



Growth and Prevalence of Participant
Direction: Findings from the National Survey of
Publically Funded Participant-Directed Services
Programs

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Overview

- NRCPPDS database project
- Changes in federal policy, law, and regulations
 - Impact of these changes on Participant-Directed (PD) Long-Term Services and Supports (LTSS) program growth
- State of PD LTSS in 2010-11
 - Program characteristics
 - Funding mechanisms
 - PD Models
- The future is now



Creating a National Data Base of Publically Funded Participant-Directed Services Programs

Data Fields		
	<ul style="list-style-type: none"> • Program Characteristics 	<ul style="list-style-type: none"> • Year Start
	<ul style="list-style-type: none"> • Funding Mechanism 	<ul style="list-style-type: none"> • Population Served • Program Size • Program Costs • Medicaid State Plan • Medicaid Waiver • State Revenue Only • Other
	<ul style="list-style-type: none"> • Financial Management Services 	<ul style="list-style-type: none"> • Model of FMS • Cost of FMS • Selection Process
	<ul style="list-style-type: none"> • Availability • Model • Services/Supports 	<ul style="list-style-type: none"> • State-Wide or PSA(s) • Employer/Budget Authority • Information and Assistance • Worker Registries • Representatives
	<ul style="list-style-type: none"> • Level of Participant Involvement 	<ul style="list-style-type: none"> • Involvement procedures and intensity




it has now become difficult to keep track of all the consumer-directed programs since states typically develop several, each one targeted to a different constituency (e.g. the elderly, physically disabled younger adults, children and adults with developmental disabilities and sometimes even more specialized programs for people with brain injuries, spinal cord injuries, etc.).




Watershed Moment:
Cash & Counseling Demonstration and Evaluation

the *Cash & Counseling* Demonstration and Evaluation (CCDE) provided the largest research base and the strongest evidence of efficacy of any participant-directed programs. CCDE showed significant differences between elders who were participants in Cash & Counseling (C&C) programs, and elders who were participants in the agency-based system. The results of CCDE have proven influential in bringing about changes in federal law, regulation, and policy that encourage and facilitate the inclusion of participant-directed services in PFPCS programs.

10 Years of Changes in Federal Law, Regulation, and Policy




2001 New Freedom Initiative
2005 Deficit Reduction Act
2010 Affordable Care Act




Administration on Aging

2006 Reauthorization of Older Americans Act
2007 Aging and Disability Resource Center Program
2010 Affordable Care Act



2008 Veterans-Directed Home and Community -Based Services Program



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This slide shows the 10 year history of the federal landscape that informs PD- it connects the dots between three federal support systems

1) CMS

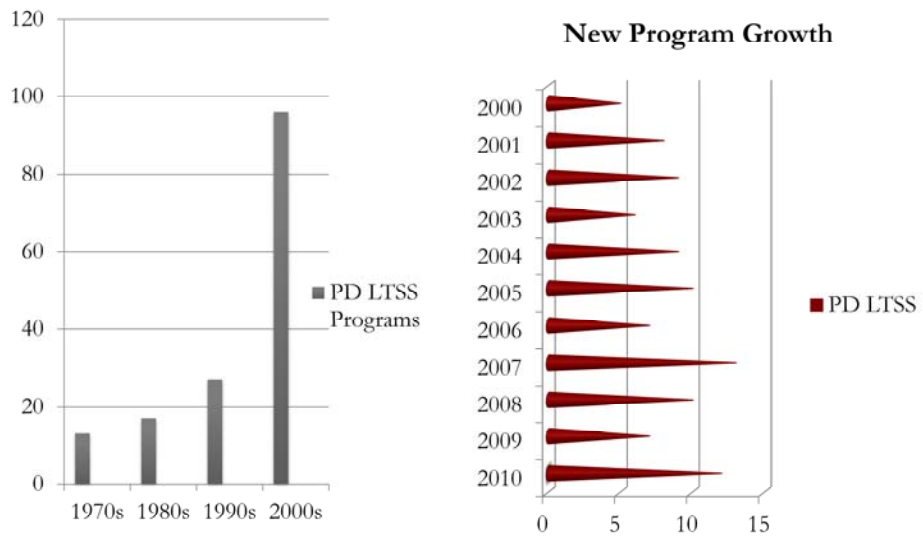
- A) The New Freedom Initiative created Independence Plus, which mainstreamed PD for first time under a 1915 (c) waiver. For the first time Medicaid recognized, encouraged, and found the means by which to put PD in waiver services. President Bush’s initiative to bring federal agencies together to reduce barriers to implement Olmstead.
- B) The DRA was passed in 2005 and was implemented in 2006
The DRA introduced the 1015 (i) and (j) and they were important because they supported community living under Medicaid state plan services. More specifically, the 1915 (i) broke the medical link to institutionalization and Colorado is the first state to take advantage of PD in the 1915(i) . 1915(j) legitimized the C&C model under Medicaid State plan
- C) The Affordable Care Act has many different components an Medicaid is one component. The Medicaid component is twofold: 1)The Affordable Care Act for Medicaid increased the financial eligibility for 1915(i) and it now allows state to target populations. 2) The ACA introduces the 1915(k), or Community First Option, and allows for a limited PD program being implemented under the state plan with an enhanced match of 6%. There is some tension between the various Medicaid authorities and PD and we hope that federal regulations resolve this tension.

