Health, Disability & Civil Rights Policy: *An Overview*

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LIFE CONFERENCE – 2021

Agenda for Today's Discussion

Review	Review recent updates in civil rights protections in accessing healthcare including around rationing medical care and hospital visitor policies, and other policies related to COVID-19.
Discuss	Discuss the critical importance to Medicaid Home and Community-based Services (HCBS) in helping people with disabilities live, work and thrive in their communities.
Consider	Consider new federal policy proposals for expanding and modernizing Medicaid HCBS.

Health, Disability & Federal Public Policy

OVERVIEW OF KEY LEGISLATIVE AND REGULATORY CHANGES MADE SINCE 2020

Fighting against Medical Discrimination During COVID (1)

In response to the disability community's strong advocacy, the U.S. Department of Health and Human Services' Office of Civil Rights (HHS OCR) published a bulletin on March 28, 2020 to ensure that covered entities follow civil rights laws, including Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which "prohibit discrimination on the basis of disability in HHS funded health programs or activities."

The guidance explains that entities funded by HHS cannot deny people with disabilities medical care "on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities." It is also discusses the obligations of hospitals to ensure equal access and effective communication.

Fighting against Medical Discrimination During COVID (2)

February 12, 2021: The Center for Public Representation (CPR), along with a coalition of civil rights groups and legal scholars have released a new report: "Examining How Crisis Standards of Care May Lead to Intersectional Medical Discrimination Against COVID-19 Patients." The report explores and addresses how crisis standards of care may perpetuate medical discrimination against people with disabilities, older adults, higher weight people, as well as Black, Indigenous, and other people of color, in hospital care.

November 30, 2020: CPR, along with The Arc, Bazelon Center, Autistic Self Advocacy Network, and Professor Sam Bagenstos, updated its Evaluation Framework for Crisis Standards of Care Plans which was developed to assist stakeholders in evaluating Crisis Standards of Care in their states. You can read the updated framework here and can find more resources on Crisis Standards of Care Plans below.

September 17, 2020: The Centers for Medicare & Medicaid Services (CMS) at the U.S. Department of Health and Human Services issued a new guidance document about visitation in nursing homes. Among other things, it describes circumstances when in-person supports are required under federal disability laws. CPR is advocating for CMS to issue similar guidance about other congregate settings. You can read the full guidance here.

Guidance on "Long COVID" as a Disability Under the ADA, Section 504, and Section 1557

- In light of the rise of long COVID as a persistent and significant health issue, the Office for Civil Rights of the Department of Health and Human Services and the Civil Rights Division of the Department of Justice recently issued guidance affirming that people suffering from "long COVID" COVID can be a disability under:
  - Titles II (state and local government) and III (public accommodations) of the Americans with Disabilities Act (ADA),
  - Section 504 of the Rehabilitation Act of 1973, and
  - Section 1557 of the Patient Protection and Affordable Care Act (Section 1557).
- Each of these federal laws protects people with disabilities from discrimination._The new guidance also provides resources for additional information and best practices.
- The civil rights protections and responsibilities of these federal laws apply even during emergencies and cannot be waived.

Medicaid Block Granting: *Proposals from States – All Eyes are on Tennessee*

- Thirteen Medicaid beneficiaries, represented by the National Health Law Program and the Tennessee Justice Center (TJC), filed a complaint in March 2021 in the US District Court for the District of Columbia challenging the Department of Health and Human Services' approval of Tennessee's 1115 waiver, which turns that state's Medicaid program into a block grant program from an entitlement program.

- The approval caps the amount of federal funding available for Medicaid services and allows the State to restrict coverage of prescription drugs. It also permits the State to continue troublesome features of TennCare, including the elimination of 3-months' retroactive coverage and the requirement that beneficiaries enroll in managed care plans–features that the State has been "testing" on low-income people since 1994.

- The lawsuit was filed on behalf of TennCare enrollees with chronic, disabling conditions, a pediatrician practicing in a rural part of the State, and TJC. The Plaintiffs argue that in its haste to approve the project, the Trump administration did not provide the required public comment period, depriving them of the opportunity to voice their objections to the project. They also claim that HHS exceeded its authority and acted in an arbitrary and capricious manner when it authorized the project as a Section 1115 experimental waiver. The approval affects more than one and a half million Tennesseans.

  - A copy of the complaint can be accessed here.

Organ Transplant Discrimination Prevention

- Despite federal protections, such as the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973, people with disabilities still face discrimination determining eligibility to receive organ transplants. Providers often have a misconception that people with disabilities, especially those with intellectual and developmental disabilities (ID/DD), are unable to manage complicated post-operative treatment. Providers may also assume that people with disabilities have a lower quality of life than those without disabilities and would not benefit from life-saving transplants.

- Charlotte Woodward Organ Transplant Discrimination Prevention Act (HR 1235) introduced in June 2021:
  - Clarifies that doctors, hospitals, transplant centers and other health care providers are prohibited from denying access to necessary organ transplants solely on the basis of a qualified individual's disability. Additionally, the bill requires that, when evaluating the likelihood of a transplant's success, health providers consider the full range of supports available to help a person with a disability manage their post-operative care. The bill also includes a fast-track procedure for challenging discrimination to ensure that people in urgent need of an organ transplant obtain timely resolutions to their claims. There are currently laws against organ transplant discrimination in the states of California, Delaware, Florida, Indiana, Iowa, Kansas, Louisiana, Maryland, Massachusetts, Missouri, New Jersey, Ohio, Oregon, Pennsylvania, Virginia and Washington. As of yet, there is no companion bill being prepared in the Senate.

