

Participant-Directed Services

What we've learned so far...



A cartoon character with a large head, wearing a suit and tie, is shown with a lightbulb above his head, indicating an idea or realization. He is pointing upwards with his right hand.

The BIG lessons...

- It is all “learn as you go”
- No one, ANYWHERE has it all figured out
- Can't just give out money with no oversight...




A cartoon teacher in a blue suit stands next to a chalkboard. The chalkboard has the equation $a^2 + b^2 = c^2$ written on it. The teacher is holding a piece of chalk and pointing at the board.

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The BIG lessons


- Making changes and improvements all along the way is critical
- “Scaling up” is challenging—making the program grow statewide and across multiple services
- Understanding new roles and responsibilities for everyone...



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The BIGGEST lesson...



Participant-directed (P-D) services build on the current system but really making P-D a reality means rethinking, reworking, redesigning and reinventing many aspects of your services system...


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And this requires

- A firm understanding of your policy aims and goals
 - What's the point of adding in participant direction?
 - What does it solve? What new problems does it bring?
- A willingness to put everything on the table—no sacred cows
 - If you are serious, this means every aspect of your system will be up for review and a determination if your current practices uphold the policy aims of participant-direction

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Resource allocation



- Individual budgets are the critical basis for participant direction
- Just using current budgets may "institutionalize" embedded inequities
- The shift to participant direction is an opportunity to rationalize resource allocation, but....

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Resource allocation means...

- Rationalizing resource allocation may also mean looking at equity...
- And if you look at equity, there may be winners and losers once re-allocation is done...
- Potentially hard decisions about what happens to each individual

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Resource allocation


- Requires confidence in what you pay for supports and services
- Doesn't assure "adequacy"—only equity
 - If the system is already under-resourced, all you do is divide things up fairly—doesn't mean consumers, families or providers will agree the resource is enough...

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Resource Allocation: TEN ISSUES


1. What goals are important to establish before embarking on IBA/LBA development?	4. What cost/expenditure data are states using to build budgets?	8. How often should states reassess support needs?
2. What factors influence the choice of a tool to measure support needs?	5. What can be done to improve the relationship between assessed individual support needs and resulting allocations/expenditures?	9. How should states roll out their assessment informed resource allocation models?
3. For budget development, is full population data or a random sample better to achieve the established goals?	6. How are states developing budget models when they have more than one HCBS waiver?	10. What should states do when new people are added, state budgets are reduced, and there is a need to keep rates current and reconcilable?
	7. How do budget models accommodate individuals with exceptional care needs and related costs?	<small>Source: Aydin, Fortune "Ten Issues for States to Consider in Implementing Individual or Limited Budget Allocation", April 2009</small>

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Participant direction is about shifting power 

- Case management to supports brokering
- “Recipient” to employer
- Family to participant-advocacy
- Services system to market place
- Quality determined by consumers and families

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Power Shifts 

- P-D services means changed roles for everyone
- P-D services (should) change who is “in charge”
- Professionals **support** the process, not direct the process

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Case management

- Typical functions
 - Eligibility, assessment, plan development and approval, investigation, mediation, program and fiscal oversight
 - Has authority to *require* changes and improvements in service delivery
 - Performs “agent of the state” functions

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Supports brokering: CMS definition

“Service/function that assists the participant (or the participant’s family or representative, as appropriate) in arranging for, directing and managing services. Serving as the agent of the participant or family, the service is available to assist in identifying immediate and long-term needs, developing options to meet those needs and accessing identified supports and services. Practical skills training is offered to enable families and participants to independently direct and manage waiver services. ...This service does not duplicate other waiver services, including case management.”

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Case management/supports brokering

- P-D services are changing the roles of case managers in some positive ways
 - Putting skilled expertise to work where it’s most needed
 - Changing how case managers relate to families and consumers
- P-D is NOT business as usual with regard to case management

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Supports brokering is NOT case management

- Supports brokering is a “direct service”, subject to freedom of choice (unlike, for example, targeted case management)
- Supports brokering has a strong training component—supports brokers are teacher/trainers
- Need to versed in using “non-traditional” providers

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Supports Brokering Issues

- Tailoring the amount of supports brokering to the situation—but a good service for everyone to have particularly at first
- New division of responsibilities between case managers and supports brokers



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What helps make the shift to supports brokering?


- Separating the functions of case managers and support brokers
 - Still need an individual with authority to require changes and to oversee quality
- Separating supports brokering from direct services
 - Mitigating conflicts of interest
- Making SURE supports brokers are qualified—it isn't just anyone!

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Example: Oregon

- Regional brokerage agencies help consumers learn to make informed decisions about their support plans
- Highly qualified
- Investment in training
- Level of support is “whatever it takes”
- Resourced outside the individual budget or as an “add-on to budgets”


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What helps make the shift to supports brokering?

- Making sure support brokers also have a system of support and supervision
 - They may need guidance too
- Oregon and Wisconsin have learned from mistakes!


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Business processes for participant-directed services

- One Fiscal Management Service (FMS) or many?
 - How much choice is required for bookkeeping functions?
- Administrative cost or service cost?
- Everything can be participant-directed? Only some services? Only certain resources (cap on dollars)?


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What services? How much money?

- Should everything be under participant-directed services?
 - Many states start with a limited service menu
 - Other start with limited dollars


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Which model(s)?

