State Advocate Experiences and Engagement in Duals Integration

March 9, 2012
With support from The SCAN Foundation, NCOA leads a coalition of national aging and disability organizations working to protect and strengthen Home and Community-Based Services.

For more information about The SCAN Foundation visit: [www.TheSCANFoundation.org](http://www.TheSCANFoundation.org)
Friday Morning Collaborative

- AARP
- Alliance for Retired Americans
- American Network of Community Options and Resources
- The Arc of the United States
- Association of University Centers on Disabilities
- Balezon Center for Mental Health Law
- Disability Rights Education & Defense Fund
- Easter Seals
- Families USA
- The Jewish Federations of North America
- Leading Age
- Lutheran Services in America
- National Alliance for Caregiving
- National Association of Area Agencies on Aging
- National Association for Home Care and Hospice
- National Council on Aging
- National Council on Independent Living
- National Committee to Preserve Social Security and Medicare
- National Consumer Voice for Quality Long-Term Care
- National Domestic Workers Alliance
- National Disability Rights Network
- National Senior Citizens Law Center
- Paralyzed Veterans of America
- Paraprofessional Healthcare Institute
- Service Employees International Union
- United Spinal Association
- Visiting Nurse Associations of America
- Volunteers of America
Webinar Overview

• Introduction
  – Joe Caldwell (National Council on Aging)

• Speakers
  – Bill Henning (Boston Center for Independent Living)
  – Dennis Heaphy (Disability Policy Consortium -- Massachusetts)
  – Laurel Mildred (California Foundation for Independent Living Centers)
  – Deborah Doctor (Disability Rights California)
  – Karen Keeslar (California Association of Public Authorities)

• Questions and Answers
  – 20 - 30 minutes

• Closing Remarks
Questions and Comments

All Lines Will Be Muted During the Call
To Ask A Question Use the Chat Function
Massachusetts Dual Eligibles Demonstration Project

An overview of the efforts of disability advocates in Massachusetts
Healthcare reform, Part II

- Dual Eligibles Demonstration Project
- Payment Reform for general population
- Implementation of Affordable Care Act
Approximately 115,000 dual eligibles

- The majority live in their communities, not institutions.
- Nearly 60% have diagnoses in two or more of three major diagnostic categories (physical, behavioral and developmental).
- Approximately 65% have behavioral health issues.
Medicaid spent $1.3 billion on the population while Medicare spent $1.2 billion.

6% of dual eligibles accounted for 30% of combined Medicare Medicaid expenditures on duals.

70% of duals had an annual per capita expenditure by Medicaid and Medicare of less than $20,000.
Expenditures

- Per capita spending on dual eligibles with a high level of long-term support needs was roughly half of the cost of dual eligibles residing in institutions.

- 72% of Medicaid spending was for duals requiring long-term supports in the community.
Primary unmet needs

- Care coordination.
- Access information.
- In-home supports including assistance with ADLs, home adaptations and personal care.
- IADLs including food preparation, shopping and housework.
March 2011–Disability Advocates Advancing Our Healthcare Rights (DAAHR) was formed.

- Cross-disability representation.
- Cross disciplinary.
- Strengths-based approach to tasks.
- Focus on maintaining collaboration with state officials.
- Emphasis on consensus and positive working relationships within the coalition.
Advocacy strategy

- Embrace change.
- Cross disability.
- Get to and remain at the table with state leadership.
- Emphasize maintaining positive relationships among stakeholders.
- Grassroots mobilizing.
- Strategic partnerships outside of the coalition (with key providers, CMS, legislators, national healthcare and disability advocates).
Behavioral health focus

- Community empowerment.
- Recovery model of mental health.
- Certified peer specialists key.
- Peer respite.
Guiding principles for DAAHR
(April 2011; comparable principles from DREDF, others exist)

1: Voluntary Participant Enrollment.

2: Person Centered Care (independent living philosophy and recovery model).

