

## Innovation in Developmental Disabilities:

Collaboration and Connections between Stakeholders Using Data and  
Technology-

Mary Lou Bourne  
Director of MCI and Quality Assurance  
NASDDDS

### Topics

- Collaboration is essential in a complex system
  - Multiple agencies, multiple roles, all are necessary
- Quality – compliance, minimum standards, and beyond
- Innovation and Learning through Data and Technology
- Federal support for Innovation and Developing Business Acumen
- Future of collaboration

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Change is Hard.....but inevitable

*“we did the best  
with what we knew  
at the time; when  
we knew more, we  
did better.”*

Maya Angelou  
(paraphrased)



Pursuing Performance Excellence: Defining a System  
**A System is\*:**

- a whole consisting of two or more essential parts
- and for which the parts must satisfy 3 conditions:
  - each part can affect the entire system's behavior or properties
  - the way each part affects the whole depends on what at least one other part is doing (i.e., no part of the system has an independent effect on the whole because they interact), and
  - the same applies to all subparts of all subsystems

This information has been excerpted from a presentation by Dr. Russell Ackoff, Wharton School of Business

Pursuing Performance Excellence  
- Systems Thinking

**Independence and Interaction\*:**  
**Because the properties of any system arise out of the interactions of its parts, the essential properties of any system, the properties that define the system, are properties of the whole that none of its parts have!**

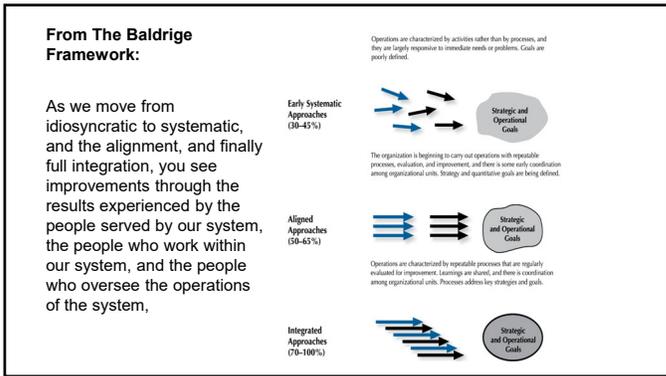
**Examples:**

This information has been excerpted from a presentation by Dr. Russell Ackoff, Wharton School of Business.

Pursuing Performance Excellence  
- Systems Thinking

**The Significance of Systems Interaction:**

- **When you improve the performance of every part of the system taken separately, you do NOT (necessarily) improve the performance of the System.**



**Fragmented Approach - early stage systemic approach**

- Minimal defined goals – sometimes absent completely
- Little recognition of impact on customers
- Highly dependent on individual motivation
- Changes are seen as necessary only as responsive to problems
- Compliance to specific, single rules (or a single set of rules) is paramount
- Corrective Action Plans in response to inspections for quality

• **Focus on activities**

**Collaborative Approach moving towards alignment**

- Goals exist for single agencies; self reported and developed.
- Customers "satisfaction" may be identified
- External agency identifies motives, gives occasional feedback
- Changes are expected, not necessarily good
- Multiple rules are understood, though sometimes contradict one another
- Continuous Quality Improvement used

• **Focus on process**

**Systemic Approach Integrated at multiple levels**

- Goals are clear and depend on multiple contributors for success; strategic as well as process goals are used
- Internal motivation to improve all parts of the system; interdependencies are clear
- Learning is routine and valued – from mistakes as well as failures
- Rules are used to promote desired results
- Shared innovation

• **Focus on Interaction**

**Collaboration is essential**

*All members of the Disability Community must work together to address the many issues we face. Together we can accomplish far more than separately.*

Governor Tom Ridge, AUCD Honoree, March 19, 2019

- Listening** – Good listeners make eye contact, provide supportive comments and give each other time to speak.
- Creative and Critical Thinking** – Group assignments rarely have specific rules or guidelines. It's up to the group members to devise a collaborative plan for achieving the best results.
- Negotiation** – Disagreements or conflicting ideas are common "side-effects" of collaboration. Team members must learn to find shared ideas and areas of agreement, as well as to present persuasive reasons to move forward in one direction versus another.
- Trial and Error** – Since there is no single clear path to success, team members must be willing to experiment, assess effectiveness, and learn from mistakes.
- Leadership and Individual Roles** – Effective groups utilize the strengths of each member, dividing up tasks and assigning roles appropriately. Groups also need an effective leader, with guidelines regarding the leader's role and level of authority.

