Considerations and Strong in I/DD Practices for Managed Care Services and Supports

Louisiana Office for Citizens with Developmental Disabilities

NASDDDS

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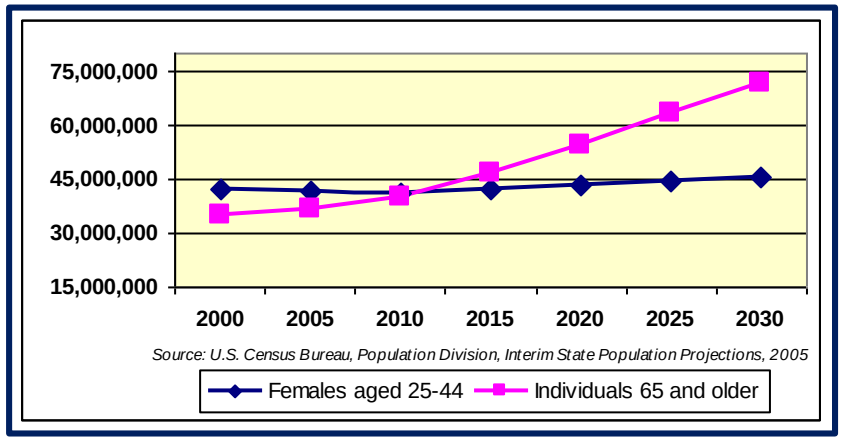
Cost of Long Term Supports - IDD

Type of Service	Cost per Person	20 yrs. Cost	30 yrs. Cost
Institution	$238,500	$4,770,000	$7,155,000
HCBS 24 hr. staffed Residential	$150,000	$3,000,000	$4,500,000
Shared Living Host Home Adult Foster Care	$50,000	$1,000,000	$1,500,000
Support in Own or Family Home	$25,000	$500,000	$750,000

Data Source: Lakin, K.C. MSIS and NCI data from 4 states (1,240 Individuals)

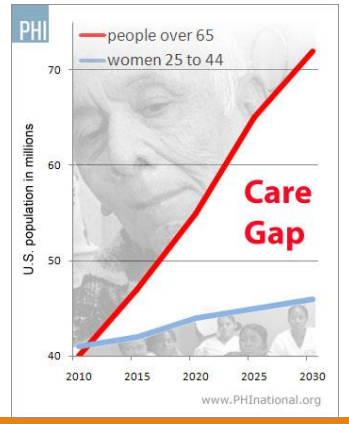
Shortage of Care Givers

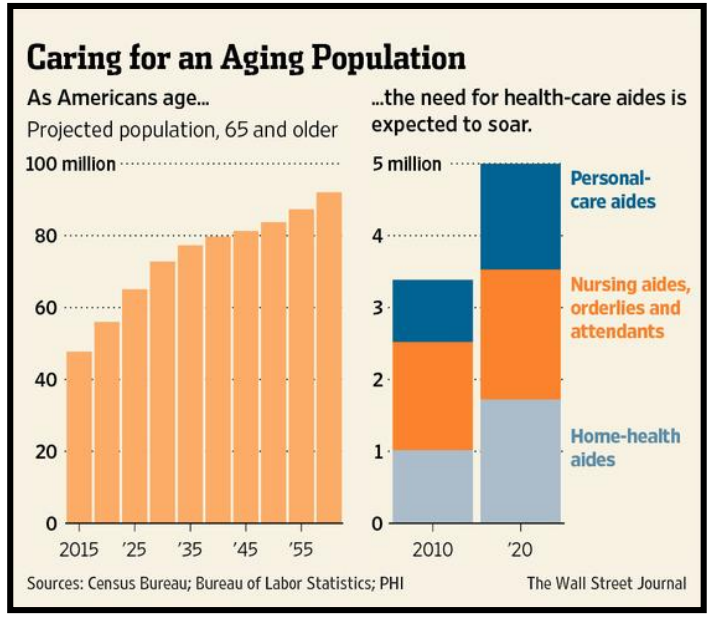


A labor shortage is worsening in one of the nation's fastest-growing occupations—taking care of the elderly and disabled-just as baby boomers head into old age.

