Developmental Disabilities Lecture Series

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Medicaid Home and Community-Based Services: Hot Topics and Emerging Trends

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We’ll Cover:

- Medicaid—the basics
- Home and Community-Based Services (HCBS) Waivers
- New authorities
- Things to watch
  - New rules: settings, person centered planning, conflict free case management
  - EPSDT and services for children with autism
- National trends
  - Supporting families
  - Employment
  - Shared living

Medicaid: A Quick Review

Really, it’s not so hard!!

Medicaid ...

- Began in 1965 to pay for health care to welfare recipients
- All 50 states and DC participate—but they do not have to
- Jointly administered by the states and the federal Centers for Medicaid and Medicare Services (CMS)

Medicaid

- Is generally "means-tested"—only available to those whose income and assets meet certain levels
- Eligible groups include individuals who are elderly, blind, disabled, using public assistance and children
Medicaid...

- Now is WAY more than health care for low-income individuals
- Is the major source of financing for long term community supports and services

Medicaid is a State/Federal partnership

- Feds "match" state contribution on an annually determined formula called the matching rate based on the state's economic picture
- The Federal share is called Federal Financial Participation (FFP) or sometimes FMAP (Federal Medical Assistance Percentage)
- The state share is called state match

State/Federal partnership

- The state operates Medicaid under it's State Plan and other "authorities" such as waivers
- The state can change coverage, eligibility and the scope and amount of services as needed
- The state submits State plan amendments (SPAs) covering different services which CMS reviews and approves

State/Federal partnership

- States must serve certain individuals who meet income and assets eligibility
- BUT states can choose to expand Medicaid to many others such as working individuals, or children with disabilities
- Can be very limited or more broad, dependent on the state
- Examples: % of Federal Poverty Level (FPL), medically needy, "spend-down", Katie Beckett, HCBS waiver

Covered Services: Mandatory services

- States must cover these services:
  - In/outpatient hospital
  - Physician, midwife, and nurse practitioner
  - Nursing home
  - Home health
  - Screening and treatment (EPSDT) for kids under 21
  - Family Planning
  - Rural health clinics, federally qualified health centers

Covered Services: Optional services

- Personal care
- ICF-IDD
- Prescription drugs
- Home and community-based services
- Therapies-OT/PT/Speech
- Targeted case management
- Mental Health Services
- HCBS waivers
- States can choose to cover these services but are not required to do so by federal regulations in order to participate in Medicaid
Other Medicaid Tidbits...

- State plan services are an entitlement to anyone who is eligible—based on meeting any specific eligibility criteria and what is called “medical necessity” (but waivers are different as we will see)

- Children are entitled to ALL mandatory and optional services even if the state does not specifically cover them for adults such as:
  - Autism treatments
  - Dental care
  - Personal care

A bit more on autism services

- Many states now cover autism treatments for kids under the HCBS waivers
- CMS issued guidance indicating states must cover autism treatment services under “regular” Medicaid under the EPSDT regulations*, thus, autism services to children can no longer be covered as a waiver service
- The state can cover these services as preventive, therapy or under the “other licensed practitioner categories
- States can choose what treatments they wish to cover—does not have to be Applied Behavioral Analysis, CMS noted: “CMS is not endorsing or requiring any particular treatment modality for ASD.”
- Several states have submitted new SPAs for autism—California and Minnesota and a few other states already had coverage: Florida and Virginia


Understanding the Pillars of the HCBS Waiver

- A waiver means that the regular rules are “waived”, that is not applied

What is a HCBS Waiver??

- Section 1915 (c) of the Social Security Act was changed to allow states to ask for waivers of existing Medicaid regulation
- The idea is that states can now use the Medicaid money for community services that would have been used for the person in an institution
- Thus, getting HCBS waiver services is tied to institutional eligibility

Institution/HBCS link

- This does NOT mean you have to go to an institution or want to go to an institution—just that you could be eligible for services in an institution
- The waiver means you can choose services in the community
Why bother having waivers?

