# Home and Community Based Services:

## *From Institutional Care to Self-Directed Supports & Services*


*Center for Medicaid & State Operations*

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**Division of**
**Disabled and Elderly**
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# HOME AND COMMUNITY BASED SERVICES: FROM INSTITUTIONAL CARE TO SELF DIRECTED SUPPORTS AND SERVICES

## I. Introduction

Health care financing and delivery systems for the elderly and persons with disabilities have steadily evolved in the nearly 40 years since Congress created the Medicare and Medicaid programs. At this point in the Program's evolution, there is a convergence of factors that directly impact upon the future design of such health care. The combination of legal factors (such as the Americans with Disabilities Act, the related Supreme Court Olmstead decision), the National Cash and Counseling and Self-Determination Projects, and President Bush's New Freedom Initiative require that persons live in communities of their choice whenever appropriate.

Demographic and fiscal projections suggest as many as one and one-half million individuals may require a level of care traditionally provided in an institution, at a cost of $70 billion. While the elderly and disabled population is expanding, preliminary information from national demonstration programs that allow families or individuals to direct their own service delivery, are positive from both satisfaction and cost perspectives.

This document, organized in eight sections, presents a summary of the evolution of Medicaid funded health care delivery for persons who require long-term supports and services. This movement has led to initiatives that facilitate states' efforts to meet the desires of beneficiaries while simultaneously addressing legal and fiscal pressures by offering new innovations in the delivery of long term services and supports.

***"By the authority vested in me as President by the Constitution and the laws of the United States of America, and in order to place qualified individuals with disabilities in community settings whenever appropriate, it is hereby ordered as follows: The Federal Government must assist States and localities to implement swiftly the Olmstead decision, so as to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life."***

***-- President George W. Bush, Executive Order 13217***

# II. MEDICAID & HOME AND COMMUNITY BASED SUPPORTS AND SERVICES

- **Medicaid** has been the primary federal source of funding available to serve persons of any age who required long-term supports or services.

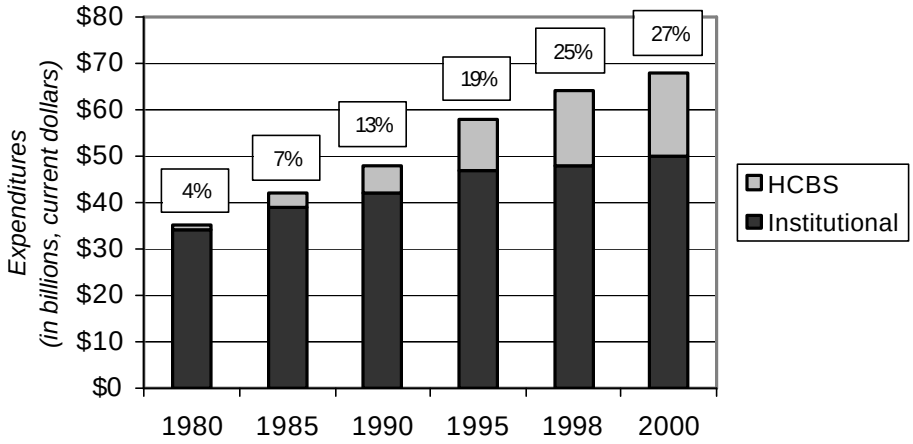
- Prior to 1981, Medicaid expenditures for these persons were essentially made for **institutional care** provided through nursing facilities or Intermediate Care Facilities for the Mentally Retarded (ICF/MR). While a limited home health benefit was available as a mandatory Medicaid State Plan service, total expenditures for community-based home health accounted only for 4% of the total Medicaid long-term expenditure.

- In 1981 Congress enacted the **Home and Community-Based Services (HCBS) waiver** program through the creation of section 1915(c) of the Social Security Act (the Act).

  - The HCBS waiver program became the Medicaid long-term care alternative to serving eligible persons in an institution, defined as a hospital, nursing facility, or ICF/MR.
  - Through implementation of the HCBS waiver program, Congress recognized that many individuals at risk of being placed in an institution can be cared for in their own homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care.
  - This program is a voluntary option for States wishing to expand HCBS beyond existing long term care State Plan services (e.g., personal care services that became available in 1985 and home health.)

- **State utilization of HCBS services** has grown.
  - By fiscal year 2000, Medicaid expenditures for all HCBS services, as a percentage of total long term care expenditure, had risen from 4% in 1980 to 27% of the $67.7 billion in 2000. However even with this growth, the majority of Medicaid expenditures remained in institutional settings.

**Medicaid LTC Expenditures:**
**Institutional vs. Home & Community-Based Services**




Source: Centers for Medicare and Medicaid Services, CMS Form 64. Institutional expenditures include nursing facility and ICF/MR charges for all years. HCBS expenditures include home health in 1980, and home health, personal care and HCBS waiver services for 1985-2000.

# III. HOME AND COMMUNITY BASED SERVICES WAIVER UTILIZATION & EFFECTIVENESS

- As of February 2002, there were **263 active HCBS waivers:**
  - Forty-nine states and the District of Columbia have at least one HCBS waiver program. (Arizona operates a similar program under a research and demonstration authority.)
  - In the first 12 months of the current Bush administration, 13 requests for new HCBS waivers have been approved.

- **States have the flexibility to define the target population** to be served under the waiver program. In 1999, 688,152 persons had been served within the following broad target groups:

**1915(c) Waiver Program Participants and Expenditures**
**1999**

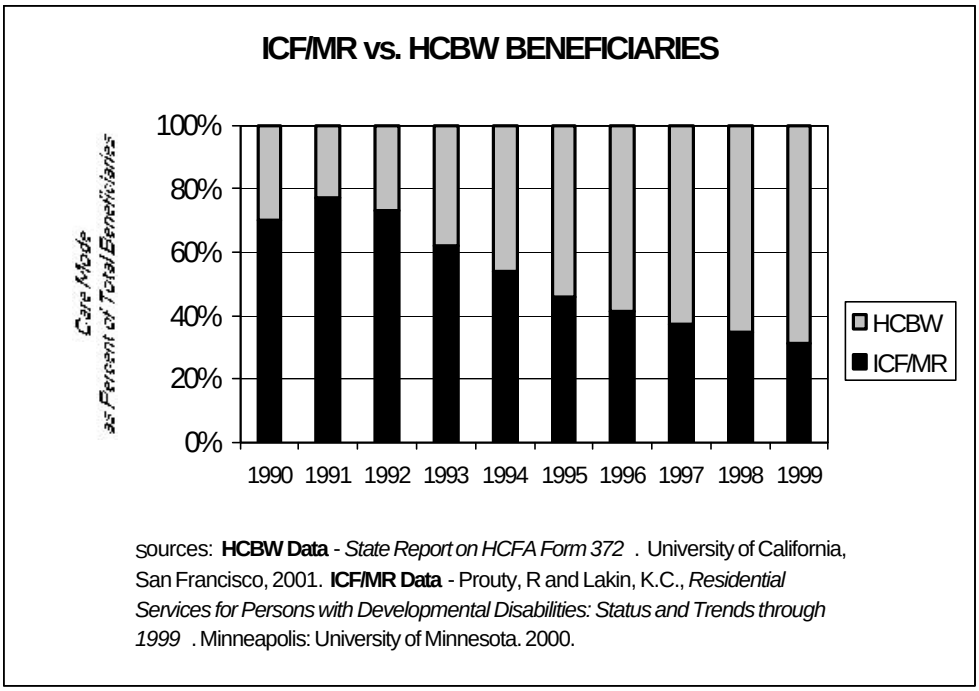
| Target Population | Expenditures | Program Participants | Annual Expenditure per Participant |
|---|---|---|---|
| Aged / Disabled | $2,368,402,389 | 381,751 | $6,204 |
| Physically Disabled | $431,954,159 | 44,706 | $9,662 |
| Mentally Ill | $9,455,104 | 2,134 | $4,431 |
| MR / DD | $8,702,454,244 | 259,561 | $33,528 |
| Total | $11,512,265,896 | 688,152 | |