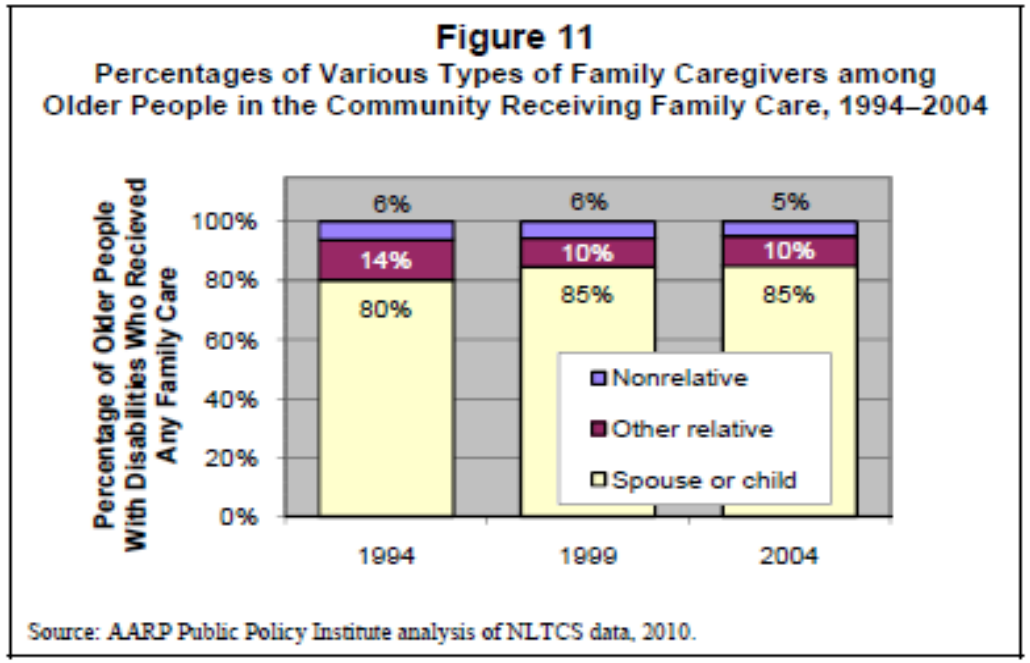
Wall Street Journal
April 15. 2013

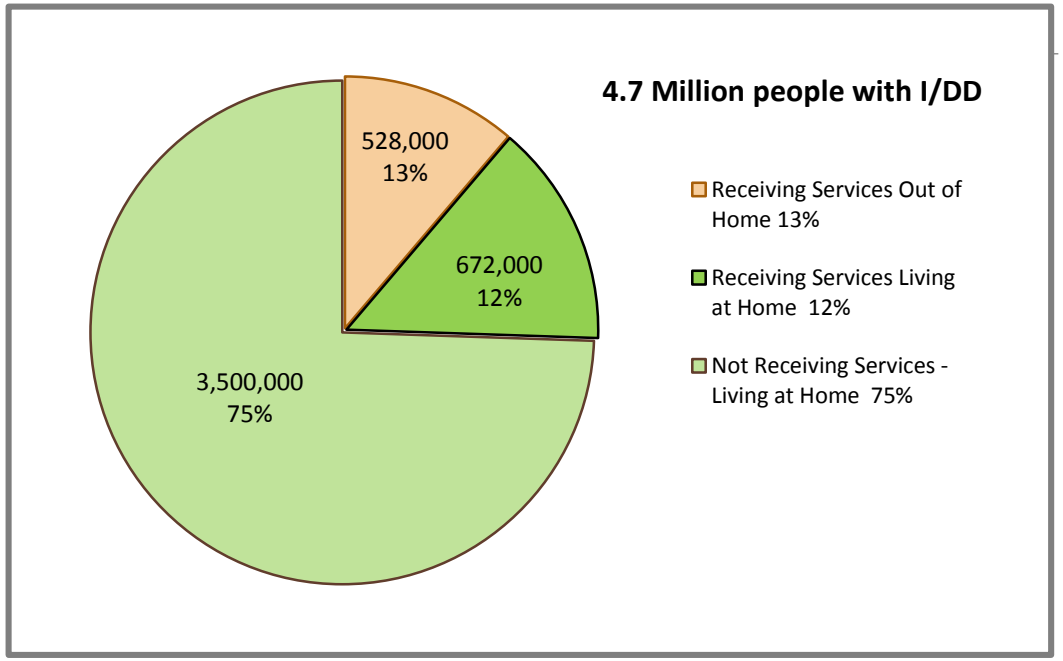
Larson, Edelstein, 2006





Family Caregivers are the Nation's Long Term Care System





85% of older family care recipients receive care from their spouses or children.

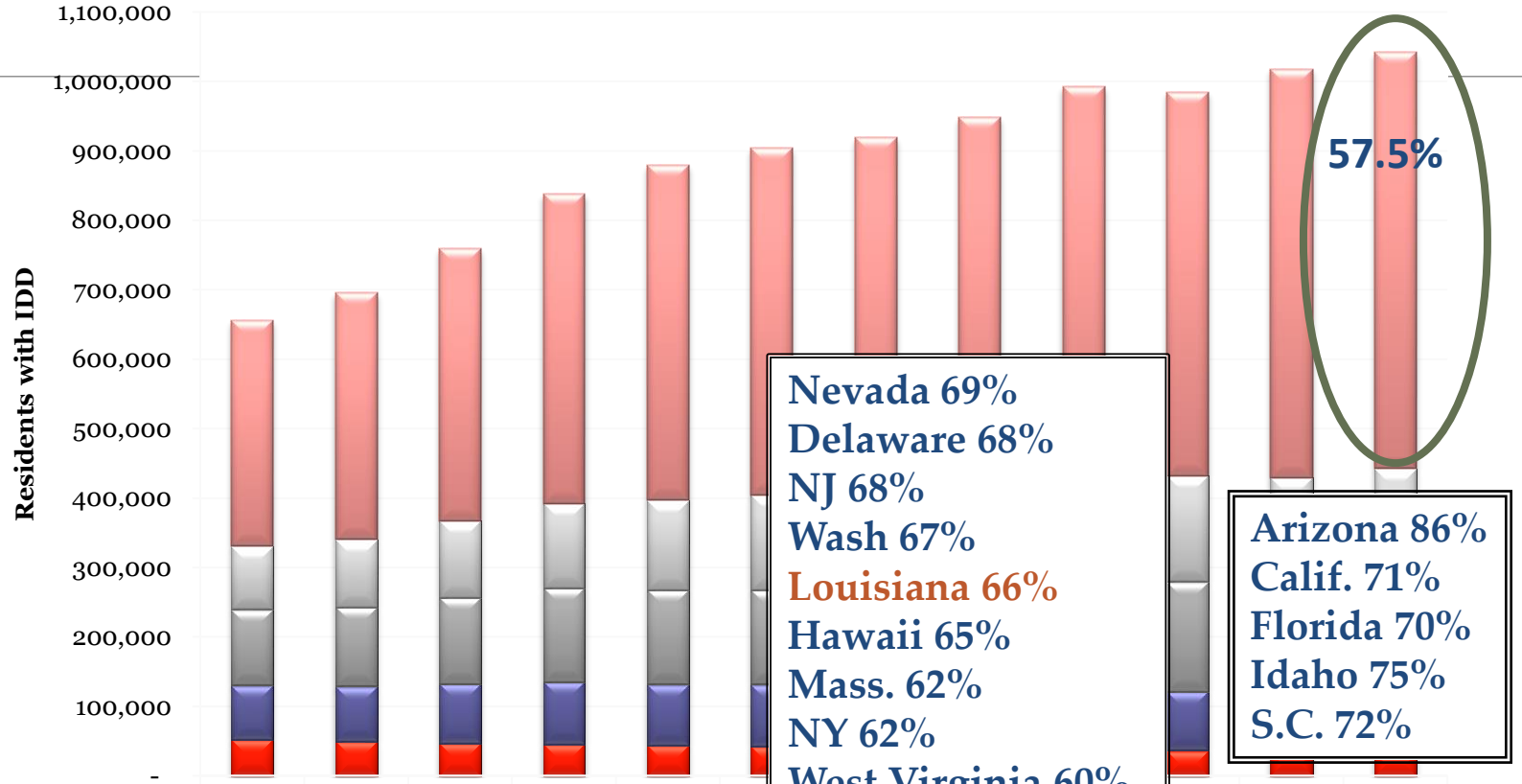
2 of every 5 adults care for a loved one who is sick or disabled.