- Bang for the buck!
- Medicaid is a matching program where the feds and the state share the financial burden
- The state pays part of the cost and the feds “match” what the state pays
- In New Jersey, the feds pay half of the costs of waiver services, and the state pays the rest

State/federal partnership

- The Centers for Medicare and Medicaid Services (CMS) provides states with an application to fill out (called the waiver format or template)
- The state fills in the template, submits the plan to CMS
- Because the waiver is a Medicaid program, the Single State Medicaid Agency must submit the application, but another agency can run the waiver day-to-day

The Waiver Application has....

- 10 Appendices = 98 pages... and a 345 page technical guide to fill it out!
  - Appendix A: Waiver Administration and Operation
  - Appendix B: Participant Access and Eligibility
  - Appendix C: Participant Services
  - Appendix D: Participant-Centered Planning and Service Delivery
  - Appendix E: Participant Direction of Services
  - Appendix F: Participant Rights
  - Appendix G: Participant Safeguards
  - Appendix H: Quality Management Strategy
  - Appendix I: Financial Accountability
  - Appendix J: Cost Neutrality Demonstration

...So let’s have some sympathy for those who have this job!

Who can a HCBS waiver serve?

- The person must be eligible for Medicaid, according to your state rules, and,
- Meet what’s called the level of care (LOC) for nursing home, ICF-DD*, hospital or other Medicaid-financed institutional care
- States can cap the number of people they plan to serve

*Intermediate care facility for individuals with intellectual and developmental disabilities

Level of Care (LOC)

- LOC means that the person has needs that could make them eligible for institutional care “but for the provision of HCBS services”
- States decide how to figure out the LOC, CMS approves the process
- The person (or parent or guardian) also must be offered the option of institutional care—even if there’s no way they’d ever want it—because under Medicaid people have the right to choose an institution instead of the community
Waiver cans and can’ts

• Okay, it is a federal program and there are some rules...so let’s first take a look at what you can’t do, so we know what we can do with a waiver...

Waiver can’ts

• HCBS waivers are federal programs and there are some rules...so you:
  ○ Can’t give cash directly to a waiver participant or parent...but consumer-directed and controlled services are perfectly permissible.
  ○ Can’t pay for room and board with Medicaid money (except for respite, nutritional supplements, or one meal/day-like Meals on Wheels)

Waiver can’ts...

• Can’t pay for exactly the same stuff under the waiver that is covered by an Medicaid card until you first use up Medicaid card services
• Can’t pay for services that Vocational Rehabilitation or the public schools are supposed to pay for
• Can’t do general home repair with waiver dollars

Waiver can’ts...

• Can’t cover a few services such as recreation**, guardianship or institutional services other than respite
• Can’t serve folks who don’t meet the Medicaid eligibility rules your state got approved under their waiver
  **but “therapeutic” recreation and community participation activities are okay...

And there are requirements...

• These are things the state MUST do. The state must promise the feds that the waiver is cost-neutral.
• This means the state spends the less than or the same amount on HCBS as they would have spent for institutional services—on average.
• This means the average cost per person under the waiver can’t be more than the average cost per person in an ICF-ID-DD.
  
  Community $ ≤ Institution $

• Individual costs can vary widely and states can cap the total amount any one individual can spend

Waiver Quality Assurances

• Assurance - The State demonstrates that it implements the processes and instrument(s) specified in its approved waiver for evaluating/reevaluating an applicant’s/waiver participant's level of care consistent with care provided in a hospital, NF, or ICF/ID-DD
• Assurance- The State demonstrates it has designed and implemented an effective system for reviewing the adequacy of service plans for waiver participants.
• Assurance - The State demonstrates that it has designed and implemented an adequate system for assuring that all waiver services are provided by qualified providers.
Waiver Quality Assurance

- Assurance-- On an ongoing basis the state identifies addresses and seeks to prevent instances of abuse, neglect and exploitation.
- Assurance- State financial oversight exists to assure that claims are coded and paid for in accordance with the reimbursement methodology specified in the approved waiver
- Assurance – The Medicaid Agency retains ultimate administrative authority and responsibility for the operation of the waiver program by exercising oversight of the performance of waiver functions by other state and local/regional non-state agencies (if appropriate) and contracted entities.