- **States have the flexibility to define the services** that are essential for their target population, choosing from a statutory list or creating new service options approved by the Secretary of Health and Human Services. This allows States to design programs specific to the unique characteristics of the State, which assist the participants to remain in or return to community settings.
- The most **frequently included services** have been:
  - Respite
  - Environmental Modification
  - Case Management
  - Expanded Medical Equipment/ Supplies
  - Expanded Personal Care
  - Personal Emergency Response Systems
  - Transportation
  - Homemaker Services
  - Adult Day Care
  - Habilitation

- Home and community based services have been **effective** as evidenced by:

  - Providing services in the home and community cost no more than institutional services. All approved waivers have been cost-neutral. This statutory requirement specifies that the federal funding be no more than the institutional costs that would have been incurred for waiver participants, and

  - The number of beneficiaries being served in the home or community rather than in an institution is increasing. The increased percentage of total beneficiaries served through HCBS waivers as compared with ICF/MR facilities, as reflected in the graph below:




sources: **HCBW Data** - *State Report on HCFA Form 372* . University of California, San Francisco, 2001. **ICF/MR Data** - Prouty, R and Lakin, K.C., *Residential Services for Persons with Developmental Disabilities: Status and Trends through 1999* . Minneapolis: University of Minnesota. 2000.

# IV. SELF-DIRECTED SUPPORTS AND SERVICES

❖ Many phrases have been created to refer to service delivery models where elderly persons or persons with disabilities have more control over their health care decisions. Consumer-direction, self-direction, person-centered, self-determination, and family and individual directed include a few. For the purposes of CMS' current efforts, the term self-directed supports and services will refer to a service delivery system whereby elderly persons, families of persons with disabilities or persons with chronic conditions have more involvement, control and choice in identifying, accessing and managing the services they obtain to meet their personal assistance needs.

❖ A recent **"Inventory" of self-directed support service programs** reveals that several such programs are operational across the country with many States utilizing Medicaid funding to sustain these efforts.

- 139 programs use a self-directed approach to the delivery of support services.
- The most frequently covered services include personal care assistance (83%), homemaker/chore (60%), and respite (52%).
- Medicaid is utilized as a funding resource in 65% of the programs with Medicaid being a primary funding source for 50%. Of those programs accessing Medicaid funds, the HCBS waiver is utilized in 77% of them.

Source: Susan Flanagan, An Inventory of Consumer-Directed Support Service Programs: Overview of Key Program Characteristics, The 19th Annual National Home and Community-Based Services Waiver Conference, October 2001.

❖ In 1996, HHS, States and the Robert Wood Johnson foundation co-sponsored the development of the National **"Cash and Counseling" Demonstration** intended to test

the effects of allowing persons of all ages the ability to self-direct their own home and community based personal assistance services and supports.

- CMS' role was to grant three states (Arkansas, New Jersey, and Florida) approval for a research and demonstration program under the authority of section 1115 of the Act.
- This allowed these States to operate a program, which could not occur without waiver authority, where individuals receive a monthly cash allowance or budget that is under their control.
- Participants use their resources to purchase supports or services appropriate to meet their personal assistance needs.

❖ **Self-direction has been effective**. Early Mathematica evaluation findings reveal the following for the group who selected the cash option. These participants expressed: :

- Significantly increased satisfaction with services
- Improved quality of life
- A modest increase in the ability to obtain equipment or modifying their home
- Slightly better medical and functional outcomes
- No adverse effects on health
- An increased likelihood of obtaining needed care
- The ability to obtain assistance at night/on weekends
- The ability to obtain assistance with wider range of services

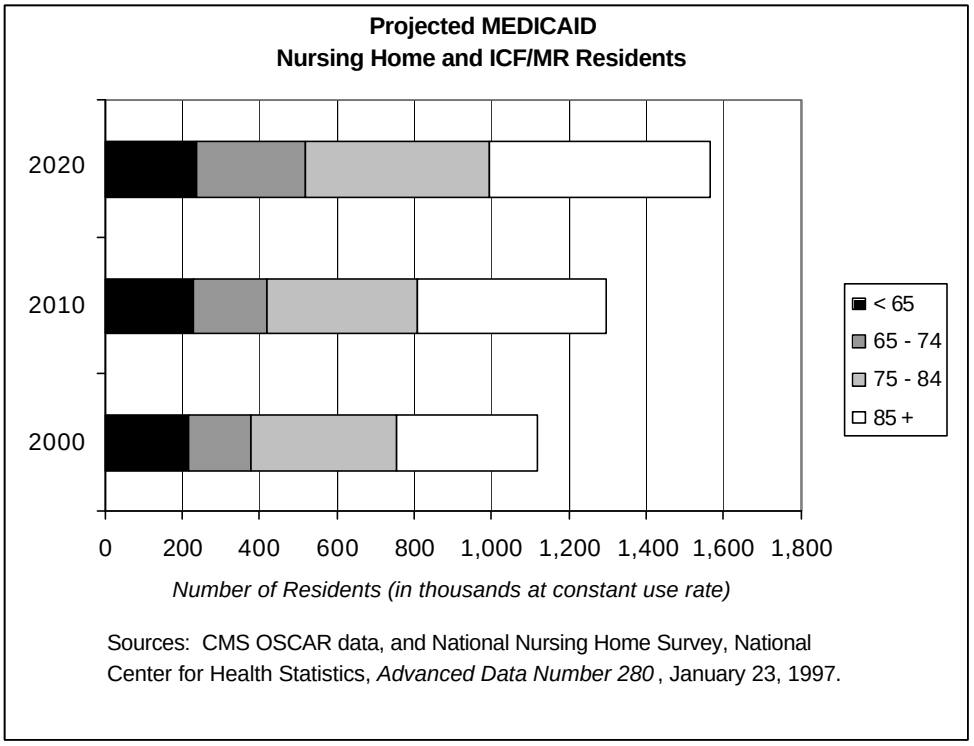
# V. DEMOGRAPHIC IMPERATIVE FOR THE FUTURE OF HOME AND COMMUNITY BASED SERVICES

❖ There has been steady growth in the States' use of Medicaid funded HCBS services.

