group where she focused on Section 1115 demonstration programs in family planning, health insurance flexibility employer-sponsored insurance programs, and SCHIP. Samantha contributed to the President's New Freedom Initiative during her tenure at CMS OL. Since 2006, Samantha has been focused on health information technology and quality at HRSA. Samantha has a bachelor's degree in American Studies from Tufts University and a master's degree in public policy from the Lyndon B. Johnson School of Public Affairs (UT Austin).

ADMINISTRATION FOR COMMUNITY LIVING

Marisa Scala-Foley

Marisa Scala-Foley is a Social Science Analyst in the Office of Policy, Analysis and Development at the U.S. Administration for Community Living (ACL). Prior to joining ACL, she served as the Director of the National Center for Benefits Outreach and Enrollment at the National Council on Aging, which helped organizations enroll seniors and adults with disabilities with limited means into the benefits programs for which they are eligible so that they can remain healthy and improve the quality of their lives. Throughout her career, Ms. Scala-Foley has focused on issues related to developing accessible educational materials and infrastructure for health-care and long-term care education (for consumers and professionals), consumer navigation of the U.S. health-care and long-term care systems, and consumer direction in long-term care for older adults. She has also authored numerous publications in these areas, including *Consumer-Directed Home Services: Issues and Models*, one of the early studies of consumer direction in state programs for older adults; *Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States*, a case study analysis of long-term care information and assistance models in three states; and *Taking Charge: A Guide to Personal Care Decision-Making in Later Life*, a consumer guide to long-term care in Ohio which was adopted by the Ohio Department of Aging. Ms. Scala-Foley holds a Masters in Gerontological Studies from Miami University (Ohio), and a Bachelor's in Sociology and Gerontology from the College of the Holy Cross. She lives in Alexandria, Virginia with her husband and two sons.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

Lisa Patton, PhD

Dr. Lisa Patton is a licensed clinical psychologist and highly skilled presenter and trainer who has worked in research/consulting for the past decade, focusing on mental health and substance abuse research with special populations such as disaster responders and those impacted by disaster; older adults; and people who are homeless. In addition to her project-related expertise, business development, particularly in the Federal sector, has been a priority for Dr. Patton. Prior to working in research, Dr. Patton worked as a therapist in community mental health; her clinical specialty is trauma. Dr. Patton continues to consult to preschools, teachers, and families through the company she founded and for which she serves as clinical director, Childhood Development Services, LLC.

VETERANS HEALTH ADMINISTRATION (VHA)

Daniel Kivlahan, PhD

Dr. Kivlahan received his doctoral degree in clinical psychology from the University of Missouri-Columbia in 1983. Since 1998, he was been Director of the Center of Excellence in Substance Abuse Treatment and Education (CESATE) at VA Puget Sound in Seattle where he has been an addiction treatment clinician and investigator since 1985. He is Associate Professor, Department of Psychiatry and Behavioral Sciences, University of Washington and from 2004 – 2010 served as Clinical Coordinator of the VA Substance Use Disorders (SUD) Quality Enhancement Research Initiative to implement evidence-based practices in treatment of SUD. He co-chaired the work group that in 2009 completed the revision of the VA/DoD Clinical Practice Guideline for SUD and participated in the VHA expert consensus panel on clinical guidance for integrated care of concurrent SUD and PTSD. In May 2010, Dr. Kivlahan accepted the new field-based position as Associate National Mental Health Director for Addictive Disorders, Office of Mental Health Services, VHA. He was recently appointed as the representative from the Office of Mental Health Services to the Pain Management Working Group chartered by the VA/DoD Health Executive Council. Among his 100+ peer reviewed publications are validation studies on the AUDIT-C to screen for alcohol misuse across care settings and reports from clinical trials including the COMBINE Study for combined pharmacologic and psychosocial treatment of alcohol dependence.