These assurances mean....

Everyone has an individual plan of care developed by qualified individuals

Must have provider standards, designed by the state and approved by CMS, that make sure the people giving support know what they are doing

Necessary safeguards have been taken to protect the health and welfare

Waiver Assurances

- And those six “basic” assurances come with about 17 “sub-assurances”
- States must develop data collection and report information that shows compliance with all these assurances
- Demonstrating compliance with these assurances is required
- If states do not meet an 85% threshold of compliance, CMS will institute a plan of correction

More things the state MUST do:

Freedom of choice of providers. This means people can choose any provider they want that is qualified under state rules, to do the work.

Portability of funding. Medicaid money “follows the person”, i.e. the benefit “belongs” to the individual, not the provider

Informed choice of institutional or community-based services.

More things the state MUST do:

Financial accountability for all funds. This means the state has to know how the money is spent, for what people and what services.

State has a formal system to monitor health and safety.
Monitoring health and safety includes:

- State oversight of the service system and providers through visits to consumers and providers
- Getting information from waiver participants about how they like their services
- A formal system to prevent, report and resolve instances of abuse or neglect

More things the state MUST do:

- Operate the waiver statewide unless the state has special permission to only have the waiver in some areas.
- Make sure everyone on the waiver can generally get the same types of services all over the state—called access to service.

More things the state MUST do:

- Make sure that people with the same type of needs get the same amount of money to spend on services—called equity of services.

And the biggest "haveta" of all...

States MUST do what they said they were going to do in the waiver application approved.. (but that doesn’t mean the waiver can’t be changed as things change)

Although the waiver has rules, within those rules it’s up to the state and stakeholders to decide......

- The values that underlie your system
- Whom you want to serve
- How many people you can serve
- The processes used to develop individual support plans
- What supports & services you cover
- Who can provide those services
- What you pay for the services, and
- How health, safety and quality are determined

And there is another kind of waiver states can use

- The 1115 Research and demonstration waivers
- These are programs that get special approval from the Federal government
- States can experiment with different ways to manage Medicaid funds such as:
  -Managed care
  - Making new populations eligible
  - Covering “non-typical” services

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What about New Jersey?

- You use the 1115 authority to offer managed care programs such as:
  - Pilot programs for children with dual diagnosis and ASD
  - Behavioral health
  - "Regular" health care
- And the 1115 authority for your Comprehensive Medicaid Waiver and your Supports Program

The New Medicaid HCBS State Plan Options

- 1915(i) State plan - Home and Community Based Services (16 states)
  - May define and limit target groups
  - HCBS for people who require less than institutional level of care as well as those who do
- 1915(k) State plan - Community First Choice Option (CA, MD, OR)
  - No targeting of populations – must provide to everyone in need of the service state wide
  - Consumer controlled, community based attendant care services – broadly defined
  - Community income rules for medically needy populations
  - 6% increase in Medicaid reimbursement
- 1915(j) State plan - Self-Directed Personal Assistance Services (9 states including NJ)
  - May define and limit target groups
  - Fully participant directed personal care for people who qualify for State Plan Personal Care
  - Can give cash to participants

1915(i) State plan HCBS

- Effective January 1, 2007, Revised October 1, 2010
- States can amend their state plans to offer HCBS as a state plan optional benefit.
- May have multiple 1915(i) State plan amendments (iSPAs)
- Breaks the “eligibility link” between HCBS and institutional care

Financial Eligibility Criteria 1915(i)

1915(c)
- Must be eligible for institutional Level of Care (LOC) under state plan
- Any eligibility group included in State plan
- Post eligibility for those eligible using institutional rules (e.g., special income level group).