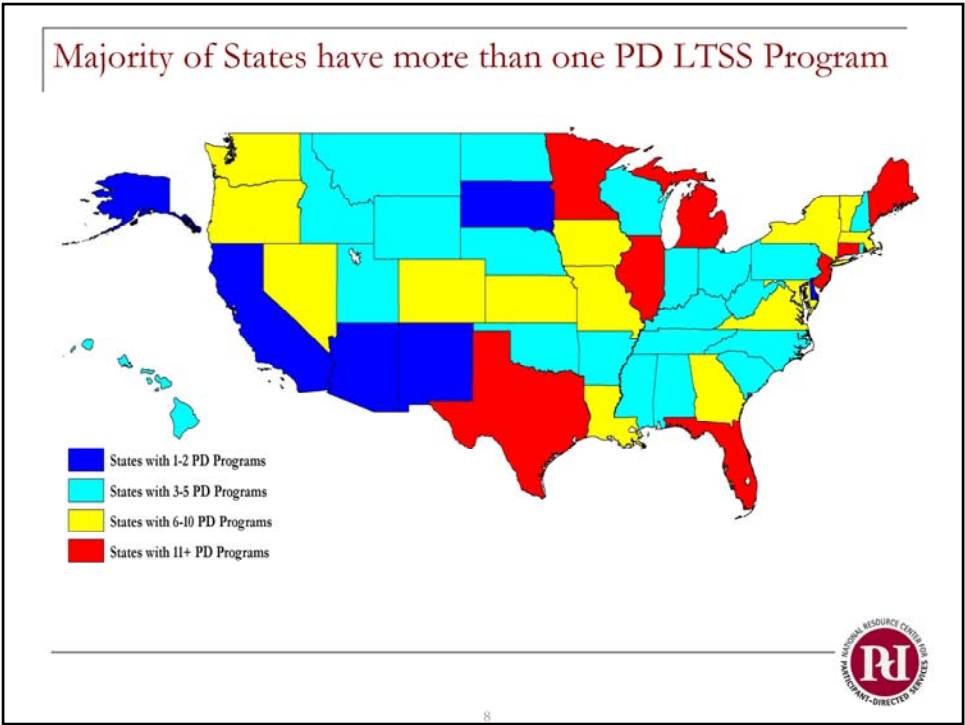
2) The next big federal funder for PD is AoA.

- A)The reauthorization of OAA did two things: 1) It created the demonstration for Community Living Programs and 2) it interpreted Title 3B funding to support FMS. The Reauthorization, Community Living, was the first attempt by AoA to infuse PD in the Aging Network.
- B) ADRCs
- C) Affordable Care Act continued and increased funding to ADRCs

3) VD-HCBS Grants the states to meet the growing long term support needs of Veterans.