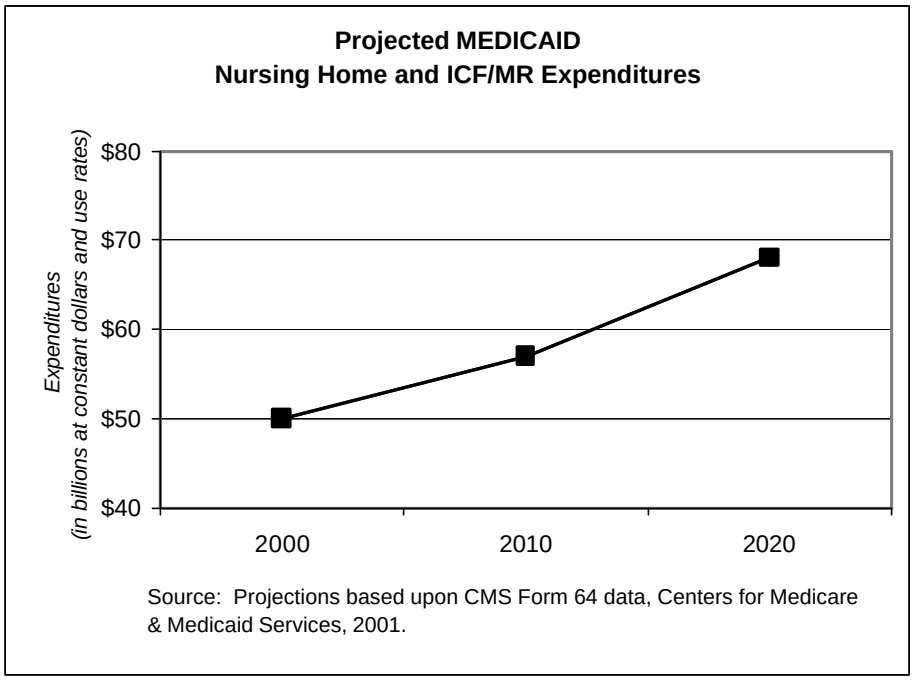
❖ Beneficiaries have made clear that perceived quality of life is profoundly improved by being able to remain in, or return to the community, as opposed to receiving care in an institutional setting.

❖ As the "baby boom" cohort moves into age groups that normally require increasing levels of health services, the sheer number will have a significant affect upon Medicaid funded service provision.

- As the graph below illustrates, if usage remains the same as was the case in 2000, Medicaid beneficiaries needing a level of care traditionally provided by an institution will increase from a little over one million individuals to over one and one-half million by 2020.




- As the graph below illustrates, if usage remains the same as was the case in 2000, Medicaid expenditures for nursing facilities and ICF/MR services will reach nearly $70 billion by 2020.



## VII. A Medicaid Initiative to Provide Tools for States and Beneficiaries to Meet the Demand for HCBS

*Independence Plus*

This initiative expedites the ability of states to offer families, individuals with disabilities and the elderly greater opportunities to take charge of their own health and direct their own services. Families and individuals will exercise greater choice, control and responsibility for their services within cost neutral standards. Two template versions will be available to enable states to tailor the program to their preferences; the §1115 Demonstration Template and the §1915(c) Waiver Template. These templates further the interests of the administration, states and beneficiaries. The program builds on the experience and research from a number of pioneer states that have pre-tested these concepts.

The Goals of the Templates

1. The templates will assist states to develop programs that will permit individuals needing long-term supports and services to obtain assistance while living with their family or in their own home. This will be accomplished by:
    - Recognizing the essential role of the family or individual in the planning and purchasing of health care supports and services by providing family or individual control over an agreed resource amount.
    - Increasing family and individual satisfaction through the promotion of personal control and choice - a major theme expressed during the New Freedom Initiative - National Listening Session.
    - Encouraging cost effective decision-making in the purchase of supports and services.
    - Allowing eligible families and individuals to receive a cash allowance (in the §1115 Demonstration) or individual budget (in the §1915(c) Waiver) to obtain personal assistant services and related supports.
    - Promoting solutions to the problem of worker availability.
    - Providing Financial Management Services and Supports Brokerage services to support and sustain families or individuals as they direct their own services.
    - Delaying or avoiding institutional or other high cost out-of-home placement by strengthening supports to families or individuals.
2. The templates will provide states the tools, resources and guidance to create effective programs and continue the CMS commitment to create a "culture of responsiveness" by:
    - Assisting states with meeting their legal obligations under the Americans with Disabilities Act (ADA) and the Supreme Court *Olmstead* decision.
    - Providing flexibility for states seeking to increase the opportunities afforded families and individuals in deciding how best to enlist or sustain home and community services.
    - Incorporating the essential elements of self-direction such as person-centered planning, individual budgets, participant protections and quality assurance and improvements.
    - Providing states with streamlined and standardized application formats to reduce the administrative burden for preparing proposal submissions and to reduce the Federal review period.

Features of the Templates

- Electronic format for easier submission.
- Database platform to enable electronic tracking, sorting, querying and analyzing.
- Additional features of the §1115 Demonstration include simplified/streamlined budget neutrality model and sample terms and conditions.

# *Self-Direction & the Independence Plus Initiative:*
# Promoting Choice & Control Options for Persons with Disabilities

## Question & Answers

*Q1. What is **Self-Direction**?*

Self-direction is a service delivery approach that provides persons with disabilities of all ages the option to exercise control and choice in identifying, accessing and managing services they obtain to meet their long-term health care needs. The Centers for Medicare and Medicaid Services (CMS) defines a self-directed program as a state program that presents participants with the option to control and direct Medicaid funds identified in an Individual Budget.

*Q 2. What is the **Independence Plus** Initiative?*

Independence Plus is an initiative developed by CMS to provide guidance and assistance to states wishing to implement self-direction programs for persons with disabilities and their families. The initiative will:

1) Assist states to achieve the goals established in President Bush's *New Freedom Initiative* . This initiative is intended "*… to ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment and to promote community life*." - President George W. Bush, Executive Order 13217.
2) Provide states with tools and resources to delay institutional or other high cost, out-of-home placement by strengthening supports to individuals, thereby encouraging individuals with a disability to live with their family or in their own home.
3) Recognize the essential role of the individual and his/her family in the planning and purchasing of health care services and supports by providing control over an agreed upon resource amount.
4) Facilitate cost effective decision-making in the purchase of supports and services.
5) Increase individual satisfaction by offering control and choice, concepts expressed by participants in a National Listening Session - *New Freedom Initiative.*
6) Assist states to meet legal obligations under the Americans with Disabilities Act (ADA) and the Supreme Court *Olmstead* decision.
7) Provide states with two distinct template applications; one to create self-directed waiver programs and one to create self-directed demonstrations.

*Q 3. Is this the first time states have used Medicaid funding to offer a self-directed service delivery model?*

No. Some states have been using a variety of mechanisms to offer participants the opportunity to control and direct their own services and supports. The National Cash and Counseling Demonstration and Evaluation Project, co-sponsored by DHHS and the Robert Wood Johnson Foundation (RWJF), operates in the states of Arkansas, Florida and New Jersey under the authority of §1115 of the Social Security Act. These demonstrations use an experimental approach to randomize enrollees into a treatment or control group. Treatment group participants are elderly and younger Medicaid beneficiaries with significant long-term functional disabilities; family caregivers serve as representatives, if necessary. Participants in the Cash and Counseling Demonstrations "self-direct" their personal assistance services. They utilize a cash allowance to purchase services or items needed to meet their personal care needs. An equal number of recipients are randomized into a Control Group. The control group participants remain in the traditional service delivery program. The evaluation compares the level of satisfaction, utilization and expenditures between the two groups. Colorado and Oregon offer comparable cash options to participants.