1915(i)
- 150% of FPL
- Can serve medically needy
- Can use institutional deeming rules for individuals who meet institutional LOC
- Post eligibility for those eligible using institutional rules (e.g., special income level group).

Program Eligibility 1915(i)

1915(c)
- Must target by LOC
- Can include multiple LOC groups in one waiver
- May additionally target by participant characteristics
  - Disease or condition
  - Diagnosis
  - Age

1915(i)
- Can target by diagnosis, age, disease or condition
- Can include multiple groups
- However, state establishes functional "needs-based" criteria specific to the general program eligibility and/or to individual services if desired
Institutional Care Requirements

1915(c)
- Must have eligibility criteria at least as stringent as the institutions.
- LOC must be: equal to or greater than institution but not less than institution

1915(i)
- Needs based, not tied to institutional
- But, institutional criteria must be more stringent.
- Needs-based eligibility criteria must be: less than institution

Program Eligibility

1915(c)
- Can cap the numbers served
- May have a waiting list
- Can cap individual expenditures

1915(i)
- Cannot cap the numbers served or individual expenditure
- All eligibles are entitled to the program
- May NOT have a waiting list
- Eligibility assessment must be independent

A lot is similar with 1915(i) and (c)
- Can target specific individuals
- Individualized assessment and planning
- Self-directed services permitted
- Allowable services are the same (statutory and other)
- Can waive comparability i.e., can target to specific individuals by age, diagnosis or condition
- May have multiple programs
- Must address conflict of interest
- Quality management requirements

And some things under 1915(i) are quite different
- Cannot cap the numbers served
- Cannot cap the individual costs
- Do not have to meet institutional LOC
- Cannot waive statewideness
- Only individuals with 150% FPL eligible (with some exceptions)
- Approval not time limited (unless targeting)
- No cost neutrality
- Requires an independent evaluation for needs-based eligibility
- Requires independent assessment for service planning

Examples of Approved 1915(i) SPAs
- Idaho: Children with developmental disabilities
- Iowa: Adult mental health population
- Washington: Acute or Chronic health needs; ADL and/or IADL deficits
- Colorado: Health risk or Chronic condition; assistance with one ADL
- Nevada: Meet two of the following:
  - the inability to perform 2 or more ADLs; the need for significant assistance to perform ADLs; risk of harm; the need for supervision; functional deficits secondary to cognitive and/or behavioral impairments
- Wisconsin: mental health
- Oregon: Mental health
- Louisiana: Mental health population over 21

1915(k): Community First Choice
Incentivizing Home and Community-Based Services

- CFC, Section 1915(k) of the Social Security Act establishes a new State plan option to provide home and community-based attendant care services and supports
- CFC provides for a perpetual 6 percentage point increase in Federal medical assistance percentage (FMAP) for these services
- Final rule issued May 7, 2012
1915(k): CFC

- CFC is a State plan amendment, NOT a waiver
  - California has an approved CFC State plan amendment (SPA) and at least two other states are in progress
- States apply using a draft preprint obtained from CMS Regional Offices
- Because CFC is a State plan amendment, it is an entitlement to all those eligible
- Services must be provided on a statewide basis
- Cannot cap the number served

Special CFC Requirement:
Self-direction

- CFC requires that states allow for the provision of services to be self-directed under either:
  - An agency-provider model,
  - A self-directed model with service budget, or
  - Other service delivery model defined by the State and approved by the Secretary

Program Eligibility Criteria

- Like the HCBS waiver, CFC requires that any individual served under the option must meet an institutional level of care (LOC)
- The individual of course must have an assessed need for the covered services, as with any of these HCBS options

Allowable Medicaid Eligibility Groups Under CFC

- Individuals eligible for Medicaid under the State plan up to 150% of Federal Poverty Level (FPL)
- Individuals who are eligible using the institutional deeming rules must be enrolled in a 1915(c) HCBS waiver and receive at least one service per month
- At State discretion as to whether CFC will be provided to individuals who meet Medicaid eligibility under the medically needy provisions