The 2000s: Decade of Significant Growth





- PA Home and Community-Based Waiver for Individuals Aged 60 and Over (Aging Waiver)
- OBRA Waiver Program Self Determination for People with Developmental Disabilities
- Independence Waiver Program
- Attendant Care Program

Program Populations (n=154)

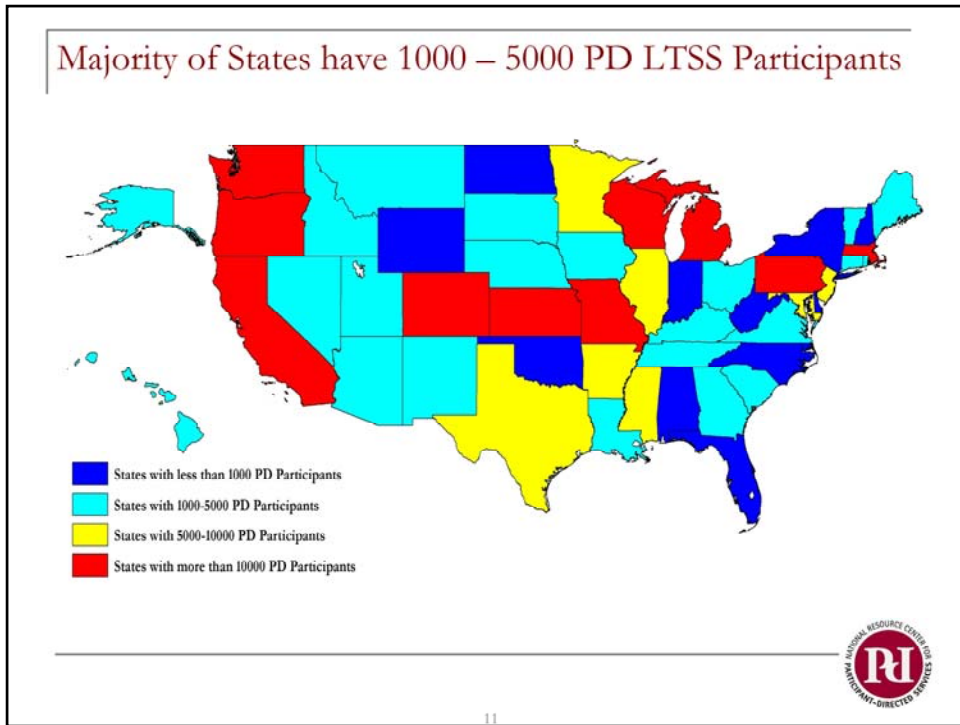
- Elders
 - 20% (n=30)
- Adults with physical disability
 - 11% (n=17)
- Elders and adults with physical disability
 - 35% (n=54)
- Adults with ID, MH, HIV/AIDS, etc
 - 13% (n=20)
- Children
 - 9% (n=14)
- All ages
 - 12% (n=19)



Program Size (n=233)

- Total enrollment: Approximately 747,000
 - California accounts for 65% of enrollments
- Average program size (n=232) approximately 1100 enrollments
 - Majority (53%) of programs have 500 or fewer participants
- Approximate program costs (2010-11): 7.7 Billion dollars
 - California accounts for 56%





PA Home and Community-Based Waiver for Individuals Aged 60 and Over (Aging Waiver)
 OBRA Waiver Program Self Determination for People with Developmental Disabilities
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PD-LTSS Funding Sources

- Medicaid is the major funding source (n=237)
 - 77% Medicaid Waiver/State Plan
 - 11% State Revenues
 - 7% VA
 - 3% Other (Tobacco funds, gaming revenue)
- CMS recognizes two basic models of PD-LTSS
 - Employer Authority
 - Budget Authority

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The Centers for Medicare and Medicaid recognize two distinct models, within which there may be some variants (employer authority, which gives participants the ability to employ workers directly, and budget authority, which gives participants the ability to manage an individual budget and make purchases related to personal care).