Similarly, nineteen pioneer states developed "self-determination" programs as a result of a Robert Wood Johnson Foundation National Program grant. The Self-Determination programs generally operate under the §1915(c) authority and emphasize "freedom, authority, support and responsibility" for participants. While Cash and Counseling is a Medicaid Demonstration Program with a major emphasis on research design, the emphasis in the Self-Determination initiative is on experimentation of program approaches. Thus a diverse array of program and research outcomes is being realized through the Self-Determination projects.

These initiatives and their related experiences have been instrumental in the design of the Independence Plus Initiative.

*Q 4 Why should states consider the self-directed option?*

Recent findings from Mathematica Policy Research of the Arkansas Cash and Counseling Project reveal that participants:

- Are significantly more satisfied and state their quality of life improves.
- Experience no adverse effects on health and are more likely to obtain needed care particularly during nights and weekends.
- Are able to obtain assistance with a wider range of services.

Arkansas also reports a reduced number of referrals to Adult Protective Services compared to program participants of traditionally delivered services. Additional findings by Mathematica on worker, caregiver and implementation issues are published on the following web site: http://www.mathematica-mpr.com/3rdLevel/cashcounselinghot.htm

Key studies conducted on the Self-Determination pilots include anecdotal descriptions of program approaches, system changes (see www.hsri.org, www.nasddds.org/publications), and pre-post surveys on individual quality of life outcomes of the participants (www.outcomeanalysis.com). The outcome data thus far from nine states confirm several hypotheses about Self-Determination (www.outcomeanalysis.com):

- Participants gained more control over their lives

- Participants experienced improved qualities of life
- Costs either decreased or remained stable

Other outcomes realized from both self-direction programs include:

- Expansion of the labor market by hiring a non-traditional labor force (family, friends or neighbors)
- Strengthening of community living thus assisting states to meet the Olmstead Mandate.

*Q5.* ***Why are two different templates*** *provided (§1915(c) and §1115)?*

The §1915(c) Waiver and §1115 Demonstration Applications have different approaches and distinctly different authorizing provisions of the Social Security Act. States should review their intended goals and objectives to determine which option best suits their proposed program design. The chart below compares the two application approaches:

| Issue | Section 1115 Demonstration Authority | Section 1915 (c) HCBS Waiver Authority |
|---|---|---|
| Cash Allowance | Participant May Manage the Cash Allowance Directly | Participant Does Not Manage Cash Allowance Directly |
| Hiring Legally Responsible Individuals | Participants May Hire Legally Responsible Individuals | Participants May Hire Legally Responsible Individuals When the State Meets Specific Conditions |
| Provider Agreements | Provider Agreements May be Waived | Provider Agreements Must be Executed |
| Direct Payment to Providers | Direct Payment by the Medicaid Agency to Providers May be Waived | Direct Payment by the Medicaid Agency (or Eligible Entity) to Providers is Required |
| Payment for Services Made Prior to Delivery of Services | Services May be Reimbursed Prior to Delivery | Services Must be Delivered Prior to Payment |
| Level of Care | Level of Care May Vary | Individuals Meeting Institutional Level of Care |
| Services Which May be Self-directed | State Plan or HCBS Waiver Services | HCBS Waiver Services Only |
| Combining Populations | States May Combine Any Population | Combing Populations is Limited to:<br>1) Aged/Disabled, or<br>2) Mentally Retarded/Developmentally Disabled, or<br>3) Mentally Ill, or<br>4) Any Subgroup Thereof |
| Cost Test | Budget Neutrality: Base Year/Trend | Cost Neutrality: Based on Institutional Cost (Individual or |

| | | |
|---|---|---|
| | Factor/Per Member/Per Month Methodology | Aggregate) |

*Q6.. Do the templates cover **individuals who are currently institutionalized** and wish to move into the community and enroll in a demonstration program?*

Yes, the templates may be used to assist persons living in institutions to return to the community.

*Q7. How will these templates **help states**?*

CMS developed these templates to further efforts toward building a **culture of responsiveness** by creating an application that reduces the state administrative burden for the submission of self-directed waivers and demonstrations and the Federal review period.

*Q8. Can a state **already do** what is proposed under these templates?*

Yes. However, states and their partnering organizations have often been confused by the existing array of choices and requirements. It has also been unclear to states as to how self-direction can fit within traditional waiver or demonstration frameworks. These templates and the related material will provide guidance and administrative simplification. .

*Q9. Are the Federal requirements for **safeguarding the health and welfare** of program participants the same for self-directed programs?*

Yes, the federal requirements are the same for both service delivery methods, however, the process by which states meet the requirements may differ. In order to comply with Federal mandates, traditionally managed programs implement a system of checks and balances to establish certain safeguards in their home and community-based service delivery systems. Generally, these systems involve: 1) establishing specific provider standards, such as requiring staff certifications and training; 2) assigning contractual obligations and assurances to providers clearly delineating responsibilities; 3) outlining expectations through detailed state policies and regulations; and 4) performing routine provider reviews and audits to ensure contractual obligations are met and policy is followed.

Self-direction represents a divergence from the traditional approach in that many of the responsibilities assumed by provider agencies are transferred to the individual or family. The Independence Plus template format offers new ways to meet the Federal requirements to assure that sufficient safeguards are in place to protect the health and welfare of persons selecting the self-directed option.

*Q10 How does the Independence Plus initiative **assure the health and welfare** of the individuals who choose to self-direct?*

Assuring the health and welfare of individuals under a self-directed service model is accomplished using traditional mechanisms as well as uniquely identified elements essential to self-direction. The development of these "essential elements" draw heavily from the

insights gathered in implementing self-directed programs. The CMS essential elements associated with a successful self-directed program include:

- Person Centered Planning,
- Individual Budgeting,
- Self-Directed Supports (e.g, Supports Brokerage and Financial Management Services), and
- Quality Assurance and Improvement

These essential elements are applied to each self-directed program.

**A. Person-Centered Planning**

Person-centered planning is a process, directed by the participant, with assistance as needed from a representative. It is intended to identify the strengths, capacities, preferences, needs and desired outcomes of the participant. The process may include other individuals freely chosen by the participant who are able to serve as important contributors to the process.

The person-centered planning process enables and assists the participant to identify and access a personalized mix of paid and non-paid services and supports that will assist him/her to achieve personally-defined outcomes in the most inclusive community settings. The identified personally-defined outcomes and the training, supports, therapies, treatments and/or other services become part of the person-centered plan.

***B. The Individual Budget***

The individual budget is the total dollar value of the services and supports, as specified in the plan of care, under the control and direction of the program participant. While states have the discretion to include both Medicaid and non-Medicaid funded services and supports in the individual budget, there must be a clear audit trail delineating the Medicaid funding stream. An individual budget is not an expenditure cap on the amount of services an individual may receive under the waiver. An individual must receive all medically necessary services provided under the waiver.