Other Eligibility Criteria

- Under CFC states cannot target the benefit
  - CFC, unlike 1915(i) and 1915(c), does not allow a state to limit the benefit to a particular group defined by age, diagnosis or condition
  - CFC must be available to all individuals who meet LOC and have an assessed need for the services—thus it is an entitlement if the individual meets all other criteria
  - Individuals are NOT precluded from receiving other Medicaid services including State plan, waiver, demonstration and grant services

Supports and Services under CFC:
Overarching Requirements

Services must be provided:
- In the most integrated setting appropriate to the individual’s needs, and
- Without regard to the individual’s age, type or nature of disability, severity of disability, or the form of home and community-based attendant services and supports that the individual requires in order to lead an independent life
Allowable Services: **MUST** Cover

- Assistance w/ ADLs, IADLs, & health related tasks.
- Acquisition, maintenance and enhancement of skills necessary for individual to accomplish ADLs, IADLs, and health-related tasks.
- Back-up systems or mechanisms to ensure continuity of services and supports.
- Some type of self-directed option including voluntary training on how to select, manage and dismiss staff (support for self-directed services).

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Allowable Services: **MAY** Cover

- May cover supports on a 24/7 basis
- May occur in provider controlled settings
- Expenditures relating to a need identified in an individual’s person-centered plan that increases his/her independence or substitutes for human assistance to the extent the expenditures would otherwise be made for the human assistance

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Excluded Services

- Assistive devices and assistive technology services
- Medical supplies and medical equipment, other than those that meet the requirements, and,
- Home modifications

***UNLESS these services/items increase independence, substitute for human assistance or are back-up systems to ensure continuity of services***

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Support System

- States must assure that individuals have the information, training, skills and supports they need to participate in CFC and must provide for:
  - Person-centered planning
  - Information on the range of options and choices
  - Information on grievance process and appeal rights
  - Freedom of choice of providers and service models
Approved CFCs

- California: basically attendant care services
- Oregon: VERY comprehensive including 24/7 residential services. Oregon has moved most of their residential services system including individuals with I/DD to CFC
- Maryland: personal care plus some assistive devices, transportation

NEW HCBS rules: The big deal stuff

- HCB Settings Character
  - What is NOT community
  - What is likely not community
  - What is community
- Person-centered planning
  - Codifies requirements
- Conflict-free case management
  - Was just in guidance, now it is in rule:
    - https://www.federalregister.gov/r/0938-A053

Before we define HCB Settings character...

- Settings that are NOT Home and Community-based:
  - Nursing facility
  - Institution for mental diseases (IMD)
  - Intermediate care facility for individuals with intellectual disabilities (ICF/IID)
  - Hospital

Settings PRESUMED not to Be Home And Community-based

- Settings in a publicly or privately-owned facility providing inpatient treatment
- Settings on grounds of, or adjacent to, a public institution
- Settings with the effect of isolating individuals from the broader community of individuals not receiving Medicaid HCBS

Settings that isolate

- The setting is designed specifically for people with disabilities, and often even for people with a certain type of disability.
- The individuals in the setting are primarily or exclusively people with disabilities and on-site staff provides many services to them.
- The setting is designed to provide people with disabilities multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities.

Settings that isolate...

- People in the setting have limited, if any, interaction with the broader community.
- Settings that use/authorize interventions/restrictions that are used in institutional settings or are deemed unacceptable in Medicaid institutional settings (e.g. seclusion).

Source: CMS guidance: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf
Examples of settings that isolate (from CMS guidance)

- Farmstead or disability-specific farm community
- Gated/secured "community" for people with disabilities
- Residential schools
- Multiple settings co-located and operationally related (i.e., operated and controlled by the same provider) that congregate a large number of people with disabilities together and provide for significant shared programming and staff

HCBS setting requirements

- 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 home and community-based services
- The setting 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

HCB setting requirements

- Ensures an individual’s rights of privacy, dignity, 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

Not Just Residential

- Be aware this is not just residential…the HCBS settings requirements apply to ALL HCB settings including day and pre-vocational programs....
- CMS noted in the comments:...
  - "To the extent that the services described are provided under 1915(i) or 1915(k) (for example, residential, day, or other), they must be delivered in settings that meet the HCB setting requirements as set forth in this rule. We will provide further guidance regarding applying the regulations to non-residential HCB settings."