3: Delivery System (beneficiary centric).

4: Cultural Competence and Health Disparities (CLAS, ADA compliance).
Principles

- 5: Prevention (emphasis on prevention of secondary disability and wellness).
- 6: Consumer Voice (consumer control).
- 7: Financing Mechanisms (risk adjustment).
- 8: Quality Measurement (real-time oversight and meaningful outcome goals).
Timeline of efforts with state

- April 2011 submitted response to EOHHS RFR.
- June 2011 initial meeting with Human Services Secretary.
- June 2011–present regular meetings with Medicaid leadership.
- November 2011–present submit legislation to State House with continued refinement.
- December 2011–January 2011 public hearings attended by 400 people on draft proposal.
- December 2011 comments on draft proposal.
- Periodic meetings with CMS leadership on duals demonstration initiative.
- March 2012 lobby day and comments on proposal.
Establishment of program.

Independent long-term service coordinator.

Benefits.

Consumer protections (LTSS protections).

Consumer oversight (ombudsman).
Payment reform legislation

- Risk adjustment.
- Americans with Disabilities Act compliance.
- Data collection.
- ACO governing boards.
- Quality measures.
- Impact health disparities.
Learnings

- Maintain constant communication with grassroots stakeholders and empower this voice.
- Offer solutions and alternatives; learn the technical and enlist experts.
- Clarify language.
- Reach out to nontraditional allies.
- Remain positive while not sparing critique.
Remain responsive to changing circumstances.
Increase communications with providers.
Build prominence of direct consumer involvement.
Continued communication with legislators.
Keep open communication channels with Medicaid and Human Services officials and identify key allies.
California Foundation for Independent Living Centers

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Olmstead Advocacy Director
California Foundation for Independent Living Centers (CFILC)
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Laurel.Mildred@mildredconsulting.com

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The State of California Proposal

• **Target Population**: All those who are full-benefit dual eligible in demonstration counties.

• **Scope**: Initial legislation authorized 4 county demonstration. Statewide roll-out now proposed.

• **Financing**: Capitated Financial Alignment Demonstration (3-way contract between CMS-State-Plan)
• **Legislation**: SB 208, Steinberg, 2010

• **Stakeholder Involvement**: Fairly intensive but somewhat ineffective engagement with state advocates to date; Minimal education and inclusion of program users.

• **Where We are in the Process**: Policy development, stakeholder outreach, 5 public stakeholder meetings, release of draft site selection criteria, and revision and release of final site selection criteria have taken place over the past 6 months.
Upcoming Processes:

• March 2012 - Announcement of site selections
• Spring 2012 - Review and approval of CA proposal by CMS
• Summer 2012 - Development of 3-way financial contracts
• August/September - 2012 Readiness Review
• January 2013 - Launch
Rapidly Evolving Context: Governor Brown Has Proposed Several Accelerated Managed Care Initiatives in California State Budget

- Proposes initial Dual Eligible Demonstration in 10 counties (rather than 4) in first year; other managed care counties in 2012; and statewide in 2015
- Expansion of Medi-Cal managed care to all CA counties
- Inclusion of long-term services and supports in Medi-Cal managed care
• California has 1.15 million people who are dual eligible.
• 71% are 65+ / 29% are under 65.
• Nearly 75% of California’s $4.2 billion in Medicaid spending is on those who are dual eligible.
• Today, only 15% of Californians who are dual eligible are enrolled in managed care.
CFILC, Meet Managed Care

- California required mandatory enrollment of seniors and persons with disabilities into managed health care services under an 1115 waiver last year. We fought and lost.

- We didn’t know them, they didn’t know us.

- Steep learning curve on the technical side.