- Name at least five critical parts of the I/DD service delivery system in Virginia.
- On a scale of 1-10, how well would you rate the overall collaboration?
- What's the reason for your rating?
- How could you improve it?

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## Changing Models of Support

Quality, compliance, minimum standards and beyond.....

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### Efforts to Build a Sustainable Future

- Supporting Families AND
- Developing Innovative Supports – Relationship based
- Expecting Employment outcomes
- Building on Technology
- Focusing on Person Centered Planning –
- Investing in Peer Networks

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### Standardized vs Customized

- **Customization** refers to the efforts of companies to offer goods and services specifically designed or customized according to the needs of a particular customer, a group of customers, or an entire market (country). The core of customization or customization strategy is the focus on specific customer needs.
- The opposite of customization is **standardization**, which refers to the efforts of companies to offer a common product or common marketing programs throughout a particular market, region, or the whole world.



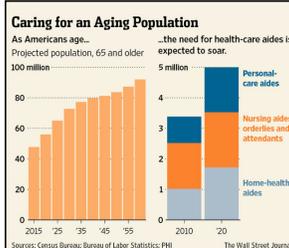
Where we are:  
"Standardized Customization"

- People want predictability in the core foundation, but the ability to customize the product or experience to meet their unique preferences.
- "Tailored to me"
- Our challenge: what can be standardized, so as to assure customized supports?
  - Process, infrastructure
  - Format of the plan can be standard, but the contents is customized
  - Format of monitoring may be standard, but the results are customized

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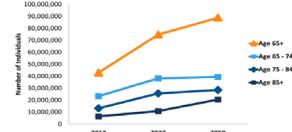
Shortage of Caregivers as America Ages

WORKFORCE



A labor shortage is worsening in one of the nation's fastest-growing occupations—taking care of the elderly and disabled—just as baby boomers head into old age. Wall Street Journal April 15, 2013

Figure 1  
The 65 and Over Population Will More Than Double and the 85 and Over Population Will More Than Triple by 2050



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National Core Indicators - Staff Stability Survey  
Turnover, Tenure and Terminations

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NCI average turnover rate:  
43.8%  
Min: 24.4% Max: 68.8%

Termination rates AVG: 18.7%  
Range 35.8% - 8.8%

State	Voluntary separations*	Employment was terminated*	Don't know why separation occurred*	Number of responding agencies
AL	18.4%	18.8%	2.8%	29
AZ	77.0%	17.7%	4.0%	107
CA	64.6%	31.0%	3.9%	35
DC	80.2%	20.2%	4.0%	53
GA	72.0%	21.1%	6.4%	102
IL	77.0%	24.7%	3.0%	106
IN	71.0%	20.9%	7.6%	90
IY	74.0%	19.0%	5.0%	140
MD	71.0%	23.5%	5.1%	39
MO	74.2%	17.9%	7.7%	152
NE	78.3%	16.4%	2.2%	38
NF	49.2%	21.9%	8.0%	201
OH	71.0%	21.0%	6.0%	755
OK	70.4%	18.0%	11.2%	51
OR	74.0%	20.0%	3.0%	158
SC	80.4%	25.8%	3.0%	40
TN	73.2%	15.5%	8.2%	99
TX	86.4%	8.0%	4.0%	54
VT	57.0%	12.0%	31.0%	13
Weighted NCI average	68.8%	18.7%	12.5%	Unweighted total: 1,838

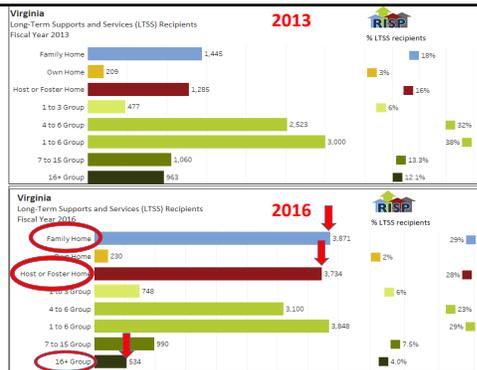
\*% of total separations between 6/1/12 and 12/31/17