Coming into compliance

- CMS has termed coming into compliance with the HCB settings requirements "Transition”.
- States will have to provide a transition plan, “detailing any actions necessary to achieve or document compliance with setting requirements”
- What states have to do—and how quickly—depends on the timing of new waivers, amendments and renewals
- You are already working on the transition plan

Person-centered planning**

- The person-centered planning process is driven by the individual
- Includes people chosen by the individual
- Offers choices to the individual regarding services and supports the individual receives and from whom
- Provides method to request updates

**Language taken directly from the new rules.
Person-centered planning

- Conducted to reflect what is important to the individual to ensure delivery of services in a manner reflecting personal preferences and ensuring health and welfare
- Identifies the strengths, preferences, needs (clinical and support), and desired outcomes of the individual
- May include whether and what services are self-directed

Written Plan Reflects

- Setting is chosen by the individual and is integrated in, and supports full access to the greater community
- Opportunities to seek employment and work in competitive integrated settings
- Opportunity to engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS

Case Management and Conflict of Interest

- “Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the person-centered service plan,

- [Providers may be allowed if] the State demonstrates that the only willing and qualified entity to provide case management and/or develop person-centered service plans in a geographic area also provides HCBS.

- In these cases, the State must devise conflict of interest protections ...which must be approved by CMS. Individuals must be provided with a clear and accessible alternative dispute resolution process.”

42 CFR §441.301

The new rules...

- Give us a LOT to think about
- Probably a LOT to do
- But the rules can potentially represent an incredible opportunity to bring our supports and services closer to what we aspire to in our system values and vision statements....

Trends Affecting HCBS

NAVIGATING A CHANGING LANDSCAPE

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<th>Year</th>
<th>Residential Capacity</th>
<th>Growth Needed</th>
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<td>2011</td>
<td>76,677</td>
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<tr>
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<td>80,047</td>
<td>14.4%</td>
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<tr>
<td>2013</td>
<td>84,000</td>
<td>15.2%</td>
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<tr>
<td>2014</td>
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Workforce will not keep pace with demand

Of everyone with I/DD in the US
89% of People with I/DD are Supported by Family

Persons with I/DD Receiving Services While Living with Family Members as a Percentage of All Persons with I/DD Receiving Services

Many families we are serving are living in poverty

So...Given the challenges of

- Limited growth in budgets
- Growing waiting lists
- Limited increases in state staff, and
- The move to managed health care in the general and Medicaid...

States are looking to managed care approaches for HCBS as a well

Managed LTSS Care in I/DD
Managed Care for individuals with I/DD

- Significant changes to existing systems
  - Case management to care coordination
  - Full freedom of choices to choice within networks
  - Potentially moving from a public system to a contracted, privately managed system (in many instances)
- And some good opportunities...
  - Full entitlement—No waiting lists for some states
  - Opportunity to make positive re-design changes in supports and services like employment and shared living or adding health services like adult dental care and eyeglasses

And what else might all these trends and new rules mean?

- We need to build sustainable supports and services through:
  - Supporting Families
  - Relationship-based living arrangements
  - Focusing on employment

Remember...Of everyone with I/DD in the US
89% of People with I/DD are Supported by Family

39 % of all adult Americans (two out of every five) are caring for a loved one who is sick or has a disability, which is an increase from 30 percent in 2010.

- Elderly
- Children with special needs
- Veterans

It is not just women doing the caregiving.

