


Participant Direction:
A Short History



Back when we were young...

- **In the land before time—uh, I mean Medicaid, there was:**
 - 1960s-70s--The Independent Living Movement
- **And then came state-funded programs(late 1960s):**
 - Oklahoma’s personal care program under Medicaid
 - New York’s “Concepts for Independence”—first self-directed personal assistance agency(co-employment)
- **And then came Medicaid with:**
 - 1981: HCBS Waiver legislation enacted
 - Self direction was not implicitly mentioned in the HCBS waiver—but some states already had elements of self-directed services in their systems—and these were “incorporated” into their waiver applications

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History of Medicaid and Participant Direction for HCBS

- And then, the golden years of development—1990s
 - Cash and Counseling
 - Robert Wood Johnson Grants
 - 15 states got grants for self-determination for ID populations
 - ASPE and AoA grants
 - More RWJ grants
 - 1115 waivers
 - 1997-consumer-directed personal care under the State plan
- Then came the HCBS Waiver-2000s
 - 2002: Independence Plus Application
 - 2003: Independence Plus grants to 12 states
 - 2004-2007 HCBS Waiver Application, Appendix E


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Participant Direction and the HCBS Waiver

- CMS is clearly committed to and promotes the use of participant direction under Medicaid
- About 18 states offer statewide participant direction options to individuals with intellectual disabilities (ID)
- Eleven states offer some type of limited options either to specific groups or through pilot projects
- States with high levels of enrollment: Oregon, Connecticut, Wisconsin, Minnesota, Florida, Michigan, Texas and Utah

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Appendix E: Participant Direction of Services



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The waiver application

- As you are well aware...the state has to fill out an application to get the waiver
- 100 pages with a 300 page "guide"
- The instructions alone for just the participant-directed part, Appendix E, are 28 pages long!



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CMS says...



“ Participant direction of waiver services means that the waiver participant has the authority to exercise decision making authority over some or all of her/his waiver services and accepts the responsibility for taking a direct role in managing them.”

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Two Basic Approaches

- **Participant Employer Authority**




- **Participant Budget Authority.**



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Employer Authority

- **The waiver participant—or family—not an agency oversees the support workers**
 - **Co-Employment.** An agency employs workers recruited by the participant.
 - **Common Law Employer:** The participant is the legally responsible employer of workers whom he or she (or his or her representative) hires, supervises and discharges directly.



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Employer Authority means:

- The participant must have the power to
 - Recruit workers
 - Hire and fire staff (common law employer) or
 - Refer to the agency for hire and discharge from providing services (co-employer)
 - Decide on staff qualifications
 - Decide staff duties
 - Schedule staff
 - Supervise staff
 - Evaluate staff performance



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Budget Authority



- Budget Authority means the person has to:
 - Determine the amount paid for each service in accordance with the state's policies or rates
 - Schedule when services are provided
 - Identify service providers and refer them for enrollment
 - Review and approve provider invoices

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Determining Budgets

- CMS requires that if the state is using individuals budgets, everyone must understand:
 - How the amount in the budget is decided
 - How the method used to set the budget relates to your needs

The state must "spell-out" how budget are determined.



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Determining Budgets

- **Everyone must understand:**
 - How information about the budget methodology is made publicly available
 - How the method is applied consistently to each waiver participant.
 - Many states are using some type of functional screen (SIS, ICP, home-grown) and analysis of spending patterns to establish budgets (Georgia, Colorado, Minnesota, Connecticut, New Mexico, Missouri)



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Managing Individual Budgets

- **There are a lot of ways budgets can be managed**
 - Can allow participant to make changes to how budget is spent without prior authorization
 - Or can require that all changes be approved before they occur
 - Must make sure that the person knows how much they have left



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Financial Management Services



- **The HCBS waiver does not allow states to give individuals cash directly.**
- **Can give the money to an agency or organization that "keeps the books" on behalf of the person- a fiscal management service (FMS)**
- **Person has full control over the money but the FMS does the paperwork and pays the bills.**
- **Best practice nationally is to use Medicaid administrative funding and limit the number of FMS entities**

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Supports Brokering



- Support for individuals (Supports brokering) to self-direct must be available if needed, but:
 - Not required if people don't need it-policy decision
 - Can be done by individuals, agencies, organizations as decided on by the state and stakeholders
 - Best practice nationally is to separate supports brokering from case management

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Who can provide services?

- The state defines who are / what are "qualified providers"
- CMS allows states to use all kinds of "non-traditional" people and services
- Can use relatives and family if the state allows it
 - Lots of important policy decisions need to be worked out when paying family members
 - Paying guardians?
 - Parent of children?
 - Safeguards for assuring choice and control for adults with ID



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Who can participate in directing their own services?

- The feds say:

"Participant direction is commonly associated with individuals who live on their own or reside with their families. Participant direction may be less feasible when individuals are served in larger, provider-controlled living arrangements such as group homes. It is up to the state to decide whether participant direction is supported in some or all types of living arrangements."

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Living arrangement and participant direction

- Best practice nationally:
 - Participant direction is available to individuals living in their own home and family home, included supported living
 - Individuals living in group homes can manage their day/vocational or other community supports



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What services can be participant-directed?