Now a Look at HCBS

TRENDS IN MEDICAID HOME & COMMUNITY BASED SERVICES: WHERE WE'VE BEEN AND WHERE WE ARE TODAY

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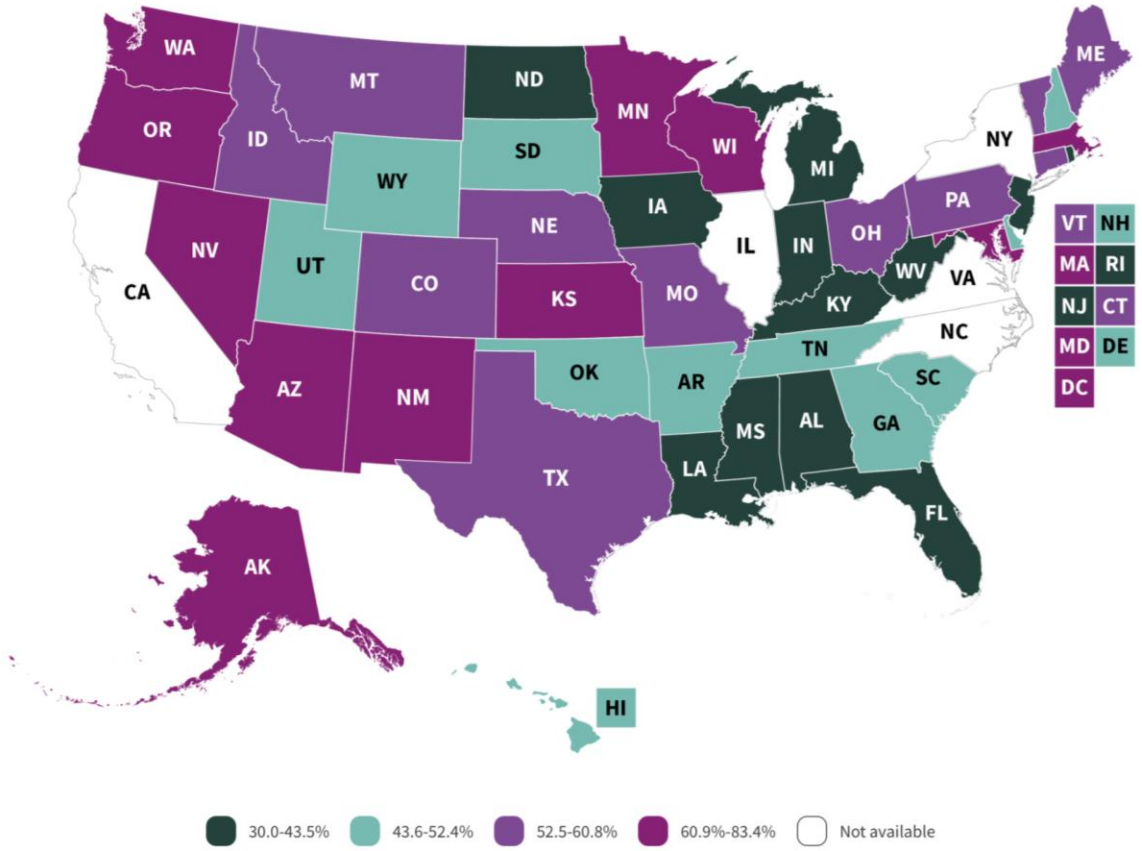
Expenditures on HCBS as a Percent of Total LTSS Expenditures



Medicaid & CHIP SCORECARD

- National Context
- State Health System Performance
- State Administrative Accountability
- Federal Administrative Accountability

Delaware is spending less than half of its Medicaid LTSS funding on HCBS

We've Been Riding the Train of "Rebalancing" LTSS for Awhile…But to What End?

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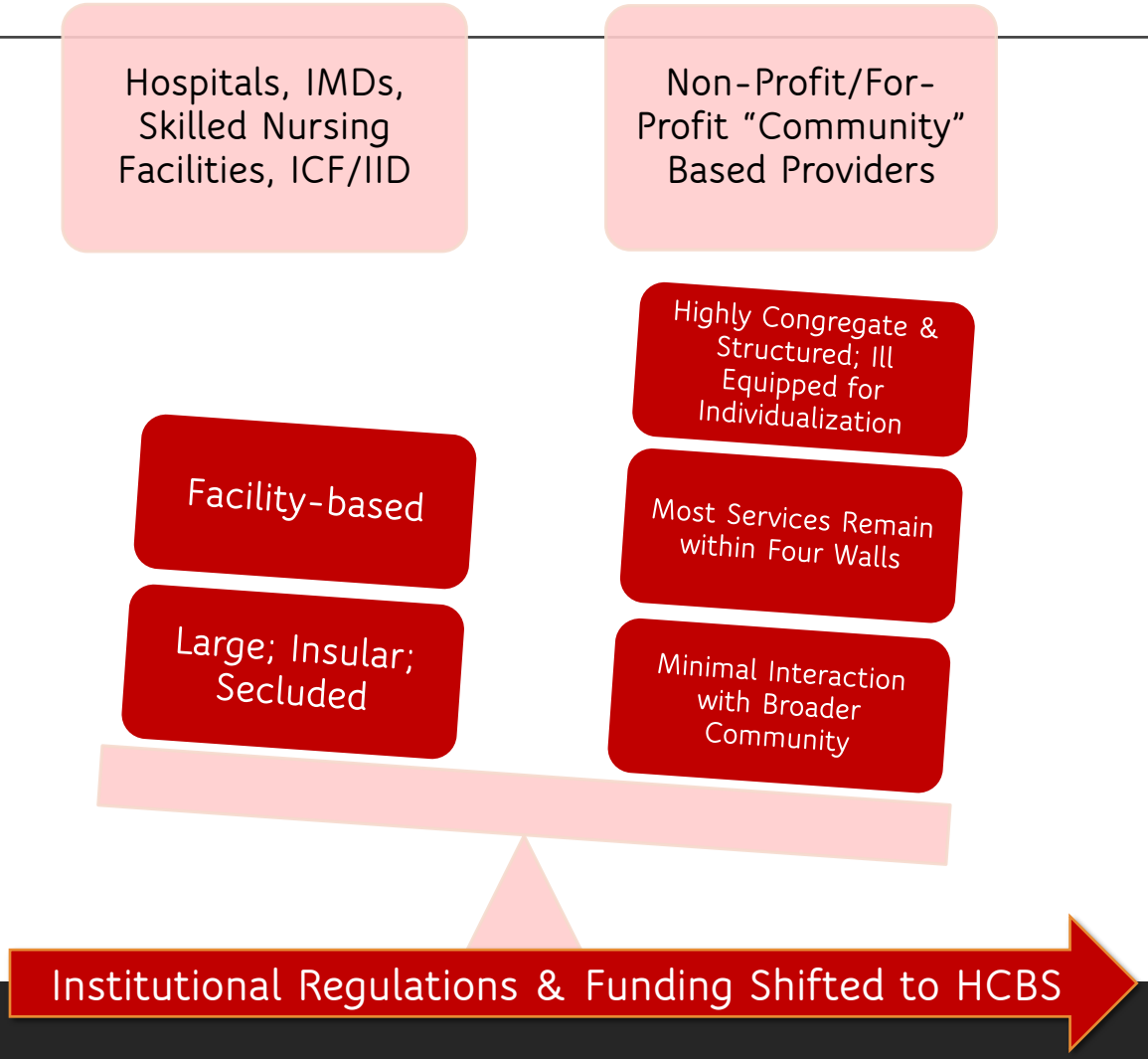