Tenure of Employed DSP's as of Dec. 31

Indicator	Value
1. % DSPs employed LESS THAN 6 Mon.	19.5%
2. % DSPs employed between 6-12 Mon.	15.8%
3. % DSPs employed 12+ Mon.	64.7%
Range	14.8% to 26.2%
Range	11.4% to 19.6%
Range	56.6% to 72.0%

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Demand means growing need, and changing needs



### What Does This Mean For States?

- All states are facing the same pressures (budget/demand/workforce)
- Strategies for long term results
  - ❖ Defining Community
  - ❖ Adjusting Service Models
  - ❖ Alternative Payment Options
  - ❖ Workforce
  - ❖ Technology
  - ❖ Collaboration among all players



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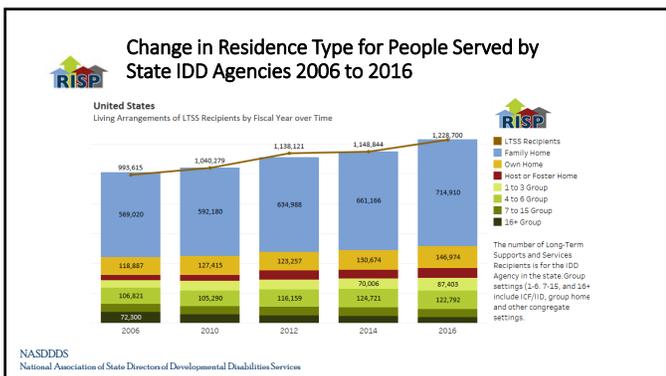
### Changes in Home and Community Based Services Regulations

- Focuses on the quality of person's experiences
- Maximizes opportunities for community living and services in the most integrated setting
- "Qualities" of the setting - integrated in and supports access to, the greater community
- Seek employment and work in competitive integrated settings, engage in community life, and control personal resources

Friends, family, self-determination, community living, social capital and economic sufficiency

- Receive services in the community to the same degree of access as people not receiving HCBS

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### Changing Models of Residential Services

- Shared Living
- Supported Living
- Complex Medical or Behavioral Supports
- Family Living

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## What is Shared Living?

- The purpose of Shared Living is to enrich the lives of people with disabilities by matching those who choose this lifestyle with a family or an individual who chooses to open their homes and their hearts.
- Sharing presupposes a *mutual* experience not a *hierarchical* one.
- An arrangement in which an individual, couple or family in the community share life's experiences with a person with a disability.
- Shared living may happen in a provider's home/apartment or the individual's home/apartment.
- Shared living may be offered by a couple, a single person, a college student, a retiree, a family, etc.



## Shared Living



- An individual lives in the home of a caregiver (typically licensed as foster care).
- Only one individual lives in the home – an exception may be made for 2 people if they are known to each other (couple/friends).
- The provider and the individual come together because of a “match” or shared interest in living together.
- Typically an **umbrella agency** provides the match and ongoing support of the relationship (arranges for respite, provides additional staffing if needed)

## What Shared Living is *NOT*

- Shared Living is not place or a “placement” that is based on a vacancy
- It is not traditional foster care
- Shared living is not a “setting” serving three or four individuals
- It is not dependent on other people living in the same home getting a service payment

## What Makes Shared Living Work Well?



### Using a Shared Living Agency

- Recruits providers
- Provides support to providers
- Arranges supplemental services including providers
- Does crisis intervention
- Manages transition

### The match

- Intensive investment of time and energy in bringing people together-PA says 3-6 months
- Requires openness and honesty about values and preferred lifestyles
  - Sometimes this means discussing difficult and “touchy” subjects...
- Involves everyone—and particularly if the match involves a family

### Support

- Training
  - ME pays for CDS training
  - GA has training specifically for shared living providers
- Consultation/intervention
- Specialized living supports coordination
  - PA has specialized individuals with small caseloads who provide support
- Networking/Peer support: Provider to provider networks
  - PA and NY have formal organizations that meet regularly
- Self-advocacy opportunities
- Respite
- Administrative support—billing, suspension of rules

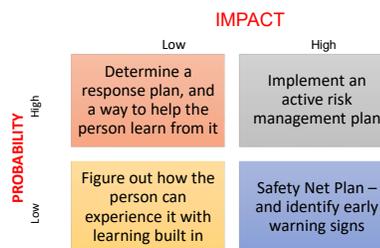
### Leadership and guidance at the state level

