

The Power of Self-direction

*Three Unique Perspectives
One Shared Vision*

Introductions

- ▶ **Julie Reiskin:** Executive Director, Colorado Cross-Disability Coalition (CCDC)
- ▶ **Lee Grossman:** Developmental Disabilities Section Administrator, Wyoming Department of Health
- ▶ **Kristy Michael:** Director of Research and Development, Northeast Pennsylvania Center for Independent Living and ACES\$ Financial Management Services

Roll Call

- ▶ Who is from a State entity or County Office (AAA or ADRC)?
- ▶ Who is from a Managed Care Organization?
- ▶ Who is from a provider (FMS or otherwise)?
- ▶ Who is from an advocacy organization or a self-advocate?
- ▶ Who is here because there might be prizes?



What is Person-centeredness and how does it relate to Self-direction?

- ▶ **Person-centered philosophy** focuses on the individual and their needs. The individual defines the direction of their life.
- ▶ **Person-centered planning** involves a "toolbox" of resources that enable individuals to:
 - define what is important to them
 - choose their own pathway to success
- ▶ **Self-direction**, as a service delivery model, is driven by the Person-centered philosophy.

Defining Self-direction

- ▶ Related Terms: Consumer-direction, Participant-direction, Person-centered planning.
- ▶ Built on the belief that the person receiving services knows their own needs best. They should plan, choose, and manage their own services.
- ▶ The vast majority of Self-directed services are funded by Medicaid.

Defining Self-direction

- ▶ Key features of Self-direction as a service delivery model:
 - **Employer Authority** - hire, fire, and supervise individual workers
 - **Budget Authority** - flexible budget to purchase goods and services
 - ❖ Many programs incorporate both features
- ▶ Models of FMS delivery for Self-direction are Fiscal/Employer Agent (F/EA) and Agency with Choice (AwC)

Self-direction and The Dignity of Risk

The normal taking of risks in life is essential for:

- Personal growth
- Development
- Maximizing quality of life

There should be a balance between health, safety and happiness.

We must all achieve the best possible outcomes in our work in Self-direction to give participants the opportunity to live within their communities and achieve unique and fulfilling lives.



Self-direction: what are our strengths, who are our partners and advocates?

- ▶ Empower others to participate and voice opinions and concerns in public forums - foster the advocates of tomorrow, today
- ▶ Encourage policy makers to solicit feedback from stakeholders and perform regular outreach
- ▶ Network! Reach out to community action organizations, participant groups, family support networks, Centers for Independent Living
- ▶ We each have a unique story and background to learn from - everyone has a “Why”
 - ▶ *Julie Reiskin*
 - ▶ *Lee Grossman*
 - ▶ *Kristy Michael*

Flexibility of Self-direction

- ▶ Self-direction is adaptable to each state's unique:
 - Demographics
 - Geography
 - Budgetary requirements
- ▶ States have a high degree of control over how their Medicaid-funded, Self-direction program(s) operate
- ▶ Variation across states regarding:
 - Integration with MCOs
 - How to address program requirements
 - Work with FMS entities



Using the Self-direction Delivery Model as a tool - Wyoming

- ▶ 805 individuals participate in HCBS self-direction in WY (July 2017)
 - ▶ 18% of total HCBS population; 25% Older Adults/Physically Disabled; 14% I/DD
- ▶ Alleviating provider shortages
 - ▶ Wyoming is a Frontier State. Sometimes Self-directed HCBS is THE primary method for delivering services to their rural participants.
 - ▶ 42% of HCBS waiver participants utilizing self-direction are in frontier counties
- ▶ Cultural Competencies
 - ▶ Tribal populations
 - ▶ Frontier counties
 - ▶ Population areas with diverse cultures and languages
- ▶ Compliance with HCBS settings regulation



Using the Self-direction Delivery Model as a tool - Colorado

- ▶ Got Choice? Choice without options is not real choice.
- ▶ The Dignity of Risk.
- ▶ Use Resources, both on a local and national level.
- ▶ Engagement. Real and meaningful community engagement must include more than one person and more than one disability.



Using the Self-direction Delivery Model as a tool - FMS Provider

▶ Quality Assurance

- Scheduled and unscheduled quality checks
- Review and enforcement of policies and procedures

▶ Training Participants

- Providing an opportunity for all Participants to learn about Self-direction and their part in the FMS process

▶ Employee Availability

- Variations in Employee requirements
- Employee registry
- Choice of FMS providers