- We’re worried about how to preserve, protect and advance the social model.
The Evolution of Our Thinking

• We strongly supported health care reform.
• We constantly battle the bad outcomes of fragmentation.
• Our system has equity problems – some populations particularly poorly served now.
• We immediately grasped the Olmstead de-institutionalization potential of integration.
• We are all about capturing savings to re-invest in home and community-based services.
We Presented Our Thinking on the Good, the Bad and the Scary Potential of Change in a Comprehensive Report to the Community:

A *Blueprint for Advocates: Recommended Next Steps to Advance California's Implementation of the Supreme Court's Olmstead Decision*

[www.californiansforolmstead.org](http://www.californiansforolmstead.org)
Our Agenda

We Developed Three Key Areas of Focus:

1. Consumer Direction and Protection
2. Preserving and Strengthening the Non-profit System of Community-Based Safety Net Providers, including Independent Living Centers
3. Setting the Right Fiscal Incentives
And then we saw the proposal…

State’s first Request for Solutions proposal was really disheartening.

“We do not feel that it accurately reflects the feedback that we have provided; nor, as it is currently conceived, that it represents progress or good policy for California’s vulnerable dual eligible population.”

CFILC’s Formal Comments on CA Duals Proposal here: http://tinyurl.com/8x98eml
Focused Areas of Advocacy

- No Pass-Throughs (Blended Capitation Rate w/ Full Risk)
- Transition Services
- No Enrollment Lock-in
- Do Not Score Up-front Savings
- Person-Centered, Independent Assessment
- Housing
- IHSS Consumer Direction
- Improvements to Behavioral Health
- Disability Access
- Quality Incentives Through Performance Measures
Keeping the Focus on Rebalancing
Rebalancing is the transformational shift from institutional to home- and community-based care in long-term living programs.

It developed over many years, primarily in fee-for-service systems.

Now, health care reform and cost concerns are rapidly driving integrated care models that combine medical and social services.
So the new question becomes:
How do traditional rebalancing concepts fit into managed care?

*Flexible Accounting for Long-Term Care Services: State Budgeting Practices that Increase Access to Home- and Community-Based Services*
Hendrickson and Mildred, 2012
http://tinyurl.com/7xlurfe
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State’s New Approach Involves a Series of Stakeholder Workgroups

- Managed Care Organizations
- Beneficiary Notification, Appeals, Protections
- Provider Outreach and Engagement
- LTSS Integration, Network Adequacy
- Mental Health/Substance Use Disorder Services Integration
- Quality Outcome Measurements and Data Management
- Fiscal and Rate Setting

www.calduals.org
@calduals
Disability Rights California

Dual Eligibles: California

Issues

Advocacy

Deborah Doctor, Legislative Advocate
NCOA/ Friday Morning Collaborative
March 9, 2012 Webinar
Organization Background

- Disability Rights California is California’s Protection and Advocacy System. We represents persons with disabilities in a wide range of legal matters:
  - Training and direct representation in civil rights, public benefits and health care cases
  - Public policy work in civil rights, public benefits and health care
  - Abuse and neglect investigations
The Best and Worst Outcomes

• If it works:
  ◦ Institutional placement fiscal incentives eliminated
  ◦ Flexibility to provide such services as home modification, diversion and transition from institutions, coordinated care for those who want it.
  ◦ Easily available, adequate, appropriate and accessible medical, mental health and social services

• If it doesn’t:
  ◦ Same problems as SPD enrollment and worse
  ◦ “Duals” bear true risk to health and life
  ◦ We lose the national model personal assistance: IHSS
Overview of Demonstrations

• Two major pieces
  ◦ Moving “duals” into managed care
  ◦ Moving long term services and supports into managed care
  ◦ Legislature authorized 4 “pilots” – Governor wants 10

• Lives at stake: 1.2 million

• Speed of transition: Way too fast

• Major Players: Governor; Legislature, Unions, Counties; Managed Care; other providers; Public Authorities; Consumers and their advocates
Our Top Ten Issues