The state should assure that the individual budget is:

1. Developed using a person-centered planning process;
2. Based on actual service utilization and cost data and derived from reliable data, preferably the state's Medicaid Management Information System (MMIS);
3. Developed using a consistent methodology to calculate the resources available to each participant;
4. Open to public inspection, and;
5. Reviewed according to a specified method and frequency.

<u>Participant Rights to Information</u>

The state must describe how the participant and/or representative are informed of the following:

1. the methodology used to calculate the individual budget,
2. the total dollar value of the services authorized,
3. any policies that apply to the participant's management of the individual budget.
4. the procedures that he/she must follow in order to request an adjustment of the individual budget.

**C. Self-Directed Supports**

Under the Medicaid self-direction option, states are required to develop a system of activities that assist the participant to develop, implement and manage the support services identified in his/her Individual Budget. Generally, these activities link the participant with community resources and enhance personal skills. Self-directed supports are broadly categorized into two groups 1) Supports Brokerage/Counseling and 2) Financial Management Services.

- Supports Brokerage provides participants assistance with:
  recruiting, hiring, managing and dismissing a service worker,
  identifying and accessing community resources, and
  serving as the agent on behalf of the participant

- Financial Management Services provides participants assistance with:
  understanding billing and documentation responsibilities,
  performing payroll responsibilities,
  purchasing allowable goods and services, and
  tracking and monitoring individual budget expenditures

The extent to which the participant uses the supports may vary with his/her abilities and preferences. States should assure a range of supports and services to respond to participant capacity and preference for self-direction.

The state should assure that the above activities are available to each participant electing to self-direct some or all of his/her services and supports.

States may design these support activities in a variety of ways including: 1) combining with existing services, 2) creating a new service category to include all or some of the activities, or 3) identifying as an administrative function.

**D. Self-Directed Quality Assurance and Improvement**

The self-directed quality assurance and improvement model will build on the existing foundation formally introduced under the CMS Quality Framework in the State Medicaid Director's Letter of August 29, 2002 and subsequent correspondence. By way of summary, the framework delineates the functions of quality:

- Design – designing quality assurance and improvement strategies into the home and community-based program at the initiation of the program.
- Discovery – engaging in a process of discovery to collect data and direct participant experience sin order to assess the ongoing implementation of the program, identifying both concerns as well as other opportunities for improvement.
- Remediation – taking actions to remedy specific problems or concerns that arise.
- Improvement – utilizing data and quality monitoring to engage in actions that assure continuous improvement in the self-directed program.

States wishing to implement Independence Plus must develop the following in their Quality Assurance and Improvement System:

1. Incident Management System – the template requires:

"***The state has a system by which it receives, reviews, and acts upon critical events or incidents (states must describe critical events or incidents). This system may include an existing process (e.g., child or adult protective services). The system must be part of the Quality Assurance and Improvement Program."***

An effective Incident Management System must include the following:

- Clear state definition of what constitutions a major and usual critical event or incident and the incident method for rapid response.
- Clear and unequivocal process for identifying and reporting critical events or incidents
- Clear and unequivocal process for investigation of critical events or incidents (i.e., person responsible, response time frames, etc.)
- Clear identification of the agency assigned responsibility to review all instances of critical events or incidents and their resolution, and
- Systematic process for the timely sharing of information among/between agencies performing the investigation and operating the waiver/demonstration.
- Regular trending of aggregated incidents to identify, address and correct systemic problems
- Observable evidence of action(s) taken to address the identified problems

2. Individual and Statewide Emergency Back-Up System:

The template requires:

***"That the state has an emergency back-up system under/or emergency response capability in the event those providers of services and supports essential to the individual's health and welfare are not available. While the state may define the plan of emergencies on an individual basis, the state also must have system procedures in place."***

An individual emergency back-up plan is needed as a participant protection, in the event the participant's worker(s) fails to show. It must be addressed in the person-

centered plan. Some participants may rely on informal supports (family, friends, or neighbors) to meet this need. Other options may include contracting with a provider agency.

In addition, states must develop a systemic back-up plan for all participants, in the event the individual back-up fails. States may use a combination of methods to meet this need, however, either independently or combined, the system must provide an immediate remedy for a life-threatening situation due to the potential failure of the individual's own back-up plan. The system must address not only the identification of the emergency back up process, but describe how participants will access the system:

*Q11. How should a state proceed if it wishes to **amend an existing 1915(c) Waiver or §1115 Demonstration** to incorporate one of the elements of self-direction (e.g., Financial Management Services, Individual Budget or Supports Brokerage)?*

States wishing to add one of the new self-directed components prior to the renewal period should contact CMS to discuss the anticipated changes. To understand fully the proposed modifications, CMS staff may request submission of a written concept paper or other means to determine the state's proposal. The decision will then be made to identify the most appropriate method by which the state will submit the changes and the required documentation.

*Q12. If a state wishes to **renew an existing §1915(c) Waiver or a §1115 Demonstration** to include one of the elements of self-direction or wishes to renew an existing waiver that includes a self-direction component, should the template be used?*

Use of the templates is optional; however, the essential elements of the template are required for Independence Plus Programs. States are encouraged to consider using the templates if they wish to obtain an expedited Federal review. Further, by using the template format, states are assured that Federal compliance criteria are identified.

*Q13. How does the Independence Plus Initiative assure **state fiscal accountability**?*

Use of the *Independence Plus* §1115 Demonstration or the §1915(c) Waiver application will maintain state fiscal responsibility by continuing to require states to meet statutory or regulatory requirements. Budget neutrality policy for the §1115 Demonstration limits federal expenditures so they do not exceed the levels that would have been realized had there been no demonstration. The similar requirement for the §1915(c) version is cost neutrality, which requires Federal funding to be no more than the institutional costs that would have been incurred for waiver participants. In addition, states must ensure the availability of Financial Management Services and options for self-directed supports for the individual.

*Q14. Will the **states be limited in the size** of the enrollment under one or both templates?*

Existing regulations for the §1915(c) Waivers require states to indicate the number of unduplicated beneficiaries to which it intends to provide waiver services in each year of the program. This number the state indicates in the application constitutes a limit on the size of the waiver program. Future state requests to increase their defined limit would require a waiver amendment.

States must include their proposed limits in the §1115 Demonstration Template application for discussion with CMS staff. Again, future state requests to increase the limit will require a demonstration amendment. The state will also be asked to submit the results of an independent evaluation demonstrating that the program has remained within budget and cost neutrality parameters and the program's ability to adequately address the health, welfare, and satisfaction of the participants.

# VIII. *Independence Plus* and the National Cash and Counseling Demonstration and Evaluation Project

*Independence Plus* is a federal initiative designed to offer states the ability to operationalize Medicaid programs utilizing a self-directed service delivery method. Self-direction allows program participants the ability to make direct choices and express control over the services and supports they feel are vital to meet their personal assistance needs. The initiative is based on the experiences and lessons learned from states that have pioneered the philosophy of self-direction. Through these experiences, the essential elements of person-centered planning, individual budgets, participant protections, financial management services, supports brokerage services, and continuous quality improvement have been identified.