- Men are now almost as likely to say they are family caregivers as women are (37 percent of men; 40 percent of women).
- 36 percent of younger Americans between ages 18 and 29 are family caregivers as well.
- Almost half of family caregivers perform complex medical/nursing tasks for their loved ones — such as managing multiple medications, providing wound care, and operating specialized medical equipment.

The Question Is.....

Not whether people who are aging and/or disabled will be living with and relying on their families for support but...... whether they and their families will struggle alone or have a great life because the supports are there for them and they are part of their community.

How states are Building Sustainable Models
The idea is to nudge a system to be person-centered, to support families, and involve people in their community.

**Nudging the System**

John Agosta HRSI

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**Focusing on Relationship Based Living Options**

- Living with Mom and Dad
- Living with siblings
- Living with other relatives
- Living with Friends
- Living with a partner
- Supported Living – supports provided in the person's own home
- Shared Living – the person matched to live with another

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**Relationship Based Living Arrangements**

- Nuclear Family
- Aunts & Uncles
- Siblings
- Cousins
- And a Job

It doesn’t matter with whom people live, the supports should match what they need to have a good life.

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**What shared living is NOT**

- Shared Living is not place or a “placement”
- It is not a “facility,” or a group home
- It is not traditional foster care or a bed in a boarding home
- Shared living is not a “setting” serving three or four individuals
- Shared Living is not a supported setting with multiple “come-in” staff
- It is not just “rebranding” old models...

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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.
Things can be great and things can go wrong... It's Life! But if it works well when we:

Have expectations for outcomes for the person - everything starts with the individual plan

Provide support/supervision that honors the person and supports the care givers

Establish rules about which and how many family members can be paid

"Prenuptial agreement"... decide what reasons would result in termination of the arrangement

MORE THAN JUST SERVICES...

A vision for supporting individuals & families

Families: will be supported in ways that maximizes their capacity, strengths and unique abilities so they can best support, nurture, love and facilitate....

Birth - Early Child - School - Transition - Adulthood - Aging

Rethinking Supporting Families

Discovery & Navigation: Knowledge & Skills
Connecting & Networking: Mental Health & Self-Efficacy
Goods & Services: Employment supports

- Information on disability
- Knowledge about best practices and values
- Knowledge of what questions to ask and how to formulate a vision for the future
- Skills to navigate and access services
- Ability to advocate for services and policy change

- Parent-to-Parent Support
- Self-Advocacy Organizations
- Family Organizations
- Sib-shops
- Support Groups
- Professional Counseling
- Non-disability community support

- Self/Family-Directed services
- Transportation
- Respite/Chilcare
- Adaptive equipment
- Home modifications
- Financial assistance
- Cash Subsidies
- Short/Long-term planning
- Caregiver supports & training

State Efforts to Support Families

Connecticut
- Two full-time people in Central office to focus on systems change to support families
- Changing eligibility process to be more family friendly
- Cross department life span team
- Creating a family friendly network

District of Columbia
- Creating waivers to support families
- Policy to add families and self-advocates to policy teams, pay stipends, and putting that in legislation
- Legislation to create a family advisory council across all DC programs with appointment by the mayor with includes grants to support it
- Regulation changes to allow families to be paid as direct support in all services
- Creating Parent to Parent Network

Massachusetts
- g+ family centers provide information and navigation assistance
- Specialized programs for families with severely medically involved kids...intense case management
- Autism family support centers
- Family Leadership Training
- Annual conference with families
State Efforts to Support Families

Tennessee
- Redesigning the process for the first point of contact
- Creating Parent to Parent Network

Washington
- Redesigning the process for the first point of contact
- Blue Ribbon Plans for the waiting list is using the three domains of support to design the response to families

Oklahoma
- Retraining intake staff
- Blue Ribbon Pane for the waiting list is using the three domains of support to design the response to families

Missouri
- States lead an 12 Regional TA positions for systems change efforts to support families
- Partnerships for Hope Waiver focuses on employment and supports to families
- Quality Outcomes redesigned to align with live domains

Why Work?

What do people do during the day?