Remember these?
Federal HCBS Setting Requirements

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Is integrated in and supports access to the greater community

Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources

Ensures the individual receives services in the community to the same degree of access as individuals not receiving Medicaid HCBS

Is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting

Ensures an individual's rights of privacy, respect, and freedom from coercion and restraint

Optimizes individual initiative, autonomy, and independence in making life choices

Facilitates individual choice regarding services and supports and who provides them

Additional Requirements for Provider-Controlled or Controlled Residential Settings

https://www.law.cornell.edu/cfr/text/42/441.301

Institutional Model Issues Persist in Current HCBS Infrastructure, 7 Years after Publication of the Federal HCBS Regulation

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- Normal relationships/natural supports v. paid relationships/supports
- Dependency
- Limited choices, often not based on exposure to more individualized, inclusive options
- Artificial environments
- Not within public view
- Becomes the provider's/agency's source of continued revenue

Bottom Line - Status Quo Persists for a lot of HCBS Participants

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People are often left with someone else's vision or plan for what is best for them:

- Doing things they don't want to do
- With people they don't want to be with
- In places they don't want to be

On the Horizon

Goal #1: HCBS Should Support Individuals to….

Live in their own home with the people they choose to live with

Enjoy the support and engagement of family and friends

Get a job, volunteer, or retire but continue to engage

Enjoy good health

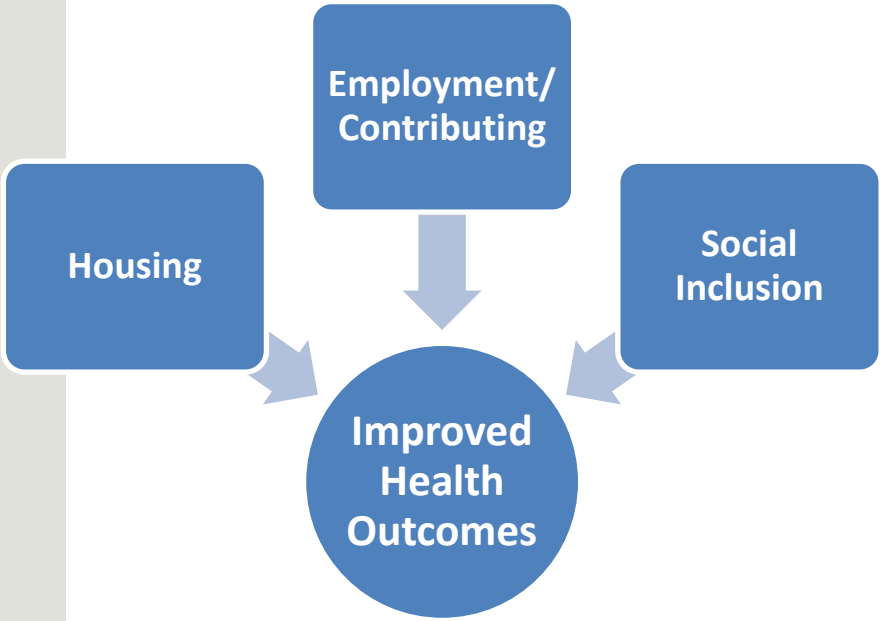
Be a meaningful part of and contribute to their community

Achieve their personal potential for independence, inclusion and self sufficiency

Goal #2: HCBS should be Focused on Preserving and Improving Social Determinants of Health among Beneficiaries

Social Determinants of Health as Cost Control

- Enlightened cost control strategy—not just for Medicaid, but health care system overall
- Increase efficiency while also improving health of enrollees
- Interventions for targeted populations have demonstrated cost savings, such as:
  - Intensive case management for super-utilizers
  - Coordinating access to safe, affordable housing for individuals who are homeless or housing-insecure