36% of people 18-29 are caregivers.

89% of People I/DD are Supported by Family

Families as Primary Care Givers

Residence of all IDD Service Recipients 1998 to 2009



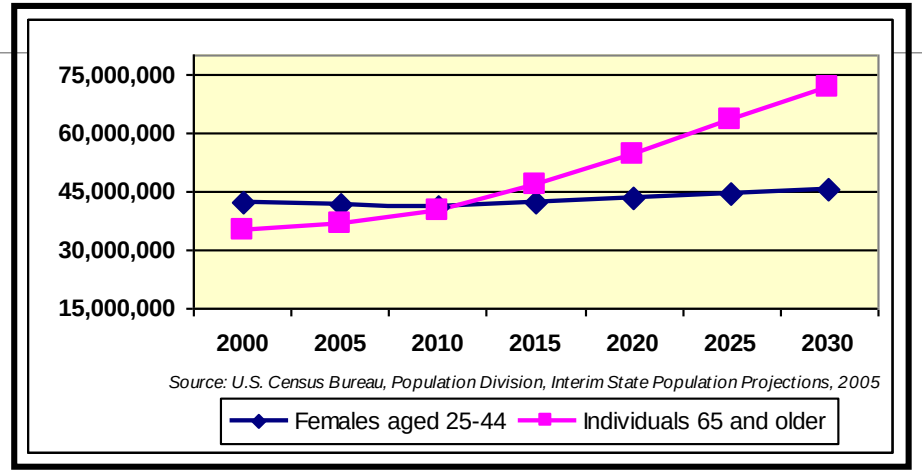
	1998	1999	2000	2001	2002	20				007	2008	2009
Family Home	325,6	355,1	391,8	446,2	482,4	50				52,5	588,5	599,1
Own/Host Home	90,79	96,89	110,5	120,9	128,9	13				52,6	154,1	162,8
1-6 Community	108,8	114,5	124,4	135,3	135,5	135,5	142,9	156,6	157,0	157,7	160,4	158,6
7+ and Nursing Homes	78,08	78,66	85,01	89,50	88,08	89,35	83,67	83,03	88,75	84,93	79,50	88,05
16 + PRF	52,45	50,03	47,32	45,94	44,06	42,83	41,65	39,09	38,17	36,65	35,03	32,90

Year

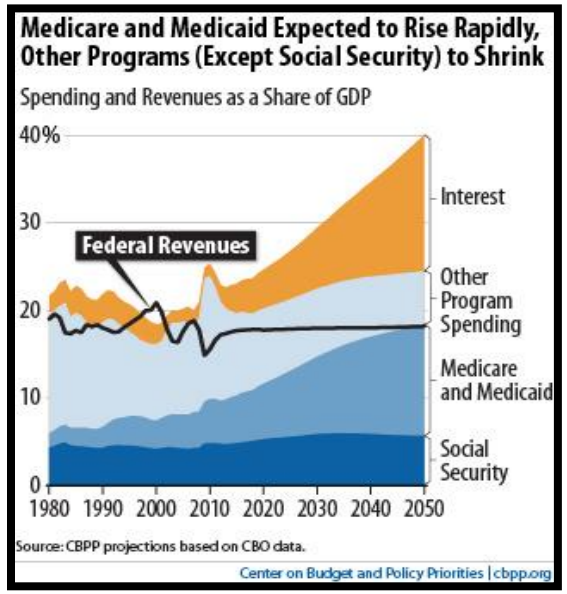
Larsen et.al. RISP 2010 –UMinn.