The older and more widely available model, referred to as “employer authority” consumer directed services, focuses exclusively on personal aide services. It gives program participants or their representatives (in the case of minor children and people with severe dementia or other significant cognitive impairments) the right to hire/fire, schedule, train, and supervise individual workers and participate in paying them by signing off on time sheets.

Within employer authority, there are two types. One type is *agency with choice*: the agency is the Common Law Employer and the participant or their chosen surrogate (representative) is the Managing Employer. The other type the participant or their surrogate (representative) is the Common Law Employer and the Vendor Fiscal/Employer Agent Financial Management Service is the Common Law Employer agent. In these programs, case managers carry out needs assessments (typically using a standardized assessment instrument) that determine how many hours of aide service the program participant may receive.

Employer Authority Characteristics

- Who sets rate of pay (n=179)
 - Participant 54% (n=97)
 - Program 31% (n=56)
 - Other % (n=26)
 - Designated pay range
 - General assembly or other entity



Employer Authority Characteristics

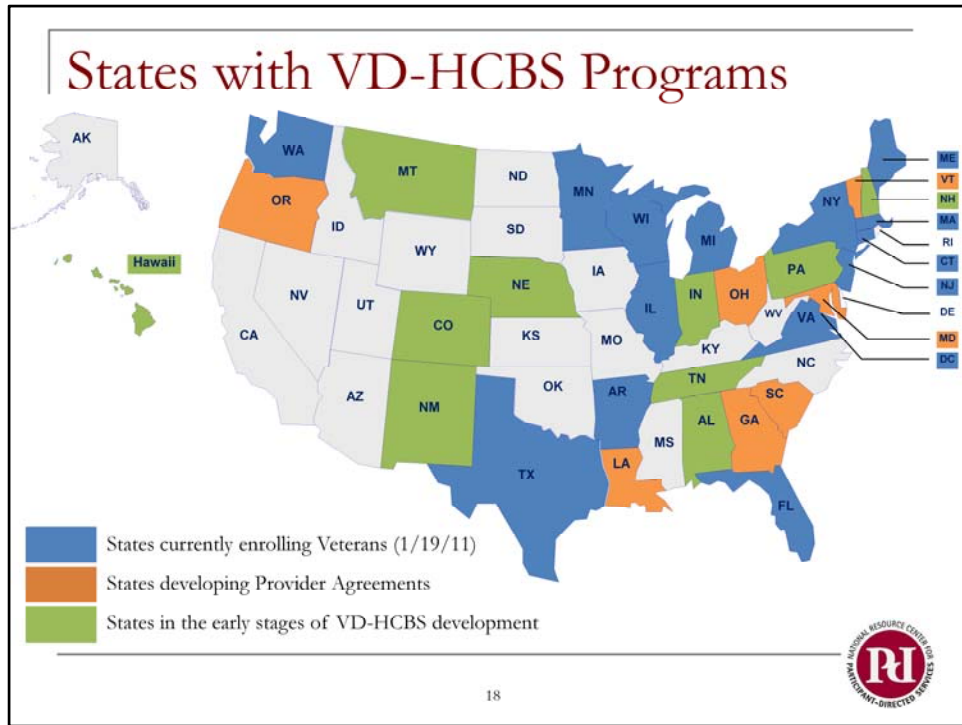
- Are there restrictions on who the participant may hire? (n=164):
 - 90% (n=148): Yes
 - Spouse
 - Legal guardian
 - Pass criminal background check
- Criminal background check required (n=180):
 - 86% (n=154): Yes
- Does the state have a worker registry? (n=163):
 - 28% (n=46): Yes; 69% (n=112): No



Budget Authority Characteristics (n=168)

- The size of the budget is determined by a professional needs assessment and a formula that converts the assessment into a monthly budget allocation
 - Varied
- Purchasing restrictions
 - Cannot exceed approved budget
 - Categorical restrictions
- Can carry forward funds into new fiscal year
 - 86% (n=98): No





This program has been gradually growing for approximately a year and a half. There are currently 17 states/28 VAMCs currently enrolling participants with approximately 800 Veterans. VA Hopes to have this option in every state by 2014.