Why HCBS are Critical to Independent Living & Integration

REFLECTIONS FROM EVAN BARKOFF

SELF-ADVOCATE, MEMBER OF THE GEORGIA COUNCIL ON DEVELOPMENTAL DISABILITIES

Four Important HCBS Developments in the Federal Government

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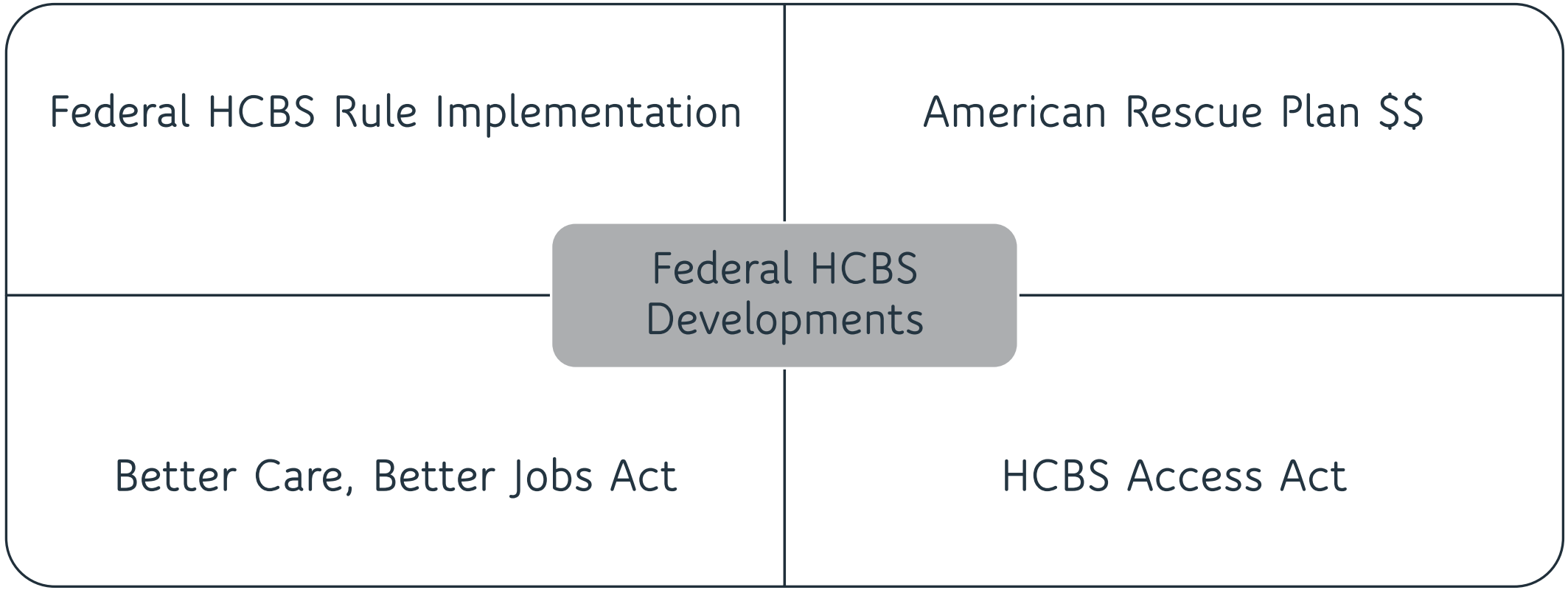

Status of State HCBS Settings Rule Implementation Efforts

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- 21 + DC Final State Transition Plan Approvals
  - Delaware received final approval of its statewide transition plan in October 2017.
- 24 Initial Approvals (including Pennsylvania)
- 5 without Initial or Final Approvals

American Rescue Plan Act provides temporary increased federal funding for Medicaid HCBS

- Under Medicaid, state funding is combined with a federal "match".
- ARPA Funding allows states to temporarily get a 10% increased federal match for certain Medicaid expenditures beginning April 1, 2021 through March 31, 2022
- Enhanced FMAP requirements includes a broad list of Eligible Services
- States must comply with Maintenance of Effort (MOE) requirements specified
- Not applicable to HCBS admin expenditures

Examples of activities states can spend the increased federal match funding on through ARPA:

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- Adding new CBS services, or increasing amount duration scope to reduce risk of institutionalization during covid
- HCBS provider payment rate to increase wages, benefit enhancements, including increasing rates, providing paid leave, hazard pay, etc.
- Purchasing PPE
- Workforce support, recruitment, training
- Caregiver support
- Assistive technology -- including internet and support using it, staffing, and other costs due to COVID-19
- Transition supports--one time community transition costs, transition coordination.
- Mental Health and Substance Use services
  - Skill rehab to regain skills lost during PHE
  - Expanding capacity
- Outreach activities-- educational materials re Covid 19, and language assistance--ASL and language interpreters
- Support for access to vaccines
- Build no wrong door systems
- Strengthen assessment and person-centered planning process
- Quality improvement, Develop cross-system partnerships
- Training and respite for caregivers
- Reduce or eliminate waiting lists
- Implement new eligibility policies or procedures -- like expedited elig for HCBS (subject to CMS approval)
- Institutional diversion and community transition improvements
- Expand provider capacity
- Address SODH
- Telehealth

Better Care, Better Jobs Act (1 of 3)

- Purpose of the bill is to enhance Medicaid funding for HCBS. States would be eligible for a permanent 10 percentage point increase in the federal Medicaid match for delivering HCBS as well as enhanced funding for administrative activities associated with improvement efforts.

Better Care, Better Jobs Act (2 of 3)

States would have to strengthen and expand access to HCBS by:

- Expanding financial eligibility criteria for HCBS to federal limits; requiring coverage for personal care services;
- expanding supports for family caregivers;
- adopting programs that help people navigate enrollment and eligibility; expanding access to behavioral health care;
- improving coordination with housing, transportation, and employment supports;
- developing or improving programs to allow working people with disabilities to access HCBS.

States would also have to strengthen and expand the HCBS workforce by:

- addressing HCBS payment rates to promote recruitment and retention of direct care workers;
- regularly updating HCBS payment rates with public input;
- passing rate increases through to direct care workers to increase wages; and
- updating and developing training opportunities for this workforce as well as family caregivers.

States would also have to show improvement over time by demonstrating:

- improved availability of services;
- reduced disparities in accessing and using HCBS;
- evidence of competitive wages and benefits for workers; and
- increases in HCBS spending.