▶ Cultural Competencies

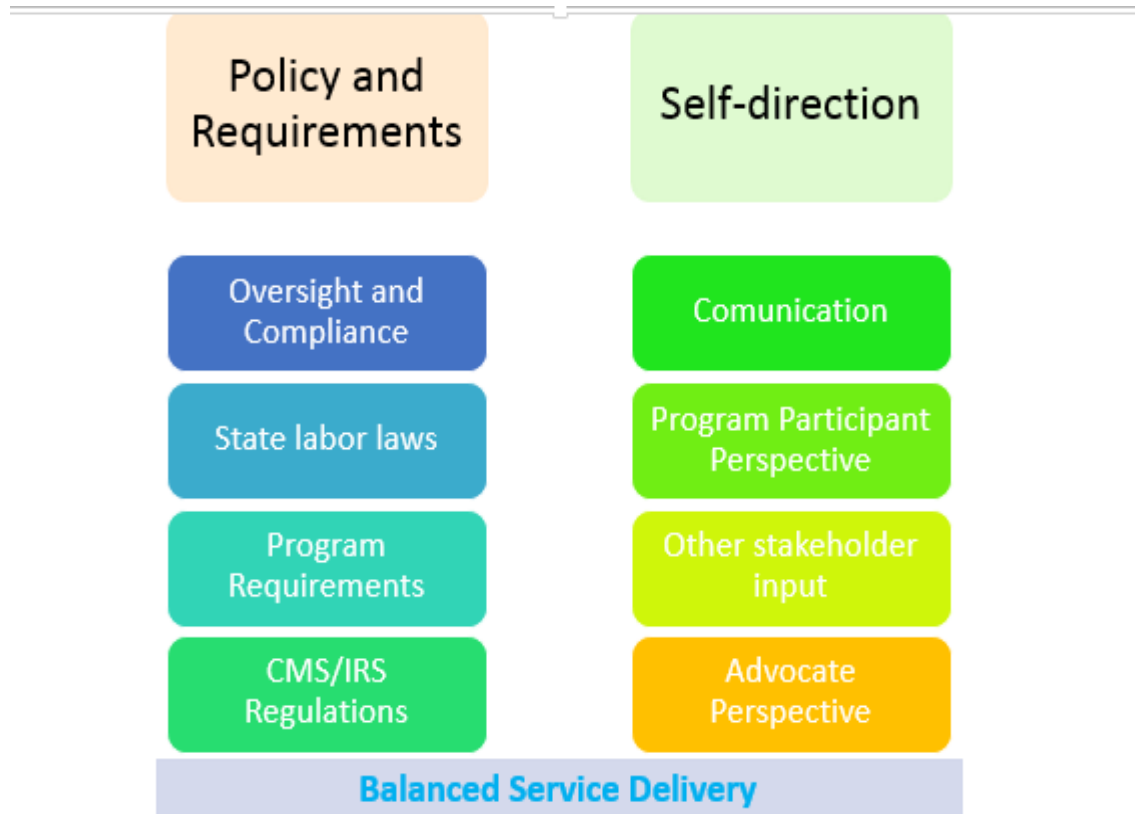
- Translators, materials in alternate languages and formats

▶ Cost Savings

- Cost efficiencies achieved through automation
- Fraud, waste and abuse detected through robust system validations
- Transparency in policies, procedures, Participant feedback and financials
- Regular reporting

Balancing Act of a Provider

- ▶ From a provider perspective, how do we remain accountable to both the contracted entity (state) and the consumer?
- ▶ What is the policy maker expecting from providers?
- ▶ What are Participants and Advocates seeking?



How do Advocates, Participants, Providers and Policy makers work together to promote and preserve Self-direction?

- ▶ Program Stakeholder Groups and Participant Feedback
- ▶ Encourage Making Medicaid Personal- tell YOUR story
 - ▶ Personal 'before and after' examples of Participants on Self-directed programs. What was life like before participating in Self-direction?
 - ▶ Are there program waitlists for Self-directed programs? What is the projected impact of budget cuts on those waitlists?
- ▶ Write Op-eds, reach out to media outlets



Advocating as a CIL and FMS Provider

- ▶ Educating: Setting meetings directly with local and state law makers
- ▶ Reporting: Tracking cost, fraud, waste and abuse data to support Self-direction
- ▶ Participating: State and/or Program Participant councils (e.g. PDPPC in CO)
- ▶ Employing: More than 51% of our employees are persons with disabilities
- ▶ Demanding: Quality, consistency and empathy - every single day



Advocating as a CIL and FMS Provider

Editor:

Sometimes current events clash with the past. A negative course of action can be diametrically opposed to a precedent which promised great change. The Medicaid debate is an example of this phenomenon, bringing overlooked consequences.

July 26 will mark the 27th anniversary of the signing of the Americans with Disabilities Act (ADA). It has ushered in tremendous increases in architectural accessibility to public and private buildings, transportation, and equal opportunity to employment for 50 million citizens with disabilities. It also enables people who need assistance with activities of daily living to receive home and community based services, mandated by the Supreme Court. The landmark Olmstead decision in 1999 declared it unconstitutional for states to force Medicaid recipients to face unnecessary placement in nursing homes and other institutions. Such segregation violated the ADA's requirement to provide services in the "most integrated setting appropriate to their needs".

Flash forward to the present. Much has been written about the drastic impact Medicaid cuts will have regarding general health care. But while this is true, less attention has been focused on the millions of people on Medicaid waivers. These programs provide millions of people with disabilities the ability to live in their own homes, maintain employment, and enjoy the same opportunities found in everyday life already available to the public. Cuts will reduce the number of service hours allocated to individuals. Quality of life will be significantly diminished. It's a certainty that, in many cases, a person's health will suffer and he/she will become hospitalized. Worse, that person could be placed in a nursing home, with the cost nearly tripling, compared to services at home from the same funding stream.

Members of Congress and Senators must honor the promise of the ADA by increasing Medicaid funded home and community based waivers. Both sides of the aisle espouse the American importance of employment and meaningful engagement in society. People with disabilities share that dream.

Assuming we can get out of bed.



Role of a State Administrator

- ▶ Guide RFP and procurement process
 - ▶ Know the outcomes and deliverables for FMS vendor
 - ▶ Identify populations to be served
 - ▶ Identify budget authority consumers will have
- ▶ Hold FMS accountable to deliverables and customer service requirements
- ▶ Consider how self-direction may further your agency's strategic objectives

Advocating as a Participant

- ▶ Learn the rules of your program but also know the federal laws, regulations, etc.
- ▶ Make sure the legislators in your state understand the value of consumer direction.
- ▶ Insist that there is a client-based governance process.
- ▶ Recruit other clients to be involved with governance.
- ▶ Be a cheerleader for consumer direction everywhere.

Give us your Ideas, Experiences and Questions!



Follow-up

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