- Budget Authority
- Employer authority
 - Co-employer (agency with choice)
 - Employer of record
- Each decision comes with lots of policy and procedural implications


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For example...

- Can/should everyone participant-direct?
- Which models?
- Should guardians/parents/family members be able to be employees?
- Who is the employer if the guardian is the person paid?
- What are the qualifications for providers under the participant-directed model?

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Examples: Qualified providers

- **Connecticut** – Vendor agencies enrolled as Medicaid providers - can hire your own staff or use an agency of choice that will hire the people you choose
- **Arizona** – State changed its regulations for purchasing to simplify contracting with service providers – agencies that meet service qualifications become “Qualified Vendors” & contract with the State so once you have your support plan, services can start quickly if you select one of them – you may also choose an individual independent provider, who may be your friend, neighbor or family member (not your spouse or your parent, if you are a minor) – once chosen the person may decide to work for a Qualified Vendor or may decide to become certified and contract directly with the State

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Examples: Qualified Providers


- **Minnesota** – May be parents (including those of a minor), spouses (if what is done falls outside what is typical), other family members, neighbors or co-workers – may also choose a provider agency, enrolled with the State to provide waiver services –
- May required each to have a criminal background check (if yes, the cost does not reduce the annual budget)

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Paying Family Members

- Assuring choice and control when family members are paid is an issue
 - Active pathways are needed to make sure the individual's voice is heard
 - Self-advocacy, having a representative or advocate may be critical
- A guardian really can't be both the employee and the employer...

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Recipient to employer 

- P-D services put individuals with disabilities and families in the driver's seat
- New roles and many new responsibilities
 - Assuring quality
 - Knowing about exploitation and abuse
 - Doing the paperwork
 - Becoming a manager-hiring, setting expectations and firing
 - Knowing the responsibilities of an employer..

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Recipient to Employer: What helps?

- Finding workers is hard
- Support to learn the roles and responsibilities of being an employer is essential
 - Arizona has a guide called the "Family and Consumer Toolbox" for hiring workers in your home
 - Connecticut offers fact sheets with good information
 - Support brokers can be vital for many people to help with finding, hiring and firing workers
 - Oregon has the Roadmap



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Family support to participant-advocacy

- Participant-directed services at first focused on families, since it was parents who pushed for participant-direction
- There has been a MAJOR shift, with individuals with disabilities themselves pushing for participant-determination and participant-direction



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What does this mean for P-D services?




- It means balancing the needs and wishes of parents with the needs and preferences of individuals with disabilities
- It may mean support brokers won't always agree with parents
- It means including participant-advocates in all decisions

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Including self-advocates

- Self-advocates now have official roles in determining policy
 - Alabama has a state position for a self-advocate to help coordinate efforts and represent self-advocates officially
 - So does New York
 - Connecticut just hired 9 part-time participant-advocates!
- Some states include self advocacy as a covered HCBS waiver service

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Including self-advocates

- Self-advocates are key members of decision-making bodies and committees
- This means attention to assuring meetings are inclusive and structured so self-advocates are full participants
 - Canadian Disability Office Guide
 - NASDDDS guide for inclusive meetings


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Service System to Marketplace



- A HUGE change is in what people want to buy and how they want to buy it
- Providers, if they wish to play, have to change
- It's not just more of the same
- No more guarantees—it's earn as you go!


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Service System to Marketplace

- But as a reassuring note to providers...
 - In states with high usage of participant direction no one was aware of any providers that had gone out of business
 - Providers do offer new options and products!


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Providers

- P-D services means new “products”
 - Customized employment
 - Community-based activities
 - Alternatives for seniors
 - New residential options
 - Agency with choice options/co-employment
- Customers are not asking for the same old things

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What helps make the shift?

- Flexible standards and qualifications for providers
- Payment systems that give incentives for employment and that support individualized residential options
- ...And willingness to sit down and work it through

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What helps?

- Many states have “employment first” initiatives that support innovative approaches
 - Connecticut, Maine, Vermont, California, Minnesota, Washington, Montana, Tennessee and Ohio to name a few!
- Housing initiatives
 - New York, New Jersey, California and Ohio have new initiatives to find housing
 - The ArcLink roommate matching system


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What Helps?

- Finding ways to qualify non-traditional individuals and providers
 - Using the planning process to set qualifications and training requirements
- Assuring people have the knowledge to negotiate
 - Information on what things *should* cost

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Quality



- The biggest changes are:
 - Looking at individual outcomes
 - Using data to understand how the system performs
 - Massachusetts designing specific measures for participant direction
 - “Customizing” quality—tailoring processes and outcomes to individual situations

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So...



- Participant direction is not just “tweaking” the system
- It means major changes for everyone—consumers, families, and providers
- But it has great promise for helping individuals design their own lives...


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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.hearclink.org/>
- **Inclusive meetings**
 - Canadian Office on Disability: http://www.tbs-sct.gc.ca/pubs_pol/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/ddo/downloads/557/Consumerinfo/DDD-1355A.pdf>
 - What is Self-Determination – compared to the "old way": http://www.abil.org/?rodrems/self_determination.htm



Resources

- **Medicaid Waiver**
 - CMS: www.cms.hhs.gov
 - Waiver application: <https://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