We are Confronted with Reality

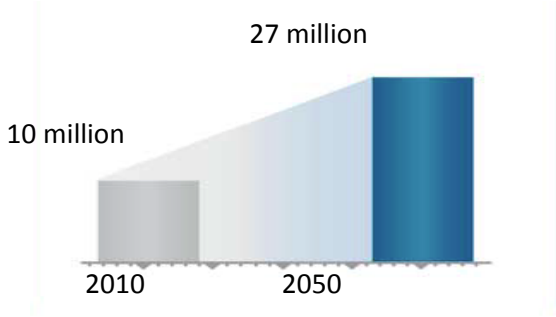
Workforce will not keep pace with demand



Growth in public funding will slow



The Demand for Long Term Supports is Growing



How states are Building Sustainable Models

The Question Is…

Not whether people who have developmental disabilities will be living with and relying on their families for support but…… whether people 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.

- Nancy Thaler, NASDDDS

Top Service Challenges for States in IDD

People with challenging behavior – highest cost individuals

- Criminal offenses adjudicated and non-adjudicated
- Sexual offenders
- Mental health disorders

Waiting Lists

Managing Cost – equity, fairness and reasonableness

Implementing promising practices – person centered practices; positive behavioral approaches; employment; Autism

People with significant medical care needs

One Approach States are Taking is Managed Care- Why?

Can allow states to achieve budget stability over time and assist in predicting costs

Assists in limiting states' financial risk, passing part or all of it on to contractors by paying a single, fixed fee per enrollee

Allows one (or more depending on design) entity to be held accountable for controlling service use *and* providing quality care

Creates the potential to provide services to more people and create flexibility in service provision - if done very carefully and all components in place- and increase community supports

Managed Care- It is not all about long term care

IN ACUTE HEALTH CARE

1 in 5 Americans are enrolled in managed care

70% of Medicaid participants are in managed care

All states except Alaska, Wyoming and New Hampshire (and NH has started roll out) have managed care for Medicaid participants

Managed LTSS Care in I/DD

In Managed Care

Arizona (1115)

Michigan (b/c)

Wisconsin (b/c)

North Carolina (b/c)

Texas – piloting IDD (1115)

Kansas (1115)

New Hampshire * (1115)

New York* (b/c)

* pre-implementation

In Planning Stages

New Jersey (1115) - delayed

Illinois & Florida – legislative exploration

Tennessee adding IDD, concept paper is out

Louisiana for IDD

Who is Managing? Public vs. Private

Public Sector as MCO – I/DD

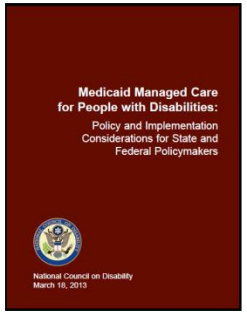
- AZ (for I/DD)
- Michigan (I/DD & BH
- NC (I/DD & BH)
- Wisconsin (A & D; I/DD) – public is an option
- Texas (I/DD)

State government: Arizona
Counties – WI;
Local Managing Entities – NC

Private Sector MCO- profit or non-profit

Kansas (All populations)
Wisconsin (A&D; I/DD)
New Hampshire (A&D; I/DD)
New York (A&D) (I/DD)
Louisiana (All populations)
Illinois (All populations)
Texas (A&D)
Most Behavioral Health and Senior Managed Care programs

National Council on Disability
20 Principles for Managed Care



1. The goal must be to assist individuals with disabilities to **live full, healthy, participatory lives in the community.**

2. Managed care systems must be designed to support and implement **person-centered practices, consumer choice, and consumer-direction.**

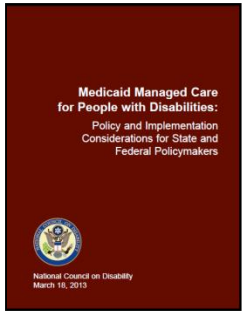
3. Employment is a critical pathway toward independence and community integration. **Enrollees must receive the supports to secure and retain competitive employment.**

4. **Families should receive the assistance** they need to effectively support and advocate on behalf of people with disabilities.

5. **Key disability stakeholders are fully engaged** in designing, implementing and monitoring the outcomes and effectiveness.

http://www.ncd.gov/publications/2013/20130315/

National Council on Disability 20 Principles for Managed Care



6. The service delivery system must be **capable of addressing the diverse needs of all plan enrollees** on an individualized basis.

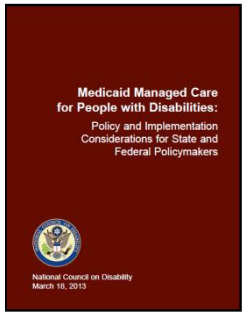
7. **States should complete a readiness assessment** before deciding when and how various sub-groups of people with disabilities should be enrolled.

8. **Each network should have sufficient numbers of qualified providers** in each specialty area to allow participants to choose among alternatives.

9. CMS should require states to include providers of institutional programs as well as providers of home and community-based supports within the plan's scope.

10. **The existing reservoir of disability-specific expertise should be fully engaged** in designing service delivery and financing strategies and in performing key roles within the restructured system.

National Council on Disability
20 Principles for Managed Care Long Term Services and Supports (cont.)



11. **Responsibility for oversight** must be assigned to highly qualified state governmental personnel.

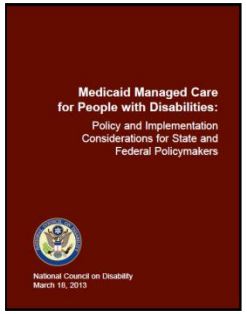
12. The federal government and the states should actively **promote innovation** in long-term services and supports for people with disabilities.