Better Care, Better Jobs Act (3 of 3)

- Comply with a strong maintenance of effort for HCBS eligibility and benefit standards to ensure that additional federal dollars go towards growing and improving HCBS programs.
  - Encourage innovative models that benefit direct care workers and care recipients: Provide additional incentives to help states build HCBS workforce programs that register direct care workers; help connect them to seniors and people with disabilities seeking care; facilitate coordination between the state and direct care workers; support care safety and quality; and help workers organize, among other functions.
  - Support quality and accountability: Provide funding to the Centers for Medicare & Medicaid Services to carry out the bill's programs; conduct oversight and monitoring; and offer technical assistance to states participating in the funding opportunities described above.
  - Additionally, participating states would be required to establish state HCBS ombudsman programs to support care quality.
- The bill would also require all state Medicaid programs to adopt HCBS quality measures.
  - Facilitate state planning: Provide funding for states to develop HCBS infrastructure improvement plans with public input, to outline how they would expand access to HCBS, strengthen the workforce, and meet requirements tied to increased federal Medicaid funding.
- States would be required to develop these plans in order to receive enhanced federal Medicaid funding for HCBS.
  - Permanent spousal impoverishment protections:
  - Permanently authorize protections against impoverishment for individuals whose spouses are receiving Medicaid HCBS.
  - Make Permanent Money Follows the Person: Make the Money Follows the Person Rebalancing Demonstration permanent.
- Cosponsors: Baldwin, Bennet, Blumenthal, Booker, Cantwell, Cardin, Durbin, Feinstein, Gillibrand, Hirono, Heinrich, Kaine, King, Klobuchar, Leahy, Luján, Markey, Merkley, Menendez, Murphy, Padilla, Peters, Reed, Rosen, Sanders, Schatz, Shaheen, Smith, Stabenow, Van Hollen, Warnock, Warren and Whitehouse

HCBS Access Act (1 of 3): *General Requirements*

Medicaid Eligibility Qualifications

Eligibility includes:

- an individual who is determined by a health care provider approved by the State to have a functional impairment that is expected to last at least 90 days; or
- an individual receiving or determined to be eligible for HCBS.

Makes HCBS as a Mandatory Benefit

Ensures coverage of HCBS for all Medicaid-eligible individuals who are eligible for medical assistance under the State plan (or waiver of such plan) and elects to receive such services.

Specified Federal Medical Assistance Percentage for HCBS

FMAP for amounts expended for medical assistance for HCBS, including any such services furnished under a waiver under section 1915, shall be equal to 100 percent.

HCBS Implementation Grants to States

Provides comprehensive, long-term implementation grants to participating states to transform their systems and offer more individualized, integrated HCBS options to people with disabilities and older adults.

HCBS Access Act (2 of 3): *Purpose*

Fulfill the purposes of ADA to ensure people with disabilities and older adults live in the most integrated setting.

Eliminate waiting lists for HCBS, which delay access to necessary services and civil rights for people with disabilities and aging adults.

Build on decades of progress in serving people with disabilities and aging adults via HCBS and not in institutions, nursing homes or other congregate settings.

Provide medical assistance for those whose income and resources are insufficient to meet the costs of necessary medical services.

Provide rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care.

Eliminate silos and ensure that people with all kinds of and with multiple disabilities, receive the services they need to live in their communities.

Streamline access to HCBS by eliminating the need for States to repeatedly apply for waivers.

Continue to increase the capacity of community services to ensure people with disabilities and aging adults have safe and meaningful options in the community are not at risk of unnecessary institutionalization.

Include people with significant disabilities, can live in the community with the right services and supports.

Support over 65 million unpaid family caregivers who are often providing complex services and supports because of a lack of affordable services, workforce shortages in the Medicaid system.

Improve direct care work quality and address the decades long workforce barriers for nearly 4.6 million direct care workers giving support to people with disabilities and aging adults in their homes and communities.

Eliminate the race and gender disparities that exist in accessing HCBS and prevent the unnecessary impoverishment and institutionalization of black and brown individuals with disabilities and aging adults.

HCBS Access Act (3 of 3): *Services to be included in Mandatory Medicaid HCBS*

Supported employment and integrated day services.	Personal assistance, including personal care attendants, direct support professionals, home health aides, private duty nursing, homemakers and chore assistance, and companionship services.	Services that enhance independence, inclusion, and full participation in the broader community.
Non-emergency, non-medical transportation services to facilitate community integration.	Respite services provided in the individual's home or broader community.	Caregiver and family support services.
Intensive case management, fiscal intermediary, & support brokerage services.	Services which support person-centered planning and self-direction.	Direct support services during acute hospitalizations.
nursing services not otherwise covered which are necessary for the individual to remain in their home and community, including	Home and community-based intensive behavioral health and crisis intervention services.	Peer support services.
Housing support and wrap-around services.	Necessary home modifications and assistive technology, including those which substitute for human assistance.	Transition services to support an individual's transition from an institutional setting to the community, including such transition services provided while the individual resides in an institution.

And at the same time this is going on…..

The Congress is working on a comprehensive infrastructure and workforce development package that may include $100-400 Billion in new HCBS investments over the next ten years.

So, What are the Chances of these Proposed Changes Becoming Law?