- Consumer preferences drive services
- No passive enrollment; no lock-in
- Consumers have central substantive role in own care and in managed care overall
- Fiscal incentives favor community-based services and supports
- Consumer protections: one due process system
- Comprehensive Benefits Package – available, accessible, appropriate services & supports
Our Top Ten Issues

- Conflict-of-interest-free assessments, care planning and services: what you need is what you get.
- Easy timely access to services and supports
- Core standardized assessment including functional social model philosophy/elements
- Targeted Care Management for those who want it
- Preserving what works: e.g. IHSS.
- Reasonable pace, meaningful evaluation
Advocacy Opportunities/Challenges

- Advocacy opportunities
  - State-sponsored stakeholder meetings
  - Written comments
  - Legislative hearings
  - Private meetings – advocates, legislators, etc.
  - Results of formal stakeholder process:
    - Most suggestions were ignored; however
    - State reports “great stakeholder support”, which leads to
    - Sensation of living in parallel universe, and
    - Many more state-sponsored stakeholder meetings.
Advocacy Opportunities/Challenges

• Advocacy Opportunities
  ◦ New alliances
  ◦ New consumer group: IHSS Consumers Union

• Advocacy challenges
  ◦ Split between traditional allies: consumers and their advocates vs. unions;
  ◦ Not all disability groups share same view
  ◦ Difficult to get “duals” informed and participating
Friday Morning Collaborative

Webinar – Dual Integration

March 9, 2012

Karen Keeslar,
CAPA Executive Director
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This presentation will briefly cover:

- History & Philosophy of the In-Home Supportive Services (IHSS) program
  - IHSS Today – Information about Consumers & Providers
    - Current funding and IHSS program structure, roles & responsibilities
      - Dual Integration: Recommendations & Concerns
        - Final thoughts....
California’s History & Philosophy of IHSS

- Younger persons with disabilities, motivated by a desire for independence and control of their own services and assistance, were the key advocates for the creation of IHSS in 1973.
- Not only did these advocates win the establishment of an in-home care program, they also won the right for a consumer to hire, train, schedule, and if necessary, terminate his or her worker — this in comparison to a more traditional home care assistance program, which retains these rights and responsibilities within a contract agency.
• Instead of being part of a medical continuum, as it is in other states, California’s social model homecare program has always strived for maximum control being placed in the hands of consumers.
• The program is responsible for low usage of California’s Medi-Cal home health care services compared to other states and for lack of growth of Medi-Cal nursing facility beds. It has been a cost-effective model for other states, and has been the cornerstone of the independent living movement.
• The key component of consumer choice is control in the selection, training, hiring and firing of care providers. The authorization of a monthly block of IHSS hours gives consumers the flexibility to schedule care providers to best meet their specific needs.
IHSS Today – Descriptive Data on Consumers & Providers

- The IHSS program is the largest publicly-funded personal care program in the United States.
- It is now a $5 billion entitlement program that serves approximately 442,000 consumers and there are about 380,000 IHSS providers.
- To qualify for IHSS, consumers must be disabled, blind, or elderly (65 or older). Their total assets must be less than $2,000, excluding their house and car. Based on income, some consumers pay a share of their providers’ salaries – but most do not.
- The average IHSS consumers receives 87.6 paid hours of IHSS per month.
- The annual cost for a consumer with an average number of IHSS hours is approximately to $13,000, compared to the annual FFS cost of an individual in a SNF which is over $65,000.
Data on IHSS Consumers

**Age**
84% of IHSS Consumers are over 45 years of age.

**Type of Aid**
About half of IHSS consumers are disabled, 45% are aged, and 2% are blind.
Distribution of Authorized Service Hours

- Domestic & Related Care includes: Housework, Meal Preparation, Meal Clean-up, Laundry, Shopping, & Errands, Transportation and Protective Services
- Personal Care Services includes: Bowel/Bladder, Bathing/Grooming/oral Hygiene and Paramedical. There are others such as: Feeding, Dressing, Bed Baths, Menstrual Care, Ambulation, Transferring, Rubbing Skin, and Prosthesis Care
Data on IHSS Consumers - Ethnicity

- White: 34%
- Asian or Pacific Islander: 18%
- Black: 16%
- American Indian: 0%
- Hispanic: 30%
Forty-four percent of IHSS recipients report their primary language is English.