13. Savings achieved through reduced reliance on high-cost institutional care, reductions in unnecessary hospital admissions and improved coordination and delivery of services should be used to **extend services and supports to unserved and underserved individuals with disabilities**.

14. P**rimary and specialty health services must be effectively coordinated with any long-term services and supports.**

15. Participants in managed care plans must have **access to the durable medical equipment and assistive technology** .

National Council on Disability 20 Principles for Managed Care



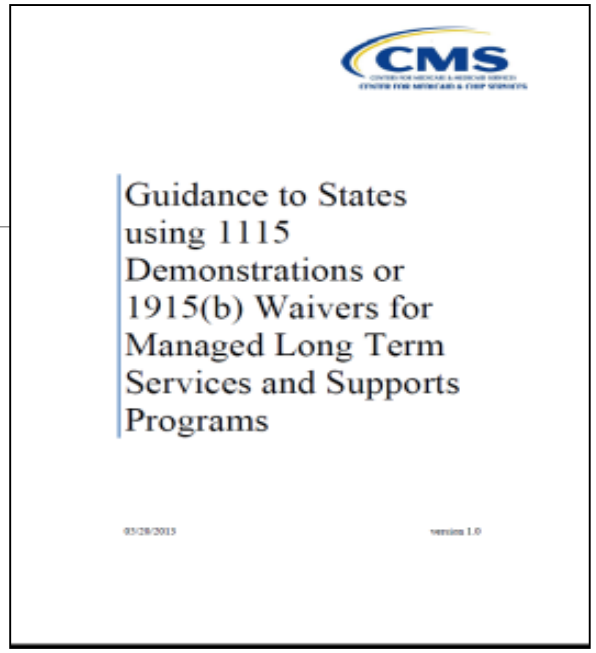
16. The state must have in place a **comprehensive quality management system** that not only ensures the health and safety of vulnerable beneficiaries but also measures the effectiveness of services in assisting individuals to achieve personal goals. 17. All health care services and supports must be furnished in **ADA-compliant settings**.

18. **Enrollees should be permitted to retain existing physicians** and other health practitioners who are willing to adhere to plan rules and payment schedules.

19. **Enrollees should be fully informed of their rights and obligations** under the plan as well as the steps necessary to access needed services.

20. **Grievance and appeal procedures should be established** that take into account physical, intellectual, behavioral and sensory barriers to safeguarding individual rights under the provisions of the managed care plan as well as all applicable federal and state statutes.

CMS Guidance for Managed Care 10 Key Elements


Guidance to States using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Supports Programs

1. Adequate Planning and Transition Strategies
2. Stakeholder Engagement
3. Enhanced Provision of HCBS (ADA/Olmstead)
4. Alignment of Payment Structures with MLTSS Programmatic Goals
5. Support for Beneficiaries
6. Person-centered Processes
7. Comprehensive and Integrated Service Package
8. Qualified Providers
9. Participant Protections/States Oversight
10. Quality

http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/1115-and-1915b-MLTSS-guidance.pdf

CMS Guidance to States Using 1115 Demonstrations or 1915 (b) Waivers for Managed Long Term Services and Supports Programs

The New Center for Medicare and Medicaid Services(CMS) Regulations

IMPLEMENTING HCBS REGULATIONS

- **Peron-Centered Planning**
- **Settings Rule**
- **Conflict Free Case management**

Keep Focused on Core Values in I/DD

Families and people with disabilities play a central role in planning & overseeing the delivery of IDD services

- ✓Families are here for a lifetime- MCOs need to learn about supporting people AND families. Self advocates need to have a meaningful seat at the table, too.

Historic managed care services, focus on medical supports and care management may not align with fundamental IDD support principles without education, contract deliverables, support- help them learn and embed officially

- ✓Use of natural supports
- ✓Emphasis on habilitation
- ✓Emphasis on community integration and in home supports
- ✓Emphasis person centered planning teams and involvement

Intake and Assessment – the First Conversation- What is person centered?

We ask intimate questions- how to make this person centered- not an assessor.

We ask about what is wrong, what the person can't do and need help with- use caution.

We ask other people around them to answer for them.- how to make this person centered- not traditional assessment- I/DD knows how to do this

We ask the same questions over and over- not person centered- build on I/DD best practices.

We don't ask the most important questions:

- Who are you?
- What is important to the you?
- What do you need to have a good day?
- What makes you happy?- this is person centered

Care Planning…. a Conversation that is Person Centered and Leads to Outcomes

What is **important to the person**? People, activities, continuing routines and rituals, possessions, traditions, experiences.

What is **important for the person** to be healthy and safe?

Plan to saturate life with things that the person enjoys, treasures, prefers.

These are best practices in I/DD and can be difficult even in I/DD and tend not to be common practices in MLTSS

Measuring Outcomes –Conversation

Are we doing what is important to the person?

Activities; people; routines; possessions; experiences

Are we doing what is important for the person?

- Is the person healthy and safe?

Is the person happy with life?