The National Cash and Counseling Demonstration and Evaluation Project, co-sponsored by DHHS (ASPE & CMS) and the Robert Wood Johnson Foundation (RWJF) has had a significant impact on CMS's decision to advance self-direction. Operating in the states of Arkansas, Florida and New Jersey under the authority of §1115 of the Social Security Act, the project offers a cash allowance to persons with disabilities, including the elderly, in lieu of Medicaid agency services.

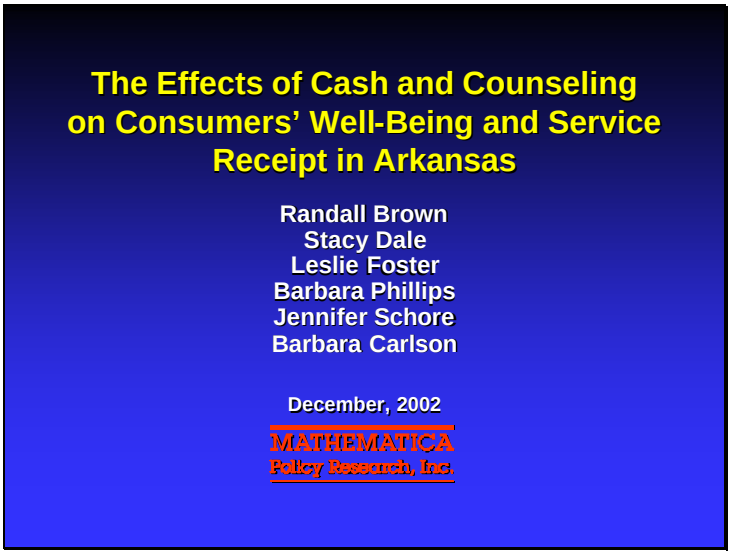
Mathematica Policy Research, Inc. using a randomly selected treatment and control experimental design is performing a rigorous evaluation. For the evaluation, program participants receiving the cash allowance and those receiving traditional agency services were asked about the quality of those services. Based on the evaluator's preliminary findings of persons participating in the Cash and Counseling Project:

- 100% are satisfied with worker arrangement in AR and NJ
- 82% of AR participants state their lives had improved; 7 out of 10 in NJ
- 93% of participants in AR and 97% in NJ state they would recommend to others
- 95% of Arkansans are please with scheduling
- Zero say they are worse off
- Regarding the scheduling of service workers under self-direction, workers are more likely to:
  - Arrive as scheduled
  - Stay as long as scheduled
- Participants under self-direction are:
  - Less likely to report unmet needs
  - Particularly please with personal care, household activities and transportation
- Regarding managing a worker, self-directed participants state they are less likely to:
  - Feel neglected or rudely treated
  - Experience theft

**Evaluation Conclusions on Self-Direction:**

- At least as safe as agency services
- Slightly better medical and functional outcomes
- Substantially enhances the quality of life
- Findings should encourage states to consider self-direction
- Assuages concerns about jeopardizing health and welfare

Slide 1

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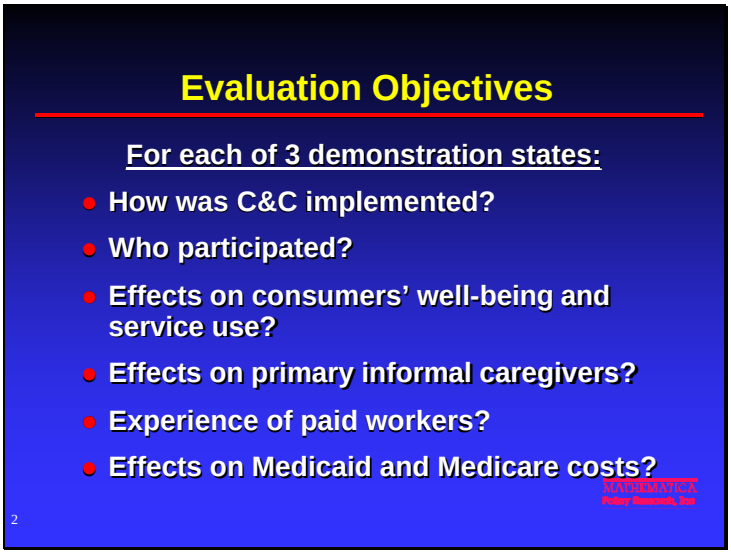

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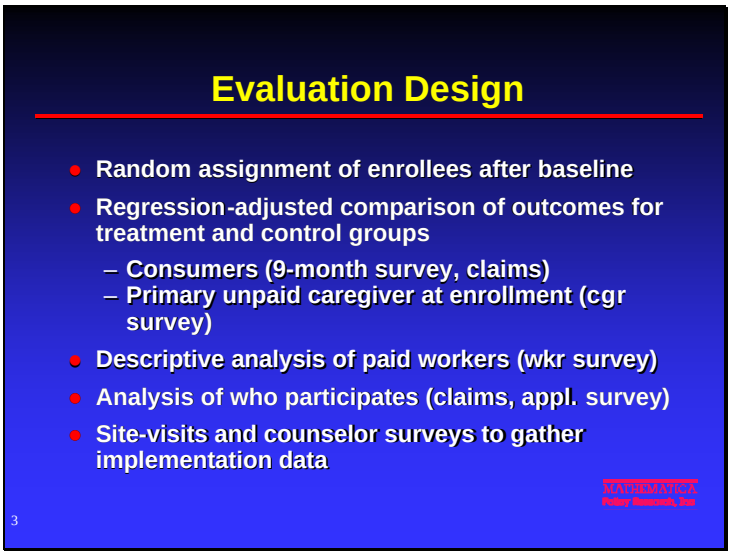


Slide 4

Slide 5

## Arkansas Survey Sample

| | Age 18-64 | Age 65+ |
|---|---|---|
| **Sample Size** | | |
| Treatment group | 243 | 642 |
| Control group | 230 | 624 |
| Total | 473 | 1,266 |
| **Percent in Community** | | |
| Treatment group | 93 | 86 |
| Control group | 96 | 88 |

Source: Survey conducted 9 months after enrollment.