MAP COORDINATING COMMITTEE CO-CHAIRS (NON-VOTING, EX OFFICIO)

George Isham, MD, MS

George Isham, M.D., M.S. is the chief health officer for HealthPartners. He is responsible for the improvement of health and quality of care as well as HealthPartners' research and education programs. Dr. Isham currently chairs the Institute of Medicine (IOM) Roundtable on Health Literacy. He also chaired the IOM Committees on *Identifying Priority Areas for Quality Improvement* and *The State of the USA Health Indicators*. He has served as a member of the IOM committee on *The Future of the Public's Health* and the subcommittees on the Environment for Committee on Quality in Health Care which authored the reports *To Err is Human* and *Crossing the Quality Chasm.* He has served on the subcommittee on performance measures for the committee charged with redesigning health insurance benefits, payment and performance improvement programs for Medicare and was a member of the IOM Board on Population Health and Public Health Policy. Dr. Isham was founding co-chair of and is currently a member of the National Committee on Quality Assurance's committee on performance measurement which oversees the Health Employer Data Information Set (HEDIS) and currently co-chairs the National Quality Forum's advisory committee on prioritization of quality measures for Medicare. Before his current position, he was medical director of MedCenters health Plan in Minneapolis and In the late 1980s he was executive director of University Health Care, an organization affiliated with the University of Wisconsin-Madison.

Elizabeth McGlynn, PhD, MPP

Elizabeth A. McGlynn, PhD, is the director for the Center of Effectiveness and Safety Research (CESR) at Kaiser Permanente. She is responsible for oversight of CESR, a network of investigators, data managers and analysts in Kaiser Permanente's regional research centers experienced in effectiveness and safety research. The Center draws on over 400 Kaiser Permanente researchers and clinicians, along with Kaiser Permanente’s 8.6 million members and their electronic health records, to conduct patient-centered effectiveness and safety research on a national scale. Kaiser Permanente conducts more than 3,500 studies and its research led to more than 600 professional publications in 2010. It is one of the largest research institutions in the United States. Dr. McGlynn leads efforts to address the critical research questions posed by Kaiser Permanente clinical and operations leaders and the requirements of the national research community. CESR, founded in 2009, conducts in-depth studies of the safety and comparative effectiveness of drugs, devices, biologics and care delivery strategies. Prior to joining Kaiser Permanente, Dr. McGlynn was the Associate Director of RAND Health and held the RAND Distinguished Chair in Health Care Quality. She was responsible for strategic development and oversight of the research portfolio, and external dissemination and communications of RAND Health research findings. Dr. McGlynn is an internationally known expert on methods for evaluating the appropriateness and technical quality of health care delivery. She has conducted research on the appropriateness with which a variety of surgical and diagnostic procedures are used in the U.S. and in other countries. She led the development of a comprehensive method for evaluating the technical quality of care delivered to adults and children. The method was used in a national study of the quality of care delivered to U.S. adults and children. The article reporting the adult findings received the Article-of-the-Year award from AcademyHealth in 2004. Dr. McGlynn also led the RAND Health’s COMPARE initiative, which developed a comprehensive method for evaluating health policy proposals. COMPARE developed a new microsimulation model to estimate the effect of coverage expansion options on the number of newly insured, the cost to the government, and the effects on premiums in the private sector. She has conducted research on efficiency measures and has recently published results of a study on the methodological and policy issues associated with implementing measures of efficiency and effectiveness of care at the individual physician level for payment and public reporting. Dr. McGlynn is a member of the Institute of Medicine and serves on a variety of national advisory committees. She was a member of the Strategic Framework Board that provided a blueprint for the National Quality Forum on the development of a national quality measurement and reporting system. She chairs the board of AcademyHealth, serves on the board of the American Board of Internal Medicine Foundation, and has served on the Community Ministry Board of Providence-Little Company of Mary Hospital Service Area in Southern California. She serves on the editorial boards for Health Services Research and The Milbank Quarterly and is a regular reviewer for many leading journals. Dr. McGlynn received her BA in international political economy from Colorado College, her MPP from the University of Michigan’s Gerald R. Ford School of Public Policy, and her PhD in public policy from the Pardee RAND Graduate School.