This is not to underestimate the importance of health, safety, EHRO, behavior support outcomes- these are additional I/DD considerations- employment, habilitation, consumer experience

NCI System Performance Measures

Individual Outcomes

- Employment
- Community Participation
- Choice & Decision making
- Personal Relationships

Family Outcomes

- Choice and Control
- Family Involvement
- Information & Planning
- Access, community connections

Health, Welfare, System

- Health and Welfare
- Respect for Rights
- Medications
- Safety
- Service Coordination
- Staff Stability

Person-Centered Funding in I/DD

- Fund services that make a difference
- Enable people to have control over how funds are spent and what services they receive
- Allow for the unexpected need - exceptions

IDD and Aging & Disabled are not the Same

Focus

- Seniors – Comfort and quality in remaining years of life
  - Medical and Health Services tend to be large focus
- I/DD - “Getting a Life”, habilitation, community connections, services over the lifespan, support coordination to be connected, health and medical less prevalent, especially in adulthood

Length of Service

- Seniors - 2 to 3 years (or more, we hope!)
- IDD - up to 60 years

MCO Financial Incentives

- Seniors– to provide HCBS to avoid NH costs-and quality of life
- I/DD – Robust Home and Community Based services and supporting families, small settings and employment over the life course.

Readiness Assessment, Planning & Phase-In

Must be clear about what problem is managed care meant to solve? Why are you doing it?

- Assumptions about savings should be tested.

Planning is different for I/DD LTSS than for acute care or other populations. Why?

- It isn't just about enough physicians, psychiatric hospitals or home health agencies …it's about employment services and supports to families.
- There is already a network of service providers known by families, consumers and the DD agency. Keeping continuity and availability of these providers within the new MCO networks will take support and intentional planning.

- Small providers are the most creative and the most at risk - no cash flow or I.T. systems.
- Stakeholders in I/DD are accustomed to have to having a meaningful seat at the table.

Supporting Beneficiaries- Support Coordination

ARIZONA EXAMPLE The case manager must

- Foster a person-centered approach
- Maximize member/family self-determination promote the values of dignity, independence, individuality, privacy and choice.
- Support the member to have a meaningful role in planning and directing their own care to maximum extent possible.
- Facilitate access to non-ALTCS services available throughout the community
- Advocate for the member and/or family/significant others as the need occurs
- Assist members to identify their goals and provide information about local resources that help transition to greater self-sufficiency in the areas of housing, education and work

Case management begins with a respect for the member's preferences, interests, needs, culture, language and belief system

Participant Protections
Rights and Responsibilities

Basic civil, human and Medicaid beneficiary rights

There are more rights and protections standard for people with I/DD:

- Right to most integrated settings
- Fair compensation for labor
- Right to own property
- Freedom from abuse and neglect
- Right to presumptive competency
- Right to be free from excessive medications
- Right to contact Human Rights Committees
- Rights specific to residential services

A Few of the State's Tools

Contract requirements and performance standards

Policies, manuals, clinical practice guidelines

Provider network plan approval and oversight

Performance measurement

Performance Improvement Projects (PIP)

Payment Incentives and Penalties

RFPs that build in I/DD expectations- focused on HCBS and habilitation

Qualified Providers

Basics are certification, licensing, background checks, credentialing (for clinical services), credentialing agencies

MCOs and providers need training in disability specific areas, history and values base, person centered processes, I/DD vs. behavioral health, self direction. Involve people with disabilities and families as trainers

Assure the training of non-certified direct support professionals; establish a core curriculum.

Keep small providers and the rich network of HCBS agencies known in the community

Providers need training in billing, encounters, coding & other insurance based knowledge

Tools to Encourage the Most Integrated Settings

Make integrated services more cost effective - build incentives for community based services in the capitation rate

Make expectations about self determination, community integration, work clear in the contracts

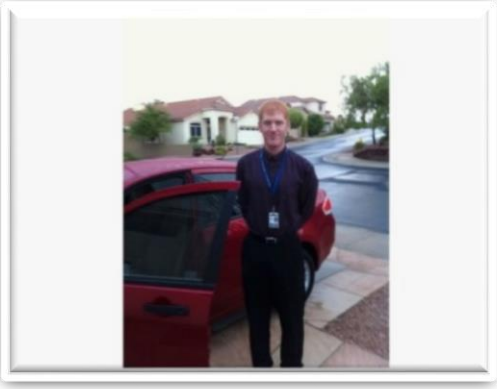
- School to work transition
- Service approvals based on desired outcomes not just the assessment

Use manuals to communicate policies about roles and responsibilities i.e. case management- binding in the contract

Build expectations into provider qualifications

Measure the delivery of services for integration value

- In family homes with support
- In their own homes
- In shared living
- Age appropriate for children and adults
- Employment outcomes
- Integration regardless of medical or behavioral labels
  - People with trachs, g-tubes, suctioning, ventilators, medical frailty
  - People with behavioral reputations; criminal offenders



Acute, Behavioral Health & MLTSS Coordination

Coordination discharge planning, avoiding illness, prevention, supporting wellness, framed around the values of community living. Support Coordinators/case managers need a unique set of skills/understanding– and to keep medical where it is needed, not overpowering LTSS

There are opportunities in LTSS to better coordinate with behavioral/mental health care-polypharmacy, understanding home environment, linking mental health supports for overall support plan- it isn't easy but it is possible!

Won't stop the "hot potato" of "it is someone else's job"– but can reduce it

Effectively Coordinate Acute and Long Term Services

Medical oversight is essential when service need is the result of untreated/ineffectively managed conditions

But most with disabilities need assistance in achieving a productive, rewarding life in the community

Managed care enrollees with complex chronic healthcare conditions need health care coordinators with specialized knowledge and experience

Why Focus on Employment?