- State decision...
- In some states ALL services are participant-directed (except group homes)
- In others, only a few services—like respite or personal care are participant-directed

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Critical Policy Decisions

- What services are included under participant-direction?
- What models? Agency with choice/co-employer, employer of record?
- Who can provide services? Family members?
- Supports brokering/ required? By whom? Should supports brokering be separate from case management?
- Who can direct their own services? What are the criteria? What if someone does not fulfill their responsibilities?
- What do you pay for services? Negotiated or set rates?
- What is the quality assurance system? How does it differ from traditional services?

So.....

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Participant Direction

- Is not for the faint of heart!!!!
- Will make you examine all your programmatic and business practices in your state
- Will surface issues in how resources are distributed
- Will surface issues in your rates and payments
- Will challenge your providers to find new opportunities
- Will challenge consumers to take on new levels of responsibility
- Will cause redesign of quality assurance approaches
- Will take into uncharted territory...

And with all that said...

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Participant Direction

Has great promise

- Can be a great way to customize services and supports
- Affords individuals much higher degree of choice and control over their supports and services
- Afford individuals real knowledge about the costs of services
- Permits interesting innovations (individually directed goods and services)
- Makes for a real partnership among consumers, providers and the state

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Resources

Participant Direction

Resources

- **Power, Choice, Self-advocacy**
 - For further questions about Connecticut's Self-Advocate Coordinators, contact Beth McArthur at: Beth.McArthur@po.state.ct.us or 860.418.6132. Visit: <http://www.dmr.state.ct.us/>
 - Arizona Family and Consumer Toolbox can be found at: <http://www.azdes.gov/DDD/downloads/557ConsumerInfo/DDD-1355A.pdf>
 - Washington DDD County Guidelines: http://www1.dshs.wa.gov/pdf/adsa/ddd/c_guidelines.pdf

Resources

- **Housing information**
 - New York: <http://www.dhcr.state.ny.us/ocd/progs/acc/ocdacc0.htm>
 - Ohio: <http://www.delawarecreativehousing.com>
 - ArcLink roommates: <http://roommates.theardlink.org/>
- **Inclusive meetings**
 - Canadian Office on Disability: http://www.tbs-sct.gc.ca/pub/pubs/hrpubs/TB_852/dwnld/gpimc-gprci_e.rtf
 - NASDDDS meeting guide

Resources

- **Employment**
 - To learn more about Tennessee's Employment First Initiative, contact Julie Huber, State Director of DMRS Day Services at: julie.huber@state.tn.us
 - Massachusetts ICI is a clearinghouse on employment: <http://www.communityinclusion.org/>
 - Washington's employment initiative: http://www1.dshs.wa.gov/pdf/adsa/ddd/policies/policy4.11_07_04.pdf
 - Self-Employment - how to become self-employed & how to get help to do so: <http://www.griffinhammis.com>
 - Dept. of Labor - great locator of resources & services in any State: <http://www.DisabilityInfo.gov>

Resources

• Employer Authority

- Hiring employees – Domestic Handbook & Domestic Policy Handbook:
<http://www.sdri-pdx.org/customers/index.html>
- Employer's Guide:
<http://www.dhsforms.hr.state.or.us/Forms/Served/SE9046.pdf>
- Self-Directed Employment Toolkit:
http://www.oregon.gov/DHS/spd/pubs/dd/adults/employ_toolkit.pdf
- Connecticut DMR Fact Sheets are found at:
<http://www.azdes.gov/DDD/downloads/557ConsumerInfo/DDD-1355A.pdf>. Look for "Hiring and Managing Your Own Supports"

Resources

• Person-centered Planning

- Training Person-Centered Planning Facilitators: A Compendium of Ideas (PDF) – Research and Training Center on Community Living, Univ. of Minn.:
<http://www.rtc.umn.edu/pdf/pcpmanual2.pdf>
- Increasing Person-Centered Thinking: Improving the Quality of Person-Centered Planning – A Manual for Person-Centered Planning Facilitators (PDF) Research and Training Center on Community Living, Univ. of Minn.: <http://www.rtc.umn.edu/pdf/pcpmanual1.pdf>
- Person-Centered Planning Instruction Manual (N. Carolina):
<http://www.dhhs.state.nc.us/mhddsas/training/access-care/pcp-instruction-manual7-11-07.pdf>
- Person-centered planning: <http://www.ncset.org/publications/viewdesc.asp>

Resources

• Self-direction

- The Consumer Directed Toolkit, Section 5:
http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/DHS_id_029442.pdf
- Center for Self-Determination-major clearinghouse for training & TA in the country
<http://www.self-determination.com/articles/index.htm>
- Oregon Self-Determination Roadmap:
http://www.ocdd.org/support_services.html
- Consumer & Family Tool Box – how to best communicate with your providers – provider interview questions, examples of job descriptions you can write for providers of different services:
<http://www.de.state.az.us/ddd/downloads/557ConsumerInfo/DDD-1355A.pdf>
- What is Self-Determination – compared to the "old way":
http://www.abil.org/Programs/self_determination.htm

Resources

- Medicaid Waiver
 - CMS: www.cms.hhs.gov
 - Waiver application: www.hcbswaivers.net
 - Promising Practices:
http://www.cms.hhs.gov/PromisingPractices/01_Overview.asp
 - A Guide to Employing Individual Providers under Participant Direction:
http://www.cms.hhs.gov/HCBS/downloads/IndividualProviders_final.pdf