NATIONAL QUALITY FORUM STAFF

Thomas Valuck, MD, JD, MHSA

Thomas B. Valuck, MD, JD, is Senior Vice President, Strategic Partnerships, at the National Quality Forum (NQF). Dr. Valuck oversees NQF-convened partnerships—the Measure Applications Partnership (MAP) and the National Priorities Partnership (NPP)—as well as NQF's engagement with states and regional community alliances. These NQF initiatives aim to improve health and healthcare through use of performance information for public reporting, payment incentives, accreditation and certification, and systems improvement. Dr. Valuck comes to NQF from the Centers for Medicare & Medicaid Services (CMS), where he advised senior agency and Department of Health and Human Services leadership regarding Medicare payment and quality of care, particularly value-based purchasing. While at CMS, Dr. Valuck was recognized for his leadership in advancing Medicare's pay-for-performance initiatives, receiving both the 2009 Administrator's Citation and the 2007 Administrator's Achievement Awards. Before joining CMS, Dr. Valuck was the vice president of medical affairs at the University of Kansas Medical Center, where he managed quality improvement, utilization review, risk management, and physician relations. Before that he served on the Senate Health, Education, Labor, and Pensions Committee as a Robert Wood Johnson Health Policy Fellow; the White House Council of Economic Advisers, where he researched and analyzed public and private healthcare financing issues; and at the law firm of Latham & Watkins as an associate, where he practiced regulatory health law. Dr. Valuck has degrees in biological science and medicine from the University of Missouri-Kansas City, a master's degree in health services administration from the University of Kansas, and a law degree from the Georgetown University Law School.

Sarah Lash, MS, CAPM

Sarah Lash is a Senior Program Director in the Strategic Partnerships department at the National Quality Forum. Ms. Lash staffs the NQF-convened Measure Applications Partnership (MAP), leading an expert workgroup focused on measuring and improving the quality of care delivered to Medicare/Medicaid dual eligible beneficiaries. The group's recommendations have been very influential in shaping the health reform dialogue around quality measurement in the dual eligible beneficiary population. Prior to joining NQF, Ms. Lash spent four years as a policy research consultant at The Lewin Group, where she specialized in supporting Federal initiatives related to aging, disability, and mental/behavioral health issues. Ms. Lash studied Public Health and Psychology at Johns Hopkins University and went on to earn a master's degree in Health Systems Management from George Mason University. Ms. Lash was recognized with GMU's Graduate Award for Excellence in Health Policy and is also a Certified Associate in Project Management (CAPM).

Amaru Sanchez, MPH

Amaru J. Sanchez, MPH, is a Project Analyst at the National Quality Forum (NQF), a private, nonprofit membership organization created to develop and implement a national strategy for healthcare quality measurement and reporting. Mr. Sanchez is currently supporting the work of the NQF Measure Applications Partnership, established to provide multi-stakeholder input to the Department of Health and Human Services on the selection of performance measures for public reporting and payment reform programs. Prior to joining NQF, Mr. Sanchez served as a Health Policy Research Analyst for the bicameral Public Health Committee at the Massachusetts Legislature. At the legislature, Mr. Sanchez influenced the passage of several novel public health and healthcare related laws as well as drafted legislative proposals relative to medical debt, chronic disease management, health disparities and health care transparency. Mr. Sanchez is a graduate of the Boston University School of Public Health (MPH, Social

Behavioral Sciences/Health Policy and Management) and the University of Florida (BS, Integrative Biology).

Megan Duevel Anderson, MS

Megan Duevel Anderson is a Project Analyst at the National Quality Forum (NQF). Ms. Duevel Anderson contributes to the Dual Eligible Workgroup, Cardiovascular and Diabetes Task Force, and Data Analytics Team of the Measure Applications Partnership (MAP). Ms. Duevel Anderson comes from the US Army Bavaria Medical Department Command where she was the Joint Commission and Performance Improvement Officer; responsible for accreditation and quality management of US Army outpatient clinics. Her post-graduate fellowship was completed at the Veteran's Administration National Center for Patient Safety Field Office; with research in Patient Safety in Women's Health and Measurement in developing countries. Ms. Duevel Anderson has a Bachelor of Arts from Gustavus Adolphus College in Minnesota and a Master's of Science from The Dartmouth Institute for Health Policy and Clinical Practice Research.

Y. Alexandra Ogungbemi

Alexandra Ogungbemi, BS, is an Administrative Assistant in Strategic Partnerships, at the National Quality Forum (NQF). Ms. Ogungbemi contributes to the Clinician, Dual Eligible Beneficiaries, and Post-Acute Care/Long-Term Care Workgroups, as well as the Cardiovascular and Diabetes Task Force of the Measure Applications Partnership (MAP). Post-graduation, she spent 2 years managing the Administrative side of Cignet Healthcare, a multi-specialty physician's practice in Southern Maryland, before joining NQF. Ms. Ogungbemi has a Bachelor of Science in Health Services Administration from The Ohio University.