- ✓Get out of poverty
- ✓More independence
- ✓Make Friends
- ✓Make a contribution to the community
- ✓Positive image and valued role within the family and community
- ✓Opportunities for learning and expanding relationships

Supporting Family Caregivers

Managed care can expand in-home supports, assist in addressing the waiting list and families can be paid to provide care

Careful planning, network development, including families each step of the way

Depends on program design

Causes of Challenging Behavior

Undiagnosed or untreated mood disorder

Undiagnosed or untreated post traumatic stress

- Sexual abuse >75%
- Exclusion, rejection, bullying and humiliation 100%
- Frustration from awareness of limitations

Undiagnosed or untreated depression

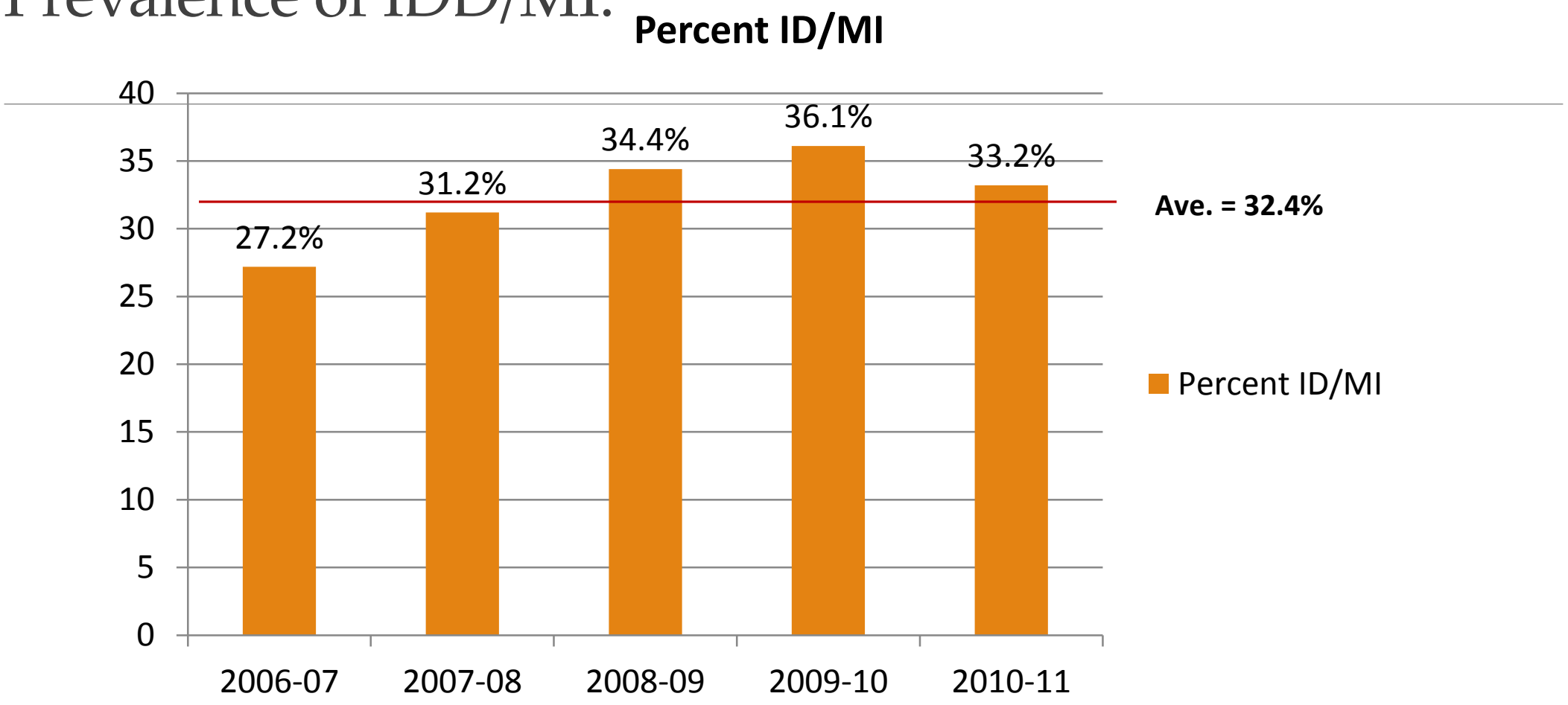
- Biological
- Environmental/social – loneliness

No knowledge of neurological challenges i.e. Autism, Fragile X etc.

Support models and practices that are not person-centered

No awareness of treatment options

Prevalence of IDD/MI:



www.nationalcoreindicators.org

Community Living- Medical Support is Important , But Community is Home

Educating and embedding LTSS as a priority:

- Network Plan
- Contract Deliverables
- Language Matters
- Manuals, Policies, Plans
- Deliverables

Find the sweet spot in the acute medical coordination

- Opportunities for improved discharge planning, DME, hospitalization prevention

Quality Management

Comprehensive QM system must not only ensure health and safety but also measure the effectiveness at achieving individual and system outcomes:

System Capabilities

Person Centeredness

Qualified Personnel

Information Technology

PERFORMANCE MEASUREMENT

Health AND LTSS

Employment (Principle 3)

Employment is a critical pathway toward independence and community integration.

Working age enrollees must receive the supports necessary to secure and retain competitive employment

Improved life outcomes across all domains

Plans must increase access to employment

Christo started working early!