VAMCs will refer eligible Veterans (or must approve Veterans referred from other avenues)

Eligible Veterans: require a considerable amount of personal care assistance and/or experience difficulties with traditional agencies and desire to self direct their care

Agency will do an assessment, and with Veteran, develop a plan of services

Agency will provide ongoing support for Veteran including use and assistance with financial management services

VA expects that the Agency, at least performs:

- Reassessments semi-annually in the first year
- Conducts quarterly visits with the Veteran to monitor well-being

Agency must provide monthly invoices for reimbursement with estimated or actual expenses as agreed between VAMC and Agency

Components of VD-HCBS

- Individual Budget
- Person-Centered Planning
- Spending Plan including Goods and Services
- Systems of support:
 - Veteran-Directed counselor
 - Financial Management Services (FMS)



Level of Participant Involvement (n=160)

- Participant involvement in program design, implementation, and evaluation
 - 86% (n=139): Yes
 - 86% (n=120): Persons with disability
 - 67% (n=93): Persons with Intellectual Disability
 - 65% (n=90): Persons with brain injury
 - 79% (n=110): Elders
 - 90% (n=125): Caregivers



Methods for Participant Involvement (n=139)

- Individual Interview: 61% (n=85)
- Surveys: 73% (n=101)
- Focus Groups: 56% (n=72)
- Advisory Board: 78% (n=108)



Summary

- By the end of 2011 there will be approximately 300 PD-LTSS programs
 - Majority being developed and implemented since 2000
 - Every state has one employer authority program offering the participant the opportunity to select and hire their own worker
 - 43 states also have at least one program where the participant has control over their service budget
- NRCPPDS will continue to collect program information and to analyze this information to learn about differences in PD program structure, financing, and operations across the states.



Financial Management Services

- FMS providers perform administrative responsibilities so that:
 - Participants can focus on managing their services and supports
 - Tax, employment and insurance regulation compliance is maintained
 - Payments to participant's providers are made in accordance with budget
 - Additional controls are in place to detect and prevent fraud and abuse



Financial Management Services

- FMS provider:
 - supports the participant through the administrative process of being an employer
 - supports the participant to ensure workers are legally hired
 - conducts criminal background checks on workers
 - ensures that workers and other providers are paid in compliance with applicable rules and regulations
 - makes payments in accordance with spending plans, authorizations and program rules
 - This includes paying workers, agencies, or other goods and services vendors



FMS Provider Statistics

- 64% require the use of an FMS provider (n=175)
- 38% of Medicaid programs provide as a service function
- 62% of Medicaid programs provide as an administrative function
 - Over 30 distinct providers in 33 states



FMS Models: Fiscal/Employer Agent

- Two types of Fiscal/Employer Agent (F/EA):
 - Government F/EA
 - Vendor F/EA
- Participant (or representative) is the common law employer of home-based workers who are employees. Participant hires, fires, trains and manages workers.
- The F/EA supports the participant to complete and file appropriate tax forms to become an employer, manages payroll duties on behalf of the employer and withholds, deposits and files applicable taxes on the employer's behalf. The F/EA may manage applicable workers' compensation duties.
- The participant can also work with agencies, vendors and other independent contractors. The participant is NOT the employer of agencies, vendors or other independent contractors. Payments to these entities can be made by the F/EA or another source.