- Strategic Planning
- Incentives
- Service definitions
- New rules that make sense
- Resources such as training, planning, payment rates

### What are the Risks?

- When moving into someone else's home
  - Potential disruptions of established routines
  - Everyone is affected
  - Family changes may mean changes for the individual
- Isolation and dependency
- Losing the voice of the individual supported
- The "usual" conflicts and irritations of individuals living together
- Moving on—growth and change

### Risk Must Be Openly Discussed:



### The single most important thing

*"Let me layout 70 years of evidence...our relationships with other people matter, and matter more than anything else in the world."*

*George Vaillant, MD Director of the Harvard Grant Study 2009 Positive Psychology News.*

### Service Examples

One state building a supports program is incorporating the following types of services:

- Family Caregiving Supports –
  - Respite
  - Family Caregiver Stipend
  - Community Support, and Navigation
  - Family-to-Family Support
  - Self-Advocacy Supports
  - Peer-to-Peer Support
- Supportive Home Care
- Family Empowerment Supports
- Family Caregiver Training
- Health Insurance Assistance
- Individual Education and Training

### States Continue to Emphasize Employment as an Important Key to Community Integration

- Employment First – not Employment only
- States are continuing work to develop an array of services that wrap around employment supports while supporting and enabling meaningful community integration

### Does Everyone Have to Work?

- What is true in our society?
- Work is an expectation
- If you want things, you have to have an income
- Work brings economic independence
- Work makes you a valued citizen
- Work makes you proud
- We learn from the work we do and the people we work with
- We make friends



### Can Everyone Work?

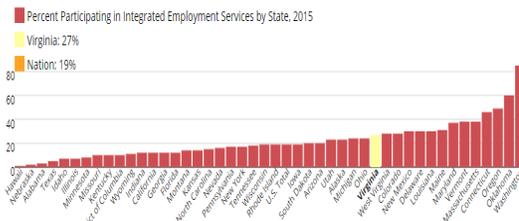
• **FACT: Among all non-disabled, working-age adults 70% are employed and not all full-time**

• *The question is not "can everyone work?" rather:*

1. How close can we get to the rate of non-disabled working adults?
2. If some states have good outcomes, how can we get there too?
3. Why wouldn't we try to get more people working?



### Integrated Employment Rates Vary Widely



### New Definitions/Flexibilities for Employment/Pre Voc

#### Employment:

- Employer check-in
- Benefits analysis
- Transportation
- Asset building
- Self-employment training, planning and start up
- Peer support and mentoring
- Career advancement services

#### And Prevocational?

- General career exploration, including self-employment
- Informational interviewing
- Soft skills training
- Job search training
- Skill building
- Job shadowing



### What Will People Do When They are Not Working?

#### Good Question

- We have to make sure that people have something to do that gets some of the same benefits or work
- We have to make sure people are busy everyday or as many days as they and their families want to be
- Work, whether part time or full time, should not create hardship for families

### Many Definitions of Community Life Engagement-(CLE) A Practical One

- People with intellectual and developmental disabilities (IDD) accessing and participating in their communities outside of employment as part of a meaningful day
- CLE is an outcome, not a service
- The *supports* given to achieve CLE may be referred to as Community Life Engagement, Integrated Day, Community Integration, Community Based Day or Community Based Non Work

### States are Changing to Support Bridges & Pathways to Employment

- Includes volunteer work; postsecondary, adult, or continuing education; accessing community facilities such as the library, gym, or recreation center; any activities that people with and without disabilities do in their spare time
  - Sometimes referred to as Community Based Day or Community-Based Nonwork
  - May support career exploration, wrap around work time, or serve as a retirement option.
- \*Many see this related to employment-a path to employment through career exploration & networking. Wraps around job to fill gaps in time, new experiences, social connections, support people in retirement in integrated ways*

### What if....

- You had to start all over again
- What would you change?

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### Innovation and Learning through Data and Technology

To infinity and beyond...