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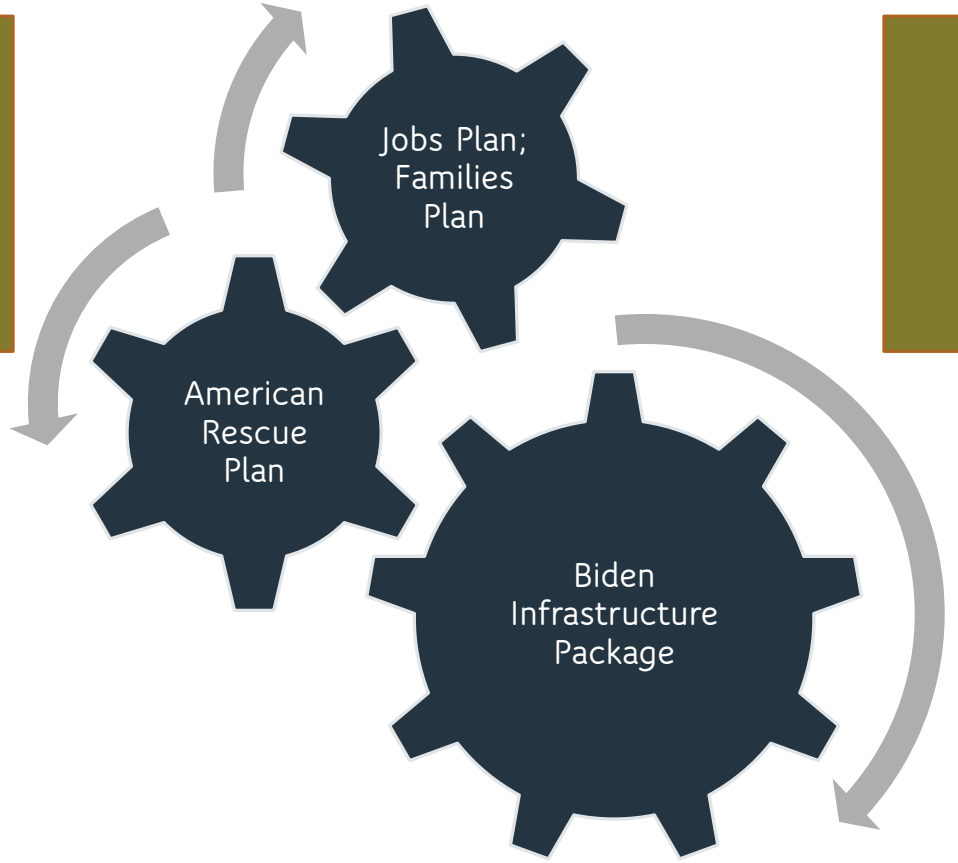
Reconciliation Process



Filibuster

Envisioning our North Star

TAKING OUR SHOT -- STRATEGIES FOR TAKING ADVANTAGE OF THE NEW FEDERAL FUNDING AND FOCUS ON HCBS

Key Elements of a Successful Approach to Providing HCBS to PWD

Figure II.1. Key Elements

Promoting Individualization and Full Community Inclusion in HCBS

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Access

- Availability of supports to allow a person to engage in the broader community for the maximum number of hours desired daily.
- Activities designed to maximize independence, autonomy and self-direction.

Variety

- Broad range of activities/offerings that are comparable to those in which individuals not receiving HCBS routinely engage.
- Access to individualized integrated activities.

Quality

- Cultural competency
- Measurement focused on Increasing Community Access, Decreasing Social Isolation

Modernizing HCBS: *Capacity Building (1)*

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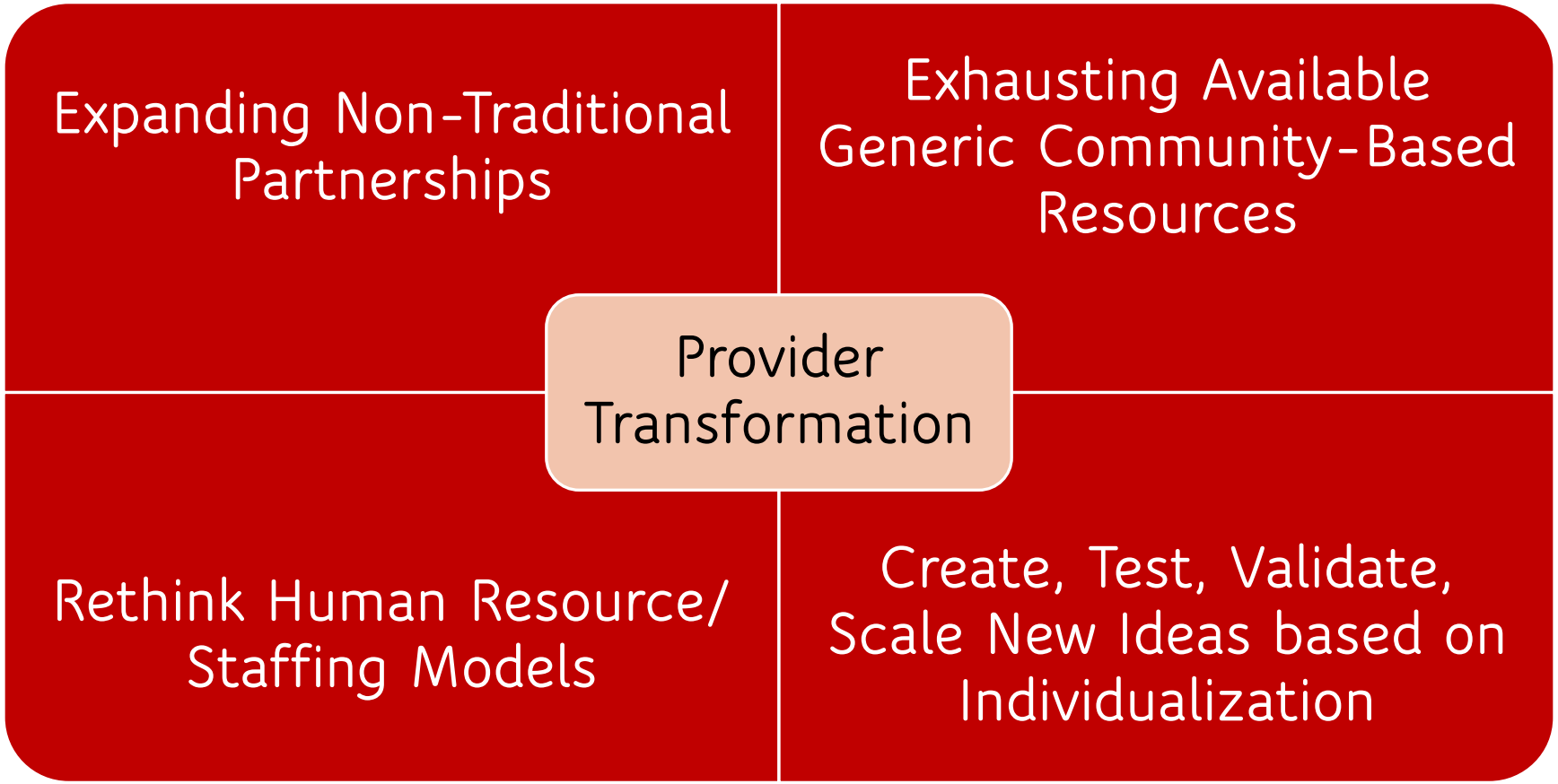

Modernizing HCBS: *Capacity Building (2)*

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Innovative Provider Service Principles

The best places to learn how to live and work in the community are in the community.