Promising Elements - Louisiana's Approach

- Focus on Strong Stakeholder Engagement

-Building off the Successes in related LA Systems Reforms

-Understanding the Complexities in Supporting People with Co-Occurring I/DD and Mental Illness/Behavioral Health Support Needs and Embedding Strategies to Address these Needs

-Increased Strategic Investment in Home and Community Based Services Part of the LA Approach

Promising Elements - Louisiana's Approach

- Lifespan Approach

-Emphasis on Support Coordination

-Integrated Service and Support Package

-Using a Phase In Approach with Deliberate Steps to Ensure a Strong Foundation for Service Delivery Changes

-Inclusion of Protections for People Receiving Services, such as MCOs Required to Contract with all LTSS Providers the first year and Phase I Planning to Enhance I/DD Protections

Promising Elements - Louisiana's Approach

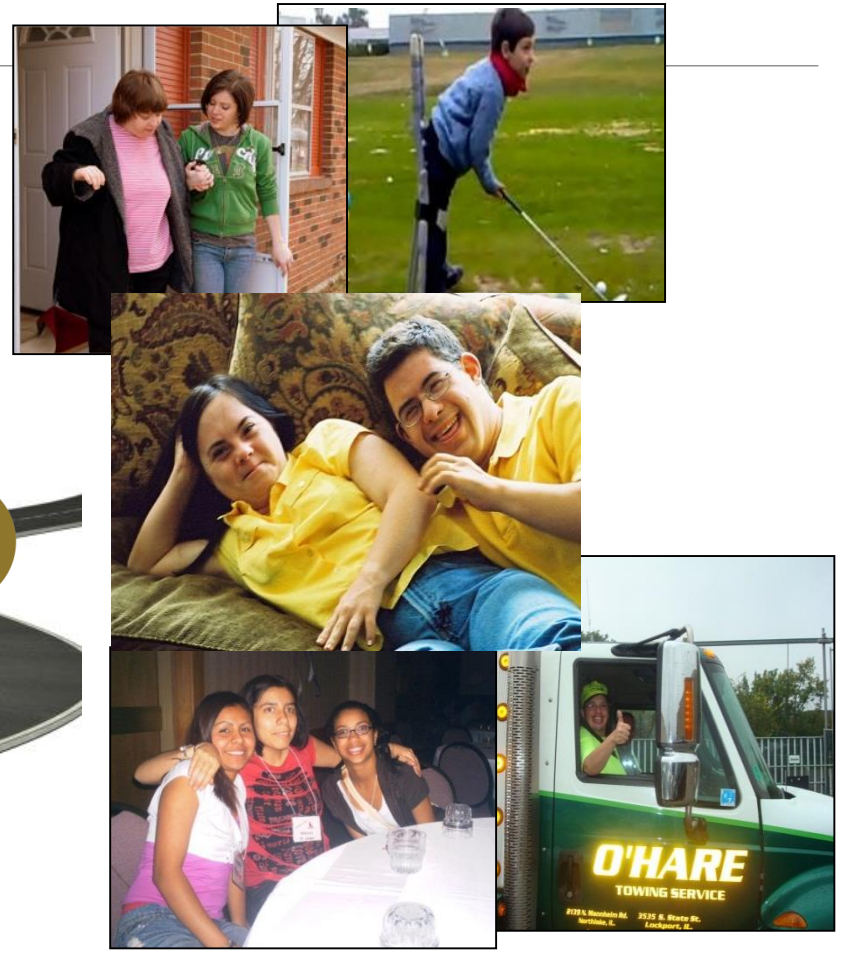
-Emphasis on Innovations

-Emphasis on Employment

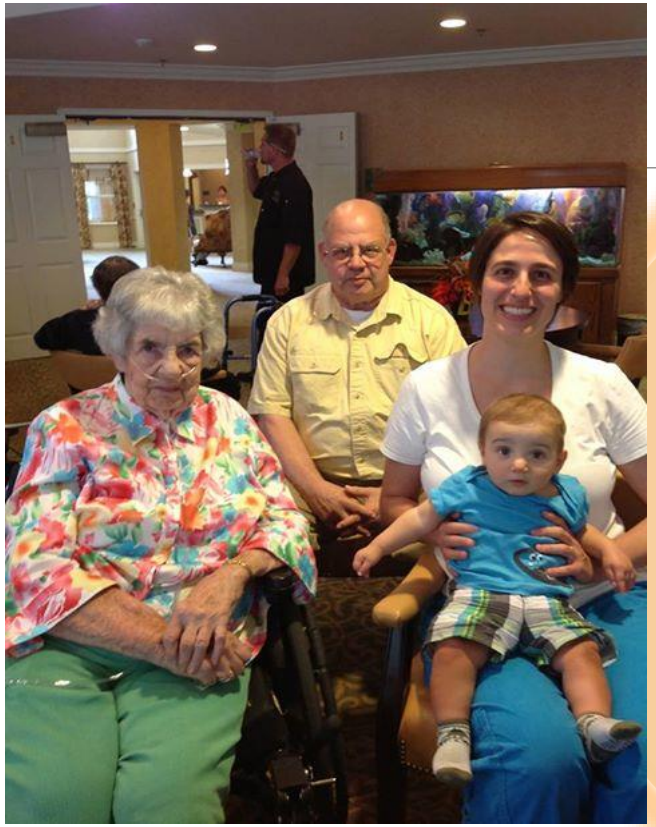
- Quality Management Encompassing Community and Work, While Still Keeping Core EQRO Measures

-Work to Define and Include Strong Outcomes in HCBS, as well as Acute and Behavioral Health

Take a Life Course Perspective



Measuring Progress



Managed care is more than a financing mechanism. Defining quality outcomes for people with I/DD, seeking opportunities for integrating care, and supporting more people and their families in the community, IF DONE WELL and CAREFULLY=
Progress.