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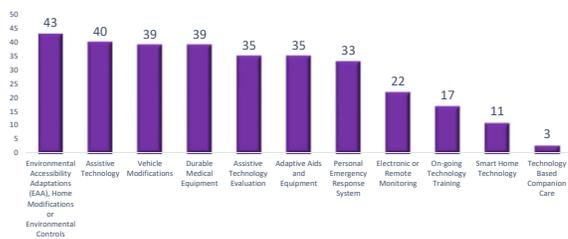
### Three Categories of Technology to Consider

- Directly in support of people who receive services
  - Remote support, voice activated, software/apps for initiation; smart homes;
- Improve efficiency of state system administration
  - Statewide data systems for case management, licensing; remote TeleHealth for rural eligibility and assessment interviews; care coordination systems; quality management data; incident management analysis of big data and AI
- Efficiency for providers
  - Electronic Records systems; mobile documentation for staff; mobile communications with staff;
- Communication – training, distribution of information via Social Media

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### What Technology Services and Supports do States Currently Fund?



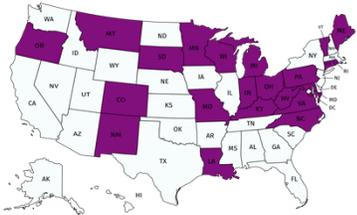
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States Funding Electronic or Remote Technologies

22 states report funding for electronic or remote technologies

Technology-based companion care is gaining in popularity for aging adults in rural areas. 3 states funding this service in IDD: NM, RI, SD

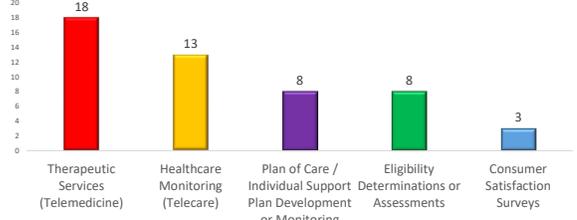


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States Report Funding of Remote Teleservices

Tech Tidbit – are smart homes, included in environment accessibility adaptations, Environmental Controls or Home Modifications? 61% NO 28% Yes 11% NA



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Is the Consideration of Technology Supports and Services a Requirement Within the ISP or Person-Centered Plan?

22 states report consideration of technology supports and services are a requirement within the ISP or person-centered plan



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How does this fit with innovation, Quality and Learning?

Moving from Compliance to innovation

### Quality – Not by inspection

- “Inspection to improve quality is too late, too ineffective and too costly – Quality cannot be inspected in..... quality must be designed in.....” *Deming*.
- Our obsession with documentation “proving” things, and Corrective Action Plans to fix things, has achieved momentous proportions – and has not improved our quality
  - New York Times article on Group Homes in NY

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### Thinking Differently About Quality

- “Without changing our patterns of thought, we will not be able to solve the problems we created with our current patterns of thought.” Albert Einstein
- “The righter we do the wrong thing, the wronger we become” “It is better to do the right thing wrong, than to do the wrong thing right” Russell Ackoff

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### Patterns/Alignment

- How direct support workers interact with people they support
- How front line managers interact with direct support workers
- How management interacts with front line supervisors
- How executives interact with everyone
- Jumps agencies – how licensors/monitors/reviewers interact with providers
- How support coordinators interact with teams
- How nurses and PT’s and OT’s interact with support teams
- Creates the culture – and the expectations -
  - Opportunity to use the same language, the same tools, the same methods/techniques for listening and learning – it is not a “soft skill” in our world, this is **the** skill

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### Both/and

- In place of either /or
- Quality measures and skills and tools AND individually defined quality of life
- What is Important TO me AND what is important FOR me
- Compliance Monitor AND technical assistant

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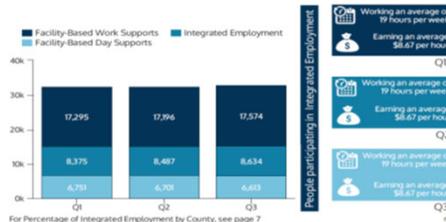
## Federal support for Innovation and Developing Business Acumen

Scorecards, Special Projects and Grants-require partnership and collaboration

## State Score Card: Employment Ohio

### Promoting Community Employment

In 2002, Governor Kasich signed Executive Order 2002-05K, establishing community employment as the priority and preferred outcome of working age adults in Ohio. This formalized Ohio's decades-long effort to support people in community jobs. Since that time, Ohio has seen an 18% increase in Community Employment.