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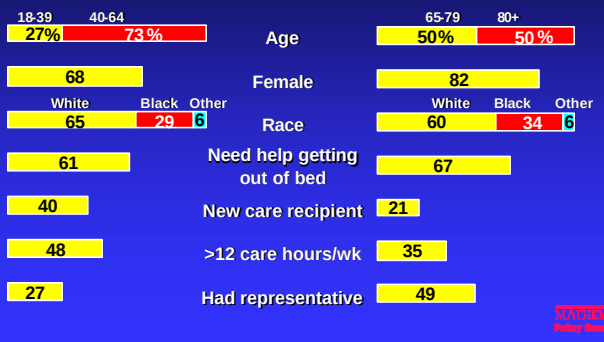
Slide 6

## Who Enrolled in IndependentChoices?

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## Measures of Service Use

- Number and types of paid caregivers
- Hours of care received (paid/unpaid)
- Time of day/wk care received
- Types of care received
- Equipment purchase/home or vehicle modifications

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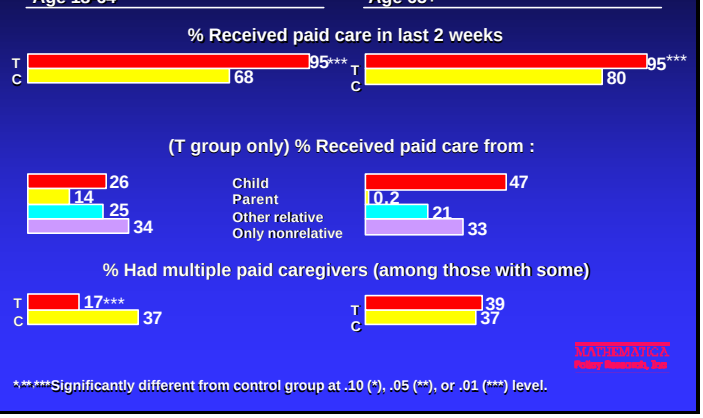
Slide 8

## Paid Care Received (For Those Alive and not in Nursing Home)

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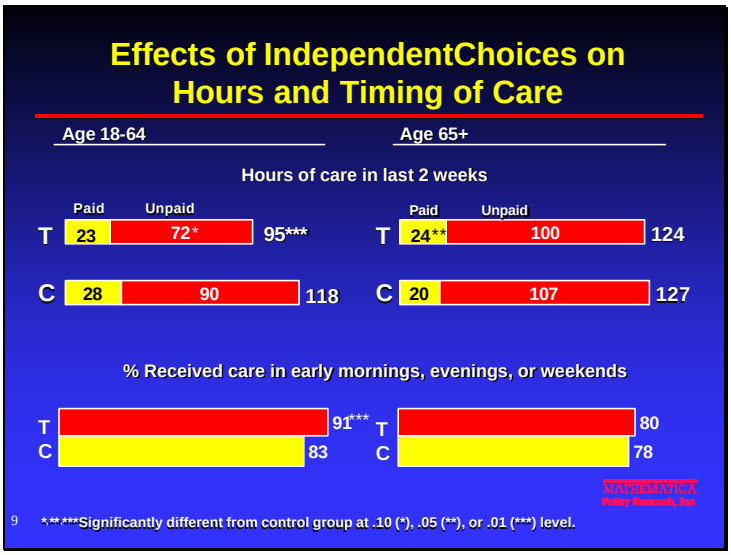
8 *,**,***Significantly different from control group at .10 (*), .05 (**), or .01 (***) level.

Slide 9

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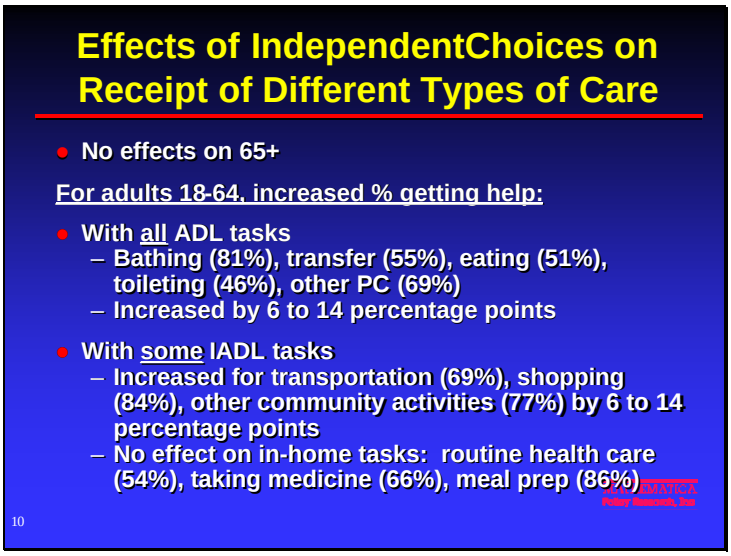

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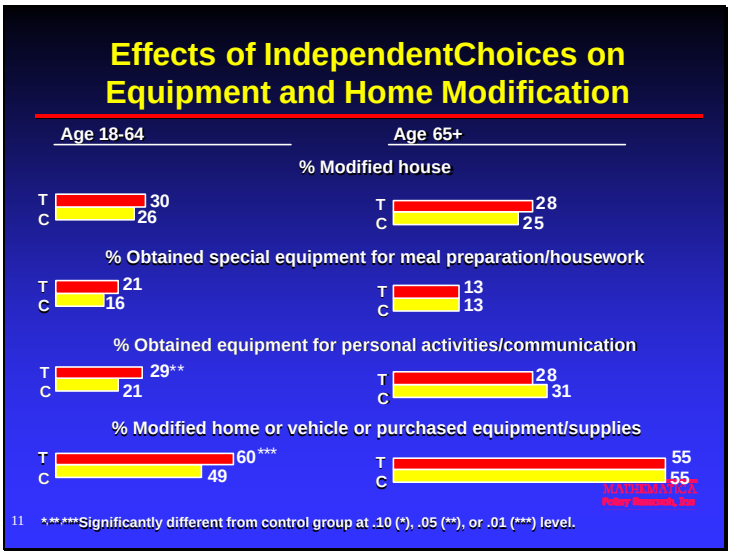


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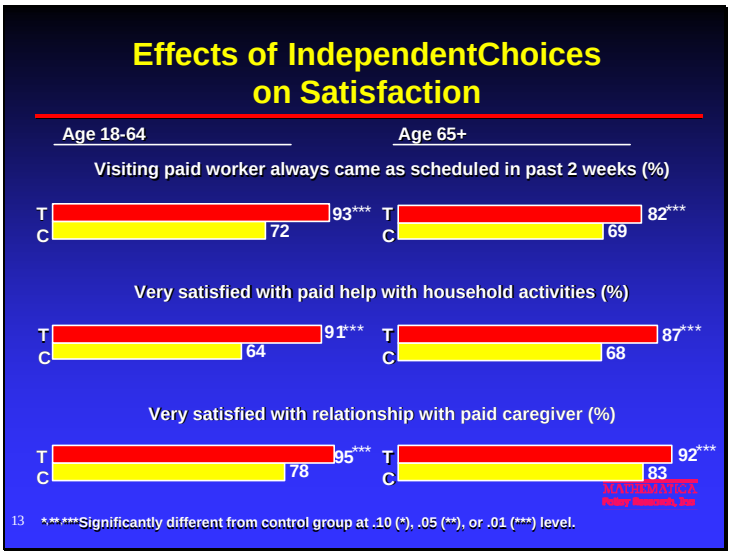