FMS Models: Agency with Choice

- Agency and participant have a co-employment relationship for workers that provide services to the participant
- The agency is the primary employer
- The participant is the managing employer
- The agency hires the worker and manages all duties related to tax, labor and workers' compensation rules and regulations
- The participant may refer a worker to the agency for hire, participate in training the worker and have some control over scheduling and dismissing the worker

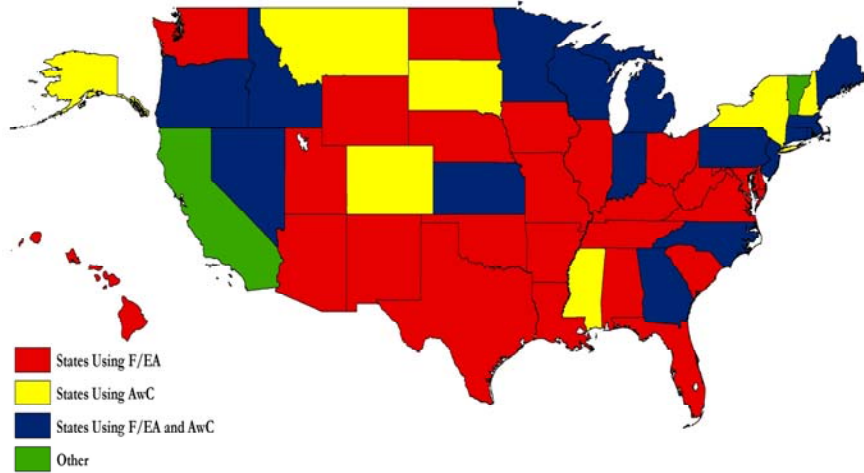


FMS Model Statistics (n=189)

- Vendor Fiscal/Employer Agent
 - 58% (n=110)
- Government Fiscal/Employer Agent
 - 12% (n=22)
- Agency with Choice
 - 21% (n=40)
- Other models (Government AwC, Billing Agent, Fiscal Conduit, Statutory Employer)
 - 11% (n=20)



Map of FMS Models by state



Average Annual FMS Cost (n=104)

- Mean
 - \$1,046.05
- Median
 - \$1,008.00
- Minimum
 - \$125.00
- Maximum
 - \$3,000.00



These cost slides will have to adjust heavily for outliers as a result of bundled costs

Average Annual FMS Cost

- Fiscal/Employer Agent
 - \$1,136.16 (n=86)

- Agency with Choice
 - \$1,177.35 (n=14)



The Future is Now

- Participant Direction is increasingly becoming a standard program offering to individuals in publically funded long-term services and support programs
- Patient Protection and Affordable Care Act
 - 2401: Community First Choice Option
 - 2402a: Common Framework Supporting PD
 - 2403: Money follows the person
 - 2405: ADRC expansion
 - Title VIII: CLASS ACT
- AoA LTSS workforce development initiative

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Among public program administrators involved with home and community-based services, at federal, state, and local levels, awareness is virtually universal. Centers for Medicare and Medicaid officials report that over the past several years, they saw an upsurge in states electing to offer such options—especially, of course, after the changes in federal Medicaid law, regulations, and policies made it so much easier for states to do so

Why make this transformation now?The national long term care system has already begun to evolve with programs such as CMS's Real Choice Systems Change Grants, Cash and Counseling, and other consumer-centered and consumer-directed programs.

Why should we work to transform the long-term care system?State budgets will not be able to support the current system of Medicaid long-term care and spend-down without creating a plan to slow the rate of its growth and expenditures.

Consumers would like a person-centered, self-directed system that assists them with identifying and accessing a range of home and community based resources which support and maintain their independence

2401 begins 10-1-11: provides new state option, with a federal match of FMAP+ 6 percentage points to provide either agency based or PD programs

Section 2402(a) calls on the Secretary of the Department of Health and Human Services (DHHS) to develop a common framework establishing principles and process elements supporting participant direction across the whole department and all of its programs.

2405: The Administration on Aging funding to support states' efforts in developing and sustaining a person-centered, self-directed national long term care system. This system should effectively assist consumers with identifying and accessing a range of home and community based resources which maintain independence of older citizens and persons with disabilities and slow the rate of growth and expenditures in the states' Medicaid programs.

CLASS Act insurance program is voluntary. The program covers anyone who becomes disabled, not just those "over 65" as claimed. It will provide in-home care, such as a home health aide, adult day care or assisted living, as an alternative to nursing home care. It will pay an average of at least \$50 per day, \$18,250 a year, with no lifetime limit.

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