## Example: Provider Score Card

### Access

- Length of time to initiate new services
- New Service units referred
- Length of time to develop new options, by service

### Finances

- Utilization to authorization ratio
- FTE retention rates
- % of FTE staff on workers comp or LTD due to workplace injury
- % Paid Claims to Rejected Claims – or
- Days needed for paid claims.

### System Collaboration

- Ratio of outcomes in plans important to/important for
- Number and % of restraints
- UI's reported and resolved within timeframes
- QI projects and progress

### Customer Focus

- Health prevention completed on time; medication usage
- Wage range per person, including median
- Hours of engagement with family, friends and community groups (outside of the provider scope)
- Listening posts/customer feedback loop

## Example: County Score Cards

### ELIGIBILITY AND SERVICE PLANS

- % of plans authorized within 5 day timeline
- Eligibility Determinations within timeframes
- LOC completed
- Number and length of days for remediation of grievance/fair hearing

### Customer Focus

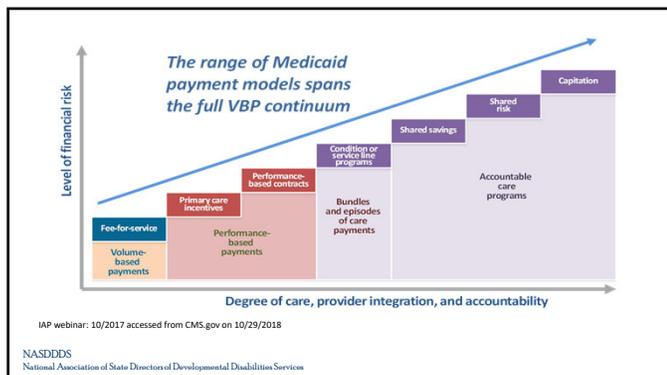
- # of families attending open meetings
- % of people who choose self direction (annual review or new to services)
- QIP's successfully resulting in improvements in health
- Medication accuracy rates per AE, per provider
- # and % of restraints

### ISC Collaboration

- % PUNS completed within 5 days of eligibility determination
- Ratio of outcomes in plans important to/important for
- Length of time for Waiver Opportunity openings
- Monitoring issues identified/resolved

### Provider Focus

- Utilization rates, per service
- Length of time for UI's resolved
- Length of retention of staff/100
- Time to initiate services, from authorized service date.
- Health prevention completed on time



## Innovation Accelerator Projects

- Missouri-
- Massachusetts
- Ohio
- Louisiana

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## Key Elements of Implementing a VBP Strategy...

- Leadership commitment
- Clear goal/objective articulation
- Measure identification – how will you gauge success?
- Clear and measurable accounting of the “as is” state – where are you starting?
- Payment strategies to move the needle
- Meaningful stakeholder engagement and education – new territory for many system partners!
- Strategies to support change and monitor efficacy – allow for course corrections

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## Relevant to Direct Support Professionals

- Relationship Based Services Expanding: Support at home, Self Direction
- Coordinated Health Care for people with complex care- (Changes in how medical services will be delivered)
- Health Standards Changing: Support for people with complex physical and mental health
- Community Engagement- dispersed settings, smaller groups, day support focused on community integrated settings
- Technology integrated into day to day work: Mobile records and documentation EVV
- Payment Models Changing

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### The Bottom Line

- To prepare for the future, States, providers, service coordinators and state Medicaid offices must work together and will be well positioned if they:
  - Keep the individuals they serve at the center of the decision-making
  - Are open to growing new and innovative approaches to meeting people's needs, in the context of their families, friends and communities
  - Develop necessary acumen to meet the data, reporting and quality requirements that are emerging

***The most dangerous phrase in our  
language is,  
"We've always done it this way."  
- Grace Hopper***

### What will you start with?

- There is no perfect place to start--- just start.
- Technology Plan?
- Innovation plan?
- Quality Plan?
- Voice of the Customer/Feedback plan?

Future of collaboration  
Take out your crystal ball.....

Defining your collaborative approach to the future:

- *Describe the Vision of how the system will be different*
- *Develop guiding principles to describe expectations- of your customers, your employees and your agency*
- *Engage all stakeholders*
- *Create a transformation plan*
- *Communicate the plan broadly and hold your agency accountable to it*



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### Questions



Mary Lou Bourne  
[mlbourne@nasddds.org](mailto:mlbourne@nasddds.org)  
703-683-4202

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