Our buildings should be places for people to come and go – not to stay.

We shouldn't provide things here that exist naturally in the community.

We should never make the people we support look incompetent in the community.

We must balance preservation of safety with the dignity of risk….there is room for both, just as there is for all other adults that do not have disabilities. The key is in striking the right balance *on an individual basis.*

Provider-to-Provider Tips on Making the Shift to Community Integration

Invest time and resources into effective practices.

Build your social capital at all levels.

Explore traditional and non-traditional revenue sources.

Do it one person at a time and do it a lot of times until you're done. You'll get better at what you do.

Start small – clear the path. Don't get stuck in planning, processing and waiting for the right "time" for change.

Hire for who you want to become, not for who you are.

Providing Supports to PWD with Integrity: *Systems-Level Operational Issues (1)*

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- How much integration is enough?
- Reverse Integration
- Flexibility in Individualization, Approach to Supports, and Pivoting when Things Don't Work Out
- Getting out of large contracting mentality and focus on individual outcomes
- Group v. Individualized Scheduling and Service Offerings
- Transportation
- HCBS direct supports provider v. employer of record
- Implications of waiver/state plan service definitions and reimbursement structures

Providing Supports to PWD with Integrity: *Systems-Level Operational Issues (2)*

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- Funding/ Reimbursment
- Capacity
- Community Integration
- Conflict-Free Case Management
- Person-Centered Planning

Potential Land-Mines (Threats) to Modernizing HCBS

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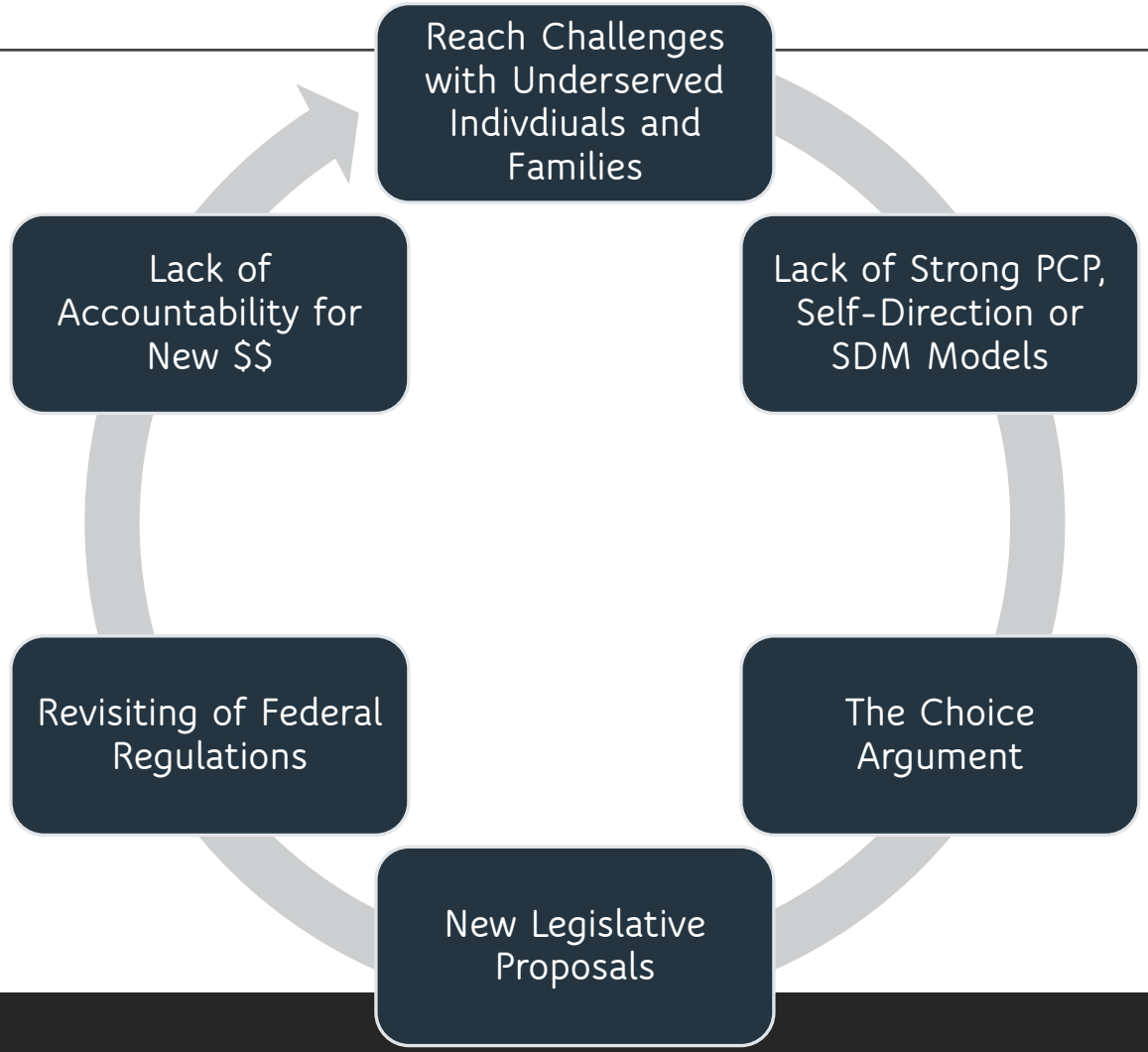

Using Person Centered Planning in the Context of HCBS

Vision for Person-Centered HCBS Systems

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1. People know what to expect
2. People who facilitate planning processes are competent
3. Systems are configured to deliver services and supports in a manner consistent with person-centered values
4. Quality measures are implemented for process fidelity, experience, and outcomes based on each person's preferences and goals.
5. Principles of continuous learning are applied throughout the system.
6. Formalized and ongoing partnerships with people with disabilities and older adults in designing and implementing person-centered thinking, planning, and practices in systems.