All Black (100%) and most American Indian (93%) recipients indicate English as their primary language.

Less than half of White recipients primarily speak English (43%).

The majority of Asian and Pacific Islander (86%) and Hispanic (69%) recipients speak a primary language other than English.
There is no single employer in the IHSS program

The consumer is responsible for hiring a worker and day-to-day management of that worker.

IHSS Provider

The state handles payrolling. On behalf of the consumer, the state also handles workers’ comp, UI & SDI.

The local Public Authority is the “employer of record” and collectively bargains for wages & benefits.
The majority of IHSS providers are related to the consumer:
- 14% are the spouse or parent of the IHSS consumer.
- 53% are other relative providers (i.e. sibling, niece, cousin, aunt, or grandparent).
- 33% of IHSS providers are not related to the consumer.
IHSS program structure, roles & responsibilities

The program involves seven major players:

1. The federal government, which provides funding and imposes mandates.
2. The California Department of Social Services, which helps to fund, regulate and operate the program.
3. The California Department of Health Care Services, which interacts with the federal government through Medi-Cal.
4. Each county is responsible for receiving applications for IHSS services, determining eligibility, assessing the need for IHSS, as well as other program integrity activities. In addition, each county pays 35% of the non-federal share of IHSS costs.
5. The local Public Authorities provides registry & emergency back-up services, training for consumers & providers, perform background checks for IHSS registry applicants. In many counties, the Public Authority handles orientation, enrollment and performs background checks on prospective IHSS providers. In addition, the Public Authorities act as the employer of record for collective bargaining.
6. Independent providers, the workers who provide care and receive hourly income.
7. IHSS consumers, who receive services under the program and serve as the actual employers of their caregivers for hiring, firing, scheduling & supervising and other purposes.
How IHSS is funded

IHSS program is funded by a combination of federal, state and county dollars.

- The federal Medicaid program pays 50 percent of the cost of wages and benefits.
- The state pays 65% of the non-federal share from the state General Fund up to a maximum of $12.10 per hour, including $0.60 for health insurance.
- The county pays 35% of the non-federal share from Realignment Funds.
Dual Integration – If it was easy, it would have been done years ago

- Stakeholders have been talking for almost two decades about ways to improve long term services and supports through integration and/or better coordination between home & community based services and institutional care.

- There are multiple complex issues that are distinct and inter-related and must be addressed up front in order to develop successful integration of services to dual eligibles.

- A “one-size-fits-all” approach does not fit all for duals or for local government. A strong and vibrant partnership between health plans, Public Authorities and counties will be essential to design and implement the Dual Integration Demonstration projects.
Integrating IHSS: Concepts & Concerns

• CAPA has been working in partnership with the California State Association of Counties (CSAC) and the County Welfare Directors Association (CWDA) to develop models for serving dual beneficiaries in the four Dual Demonstration pilot counties. We believe that:
  • IHSS should remain an entitlement to participants in the Duals Demonstration. IHSS consumers should retain their ability to select, hire, fire, schedule and supervise their IHSS care provider, should participate in the development of their care plan, and select other individuals to also participate in their care planning. Consumers must have informed choice in the services they receive, and from whom they receive those services.
  • The consumer must be on the care team and have the right to determine which providers (including the IHSS worker) are on their care team.
• We oppose passive/mandatory enrollment.
Some health plans have expressed concerns about liability exposure if they are held responsible for tort claims associated with the provision of service by an IHSS provider. Under current law, the state and counties enjoy total immunity from tort claims when IHSS is administered through a local Public Authority. We believe that contract language can be established between demonstration sites and Public Authorities that will address liability concerns and preserve the right of consumers to have the person they want perform personal care assistance.