Plans Don’t Match People’s Desire to Work

Focusing on Employment
Focusing on employment

- Make a contribution to the community
- Positive image and valued role within the family and community
- Opportunities for learning and expanding relationships
- And, oh, by the way...deal with the new CMS requirements

Think for the Long Term About Cost - Employment

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>1 yr. Cost</th>
<th>3 yr. Cost</th>
<th>10 yr. Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sheltered Work/Day Habilitation</td>
<td>$20,000</td>
<td>$60,000</td>
<td>$200,000</td>
</tr>
<tr>
<td>Employment Services</td>
<td>$20,000</td>
<td>$60,000</td>
<td>$120,000</td>
</tr>
<tr>
<td></td>
<td>$20,000</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>$10,000</td>
<td>$10,000</td>
<td></td>
</tr>
</tbody>
</table>

Estimated figures - use your own figures and do the math

So...where do all these trends lead us?

- To assuring we support families
- To offering flexible and thoughtful ways for people to establish mutual relationships with those who provide support
- To making employment options a priority for all individuals with I/DD
- To a real life as a full member of the community

Resources

- Paper on "Medicaid Managed Care for People with Disabilities: NCD_ManagedCare_Mar4FINAL108.pdf"
- National Core Indicators: www.nationalcoreindicators.org
- Medicaid:
  - HCBS rules: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html
  - Information on HCBS waivers: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers_faqed.html
- Supporting Families: http://www.nasddds.org/resourcelibrary/supporting-families/
Resources

- Shared living programs:
  - Arizona:
  - Pennsylvania:
    [http://www.dpw.state.pa.us/cg/groups/webcontent/documents/communication/p_0447pdf.pdf](http://www.dpw.state.pa.us/cg/groups/webcontent/documents/communication/p_0447pdf.pdf)
  - Shared Living Guide:

- Employment:
  - State Employment Leadership Network:
    [www.seln.org](http://www.seln.org)
  - State Data: National Report on Employment Services and Outcomes:
    [http://www.statedata.info/statedatabook/](http://www.statedata.info/statedatabook/)

Secret Acronym Key

- ADLs: Activities of daily living
- ASD: Autism Spectrum Disorder
- CMS: Centers for Medicare and Medicaid
- CFC: Community First Choice (1915(k))
- EPSDT: Early Periodic Screening, Diagnosis and Treatment
- FFP: Federal Financial Participation
- FMAP: Federal Medical Assistance Percentage
- FPL: Federal Poverty Level
- HCBS: Home & community based services
- IADLs: Instrumental activities of daily living
- I/DD: Intellectual and Developmental Disabilities
- LOC: Level of Care
- SPA: State plan amendment
- 1115: Research and demonstration waiver
- 1915(c): Home and community-based services waiver
- 1915(i): State plan home and community-based services
- 1915(j): State plan self-directed personal care
- 1915(k): CPC-state plan attendant care—6% increase in FMAP
Resources

Prepared by Robin Cooper, October 2014

- Paper on "Medicaid Managed Care for People with Disabilities:
  NCD_ManagedCare_Mar4FINAL508.pdf"
- National Core Indicators; www.nationalcoreindicators.org
- Medicaid:
  - HCBS rules:
    http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html
  - Information on HCBS waivers:
    http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers_faceted.html
- Understanding Medicaid Home and Community Services: A Primer, 2010 Edition, HHS, ASPE found at:
- Administration on Intellectual and Developmental Disabilities (AIDD), 2012 — Managed Long-Term Services and Supports Report to the President
- Supporting Families:
  http://www.nasddds.org/resourcelibrary/supporting-families/
- Shared living programs:
  - Arizona:
  - Pennsylvania:
    http://www.dpw.state.pa.us/cs/groups/webcontent/documents/communication/p_014376.pdf
  - Shared Living Guide:
- Employment:
  - State Employment Leadership Network:
    www.seln.org
  - State Data: National Report on Employment Services and Outcomes:
    http://www.statedata.info/statedatabook/