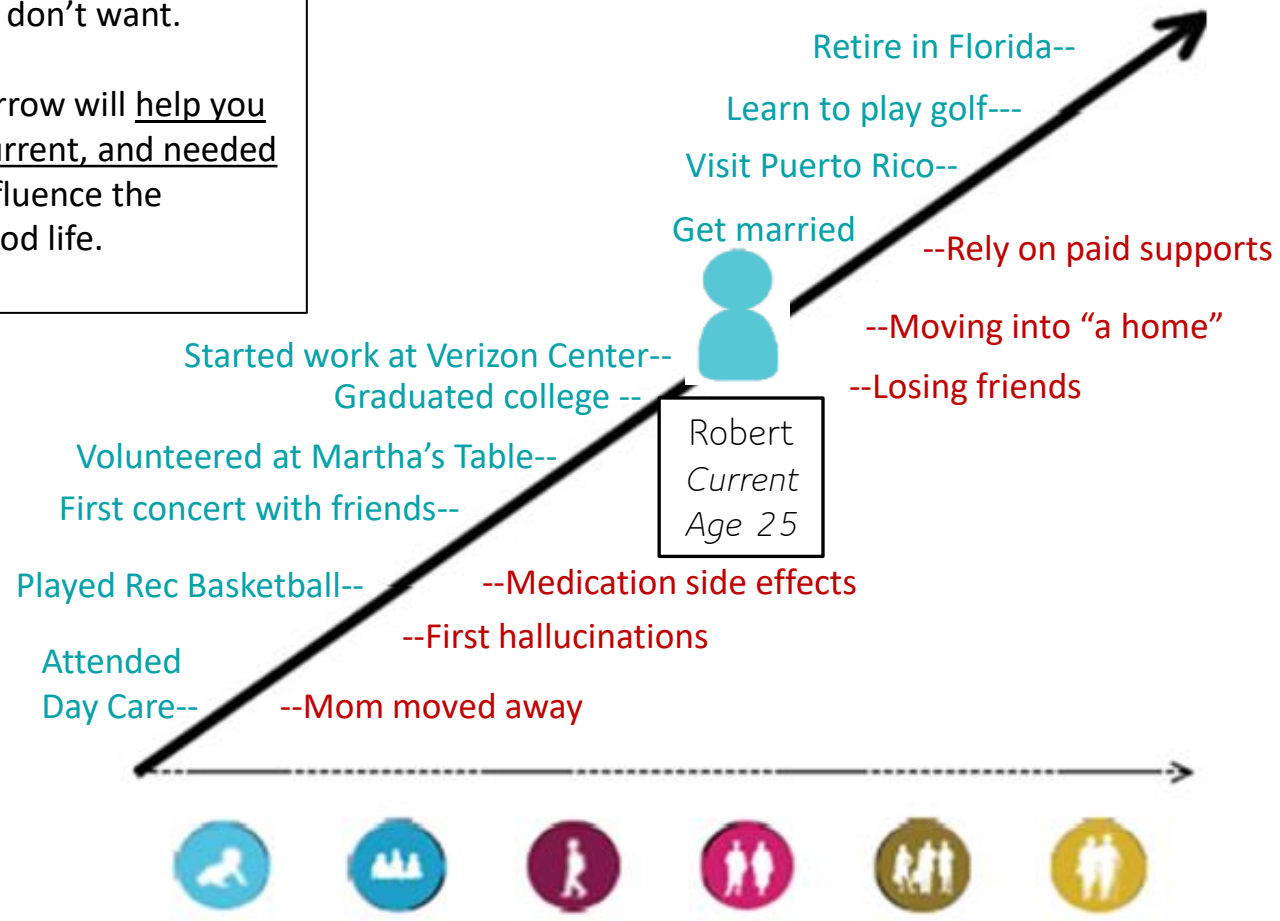
PATH


16th November 2012
MOLLY'S PATH
NOW
ENROL
STAYING STRONG
ACTIONS
ONE YEAR FROM NOW
16th November 2013
HAWAII
THE DREAM

Example of Person Centered Planning Results with Life Trajectory Tool Completed with Person Supported: Robert

Everyone wants a good life. The boxes on the right will help you think about what a good life means for you or your family member, and identifying what you know you don't want.

Space around the arrow will help you think about past, current, and needed experiences that influence the direction of your good life.



Vision for a GOOD Life

-Money, job or own business
-Healthy and fit
-Staying active
-Married (5 kids?!)
-Attending concerts
-Vacations to Puerto Rico
-Contribute to my community
-Living in my own home

Vision for what I DON'T Want

-Poverty, no savings
-Guardianship
-Institution/group home living
-Being lonely and isolated
-Frequent hospitalization
-Family separated from me
-No friends

What Can You Do?

ACTIONABLE STEPS THE GEORGIA DD COUNCIL CAN TAKE TO PROMOTE ACCESS TO HIGHER QUALITY HCBS

Recommendations on Next Advocacy Strategies in DE

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Increase Financial Resources to Spur Focus on Individualized, Integrated Supports

- Recommending that DE State Medicaid Agency NOT cover or prioritize facility-based, congregate services at the same level (100%) as services provided under an individualized, integrated model. The state should use extra funding from ARP, the future *Better Care*, *Better Jobs Act*, and reconciliation package to offer the most integrated service options based on evidence-based practices that lead to competitive integrated employment, independent living, and full community inclusion.
- Provide additional outcomes-based financial incentives that focus on transitioning HCBS participants from large congregate day/prevocational settings to individualized integrated employment supports, and simultaneously make significant investments in TA, training, and ongoing support to providers of facility-based, congregate day and pre-vocational services who have committed to prioritizing the provision of individualized, integrated day and employment supports.

THANK YOU!!!

If you have any questions, please do not hesitate to reach out to us at:

EWOLANERES@gmail.com