The Public Authority will provide Registry services:
- Match IHSS Consumers who request assistance to obtain properly trained providers who have cleared a background check;
- Investigate the qualifications and background of registry applicants, including DOJ criminal background checks.

Public Authorities operate Emergency Back-up or On Call programs that employ home care providers who are willing to be called on short notice and dispatched to assist consumers who need a replacement worker. These providers may be available for consumers being released from a hospital or nursing facility. When sent to the consumer’s home, these providers may be hired or declined by the consumer.
• Additional training opportunities should be made available through the local Public Authority to IHSS consumers and providers under the Duals Demonstration. Public Authorities, consumers, unions, and health plans should collaborate to identify training needs and create materials, tools and work aids that will enable home care providers to (1) improve the quality of care and create opportunities for career ladders, and (2) help consumers understand how to access and manage personal assistance.

• We recognize that work stoppages such as strikes can have a devastating impact on those losing support services. Every Public Authority in California has “No Strike/No Lock-out” language in the ordinance and/or contract with the union. This is a critical protection for consumers to ensure that they receive care during periods of labor strife that may occur in the future and must be retained in the implementation of Dual Demonstration projects.
Contracting with county social services

- IHSS social workers have expertise that the Health Plans do not — social workers perform in-home assessments of persons’ functioning and determine their need for assistance with Activities of Daily Living.
- We believe that IHSS Services should continue to be authorized by the County IHSS Worker using the Uniform Assessment and guided by the Hourly Task Guidelines. The IHSS Uniform Assessment Tool is based on a Functional Index Scale (not a medical analysis) to evaluate a consumer’s capacity to perform certain activities of daily living, and instrumental activities of daily living, safely. Social workers who have been trained in functional assessment are best equipped to assess the consumers’ needs and determine the amount of time needed for personal care assistance.
- By contracting with counties for IHSS, counties can maintain the integrity of the IHSS program and provide an assurance that consumers will continue to receive services to which they are entitled under the State Medi-Cal program.
- In the future, counties will work with the State, consumer advocacy organizations and health plans to develop a statewide, comprehensive assessment tool.
Final thoughts...

- CSAC, CWDA and CAPA are opposed to the Governor’s State Budget Proposal to expand the existing Duals Demonstration from four to ten counties, to mandatorily enroll all duals into Medi-Cal managed care and to convert the In-Home Supportive Services (IHSS) Program, and other Long Term Services and Supports, from fee-for-service entitlements to managed care benefits.
- While we support the stated goals of efficiency and better outcomes for the beneficiaries, we have serious concerns with the proposal’s broad scope, untested assumptions, lack of detail and aggressive timeline.
To Ask A Question
Use the Chat Function
Expressed interest in testing capitated model

Expressed interest in testing managed FFS model

Expressed interest in testing both models

Did not submit letter of intent

States Interested in Duals Integration Models

For More Information

• **www.ncoa.org/duals**

• What you can find:
  – Links to state websites (if available)
  – Links to publically posted proposals (MA, OH, IL, OR)
  – Resources for state advocates
    • DREDF and NCOA webpage with many additional resources
    • Links to archived recordings of previous Friday Morning Collaborative webinars
Save the Date

Next Friday Morning Collaborative Webinar

Managed Long-Term Services and Supports
Friday, April 13  2:00 – 3:30 PM ET

Speakers:
  Laura Summer, Georgetown Health Policy institute
  Sara Barth, Center for Health Care Strategies

Look for registration in next couple weeks
Continue the Conversation

Join to discuss what you learned today!

www.NCOACrossroads.org/HCBS

• Online community with over 300 aging and disability advocates across country interested in home and community-based services
  – Listserv and message board functions
  – Share information and resources with others
  – Post questions and discuss issues

• Please complete follow up survey