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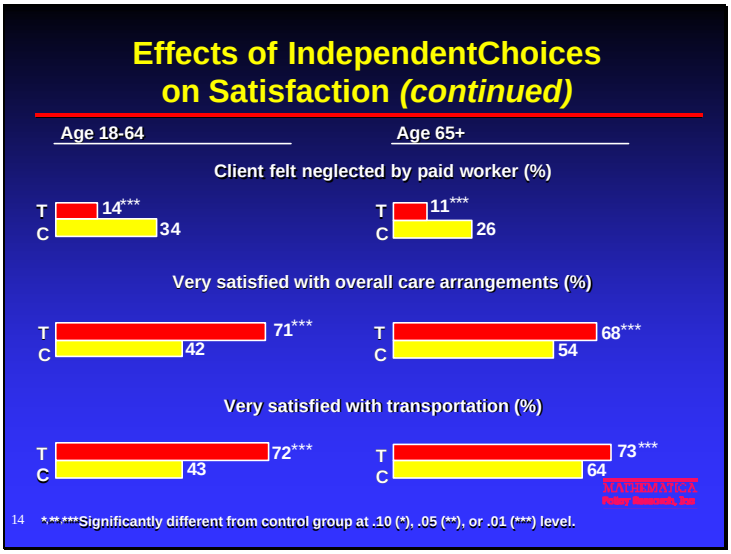

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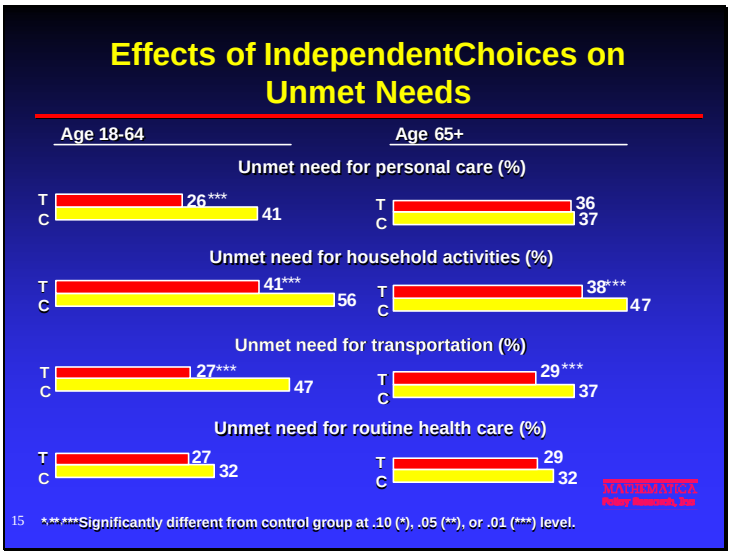


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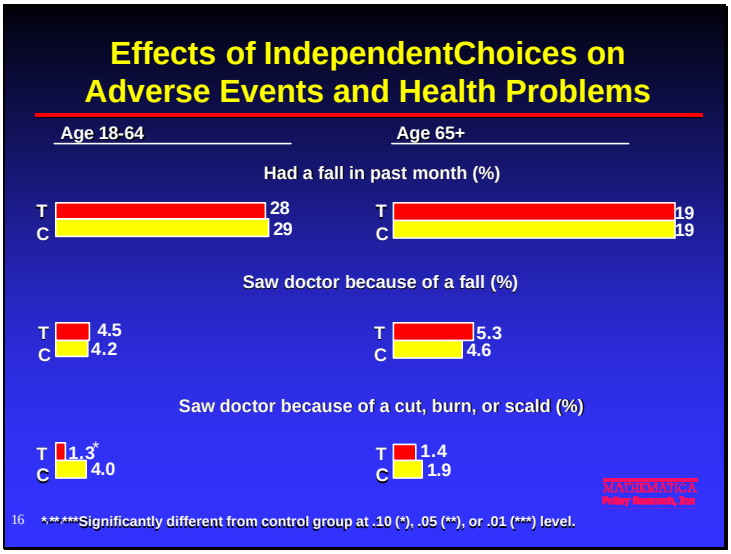

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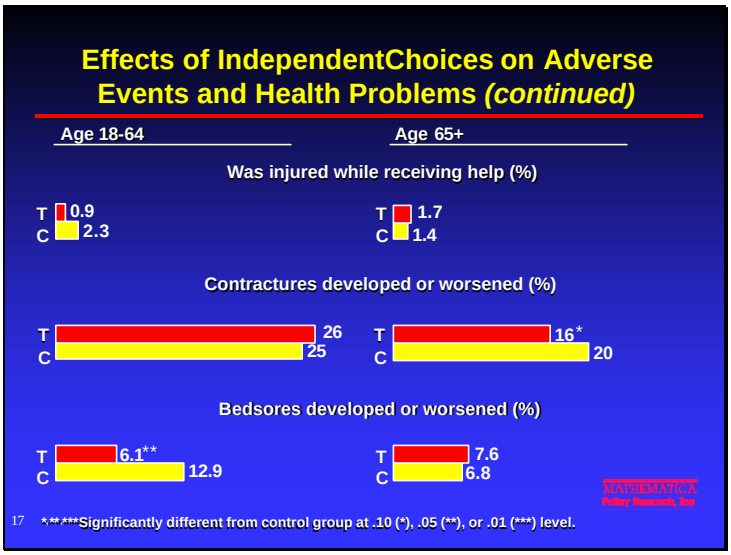


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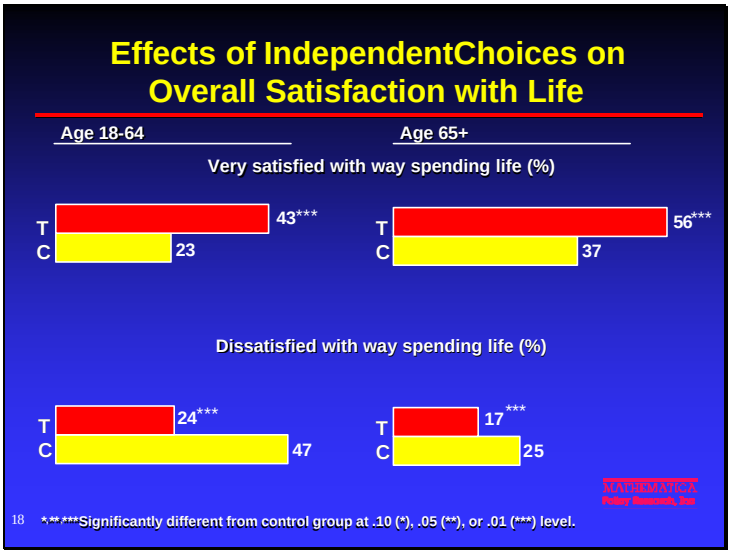

Slide 19

## C&C Effects in AR, to Date

- Consumers more likely to receive paid care, especially among new PAS applicants
- Program participants hire mostly family members
  - More get help outside normal business hours
  - Get help with range of services
- Unpaid hours and total hours of care declined for adults under 65
- Modest increase in proportion obtaining equipment/modifying home
- Consumers are much more satisfied
- No adverse effects on health

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## Targeted Release Dates for Future Reports

| Report on: | Arkansas | Florida Children | All 3 States |
|---|---|---|---|
| Quality of Care | 11/02 | 3/03 | 3/04 |
| Use of Personal Care/Services | 11/02 | 3/03 | 3/04 |
| Informal Caregivers | 1/03 | 5/03 | 5/04 |
| Paid Workers | 1/03 | 5/03 | 5/04 |
| Medicaid Use/Cost | 7/03 | 11/03 | 8/04 |
| Participation | 9/03 | 1/04 | 10/04 |
| Implementation | 2/03 | 2/04 | 8/04 |

Targeted release dates are 3 months after MPR expects to deliver draft reports to the National Program Office for review.

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