

# **Embracing the Challenges of Integrated Care for People with Intellectual and Developmental Disabilities**

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# Systems Change

## CMS Quadruple Aim

- Improving the health of the population
- Enhancing the patient experience of care
- Reducing the cost of care
- Improving the work life of health care providers

## NC DHHS Program Design for Medicaid Managed Care

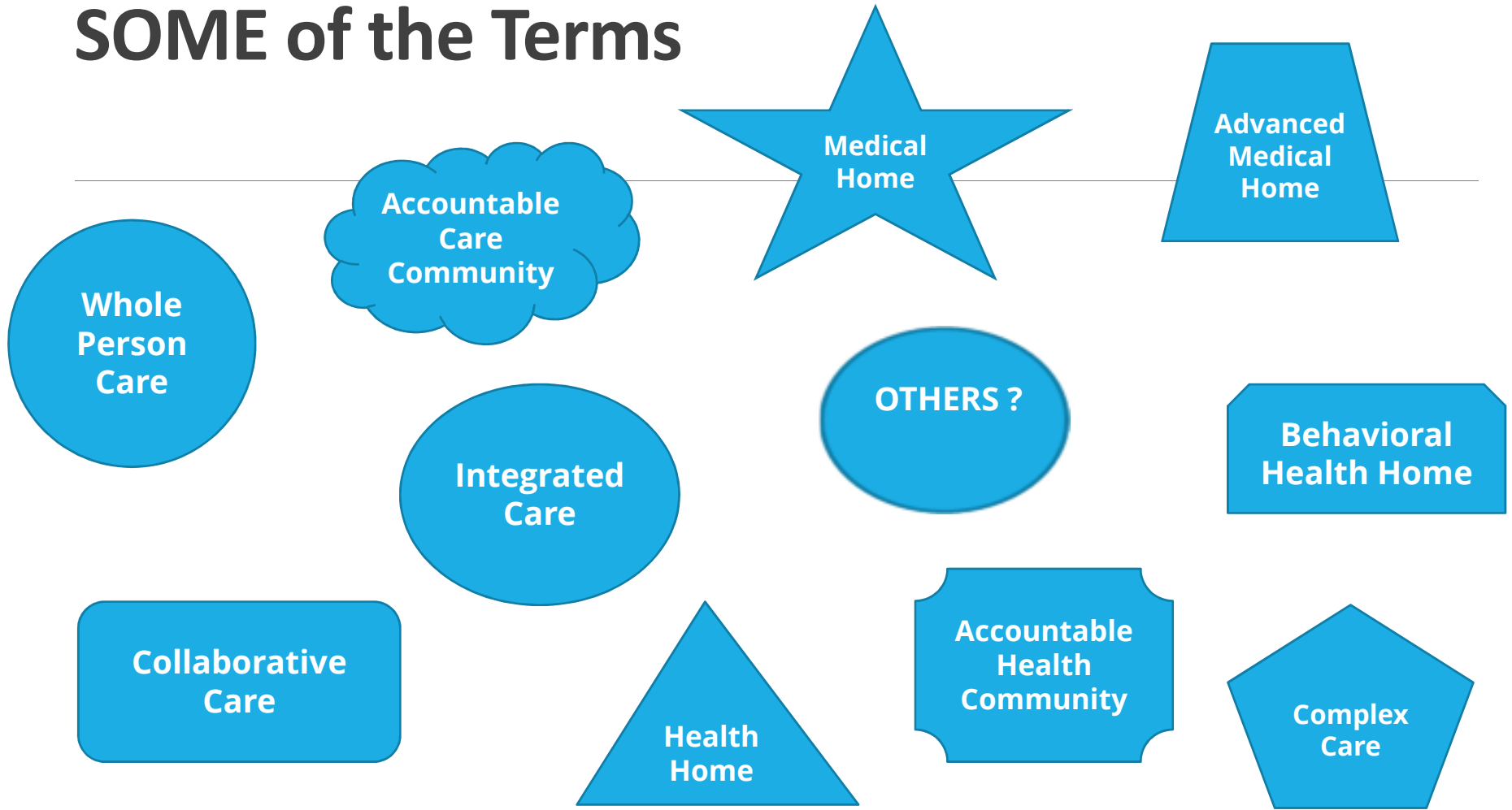
- Advance high-value care
- Improve population health
- Engage and support providers
- Establish a sustainable program with predictable costs



# What Are You Hearing?



# SOME of the Terms



# Terminology Confusion

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Definitions are

- complex and evolving
- mean different things to different audiences

Confusing terms and definitions can lead to:


- misunderstandings
- discounting viewpoint of some stakeholders
- faulty planning and conclusions
- disengagement

# Core Elements Across Multiple Models and “Terms”

Person centered	Relationships
Comprehensive assessment	Integrated plans
Informed and engaged patient	Family Support
Life concerns (Social Determinants of Health)	Care coordination, case management, navigation
Competent providers	Evidence-based
Multi-disciplinary Team	Complex needs
Valued outcomes	Data, decision supports


# Integrated, Collaborative Care is Essential because People with I/DD Experience

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- Complex health conditions and chronic disease
  - Genetic predispositions to certain health conditions
  - Misdiagnosis and diagnostic overshadowing
  - Co-occurring psychiatric conditions and poly-pharmacy
  - Challenges navigating across multiple systems of care
  - Aging with a life-long disability
  - Aging caregivers
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# Evolving Service Delivery Model

(David Johnson)

<b>Moving From</b>		<b>Moving To</b>
Admit/discharge		<b>Engagement and follow-up</b>
Acute—in the moment focus		<b>Long-term, life course</b>
Specific presenting condition		<b>Whole person</b>
Compliance		<b>Support, Adherence</b>
Physician decision-making		<b>Shared decision-making</b>
Passive patient		<b>Active, engaged individual</b>
Episodic documentation		<b>Registries, alerts and reminders</b>
File audits, episodic events		<b>Outcomes—clinical, financial and member</b>
Disease coping		<b>Disease management and health behaviors</b>
Individual provider		<b>Service team</b>
Volume financial model (FFS)		<b>Value financial model (shared risk)</b>



# Perceptions of Health and Healthcare of People With I/DD in Medicaid Managed Care

(Heller)

## Good health is

- absence of pain, disease, and symptoms
- being able to follow treatment or not needing treatment
- physical self-care
- mental or spiritual self-care
- ability to perform the activities one wants to do



## Good healthcare is

- ensuring needs are met through access to services
- timeliness, quality, continuity
- obtaining quality services
- navigating the healthcare system successfully
- receiving humanizing healthcare



# Individual Barriers to Good Health



<b>Barriers</b>	<b>Possible Solutions</b>
Difficulty communicating health concerns	<ul style="list-style-type: none"><li>• Identify concerns; write down prior to appointment</li><li>• Talk about health throughout the year, not just before an appointment</li></ul>
Lack of knowledge of family history	<ul style="list-style-type: none"><li>• Discuss in the annual PCP/ISP meeting</li></ul>
Information not available in formats appropriate for the individual	<ul style="list-style-type: none"><li>• Request longer appointments</li><li>• Ask for information to be available in large print, with visuals or audio</li></ul>
Difficulty understanding medical orders and recommendations	<ul style="list-style-type: none"><li>• Ask doctor to write out instructions and review with patient and family/caregiver.</li></ul>

# Family Barriers and Possible Solutions



<b>Barriers</b>	<b>Possible Solutions</b>
Family attitudes and values	<ul style="list-style-type: none"><li>• Acknowledge family values, use PCP/ISP to gather information</li><li>• Identify family assets and strengths</li></ul>
Lack of resources	<ul style="list-style-type: none"><li>• Identify needs and options</li><li>• Link to community assets</li></ul>
Poor health of family members Caregiver stress	<ul style="list-style-type: none"><li>• Direct family members to health resources, e.g. community health centers, support groups, local organizations (YMCA)</li></ul>
Negative health experiences	<ul style="list-style-type: none"><li>• Discuss health experiences</li><li>• Provide information to “challenge” myths</li></ul>
Limited health literacy	<ul style="list-style-type: none"><li>• Use plain language</li><li>• Ask provider to simplify information</li><li>• Review for comprehension</li></ul>

# System Barriers and Possible Solutions



<b>Barriers</b>	<b>Possible solutions</b>
Inaccessible facilities and medical equipment	<ul style="list-style-type: none"><li>• Identify accessible facilities</li><li>• Talk about accessibility needs prior to appointment</li><li>• Encourage facility to have an accessibility survey conducted</li><li>• Advocate for ADA requirements</li></ul>
Lack of disability education for Health Care Providers	<ul style="list-style-type: none"><li>• Identify providers that have experience working with people with I/DD</li><li>• Share educational resources with provider</li></ul>
Tendency to focus on the “disability” and not overall health	<ul style="list-style-type: none"><li>• Share health concerns and health history during appointment</li><li>• Organize information prior to appointment</li></ul>
Discounting chronic health conditions	<ul style="list-style-type: none"><li>• Know and advocate for age specific screenings</li></ul>



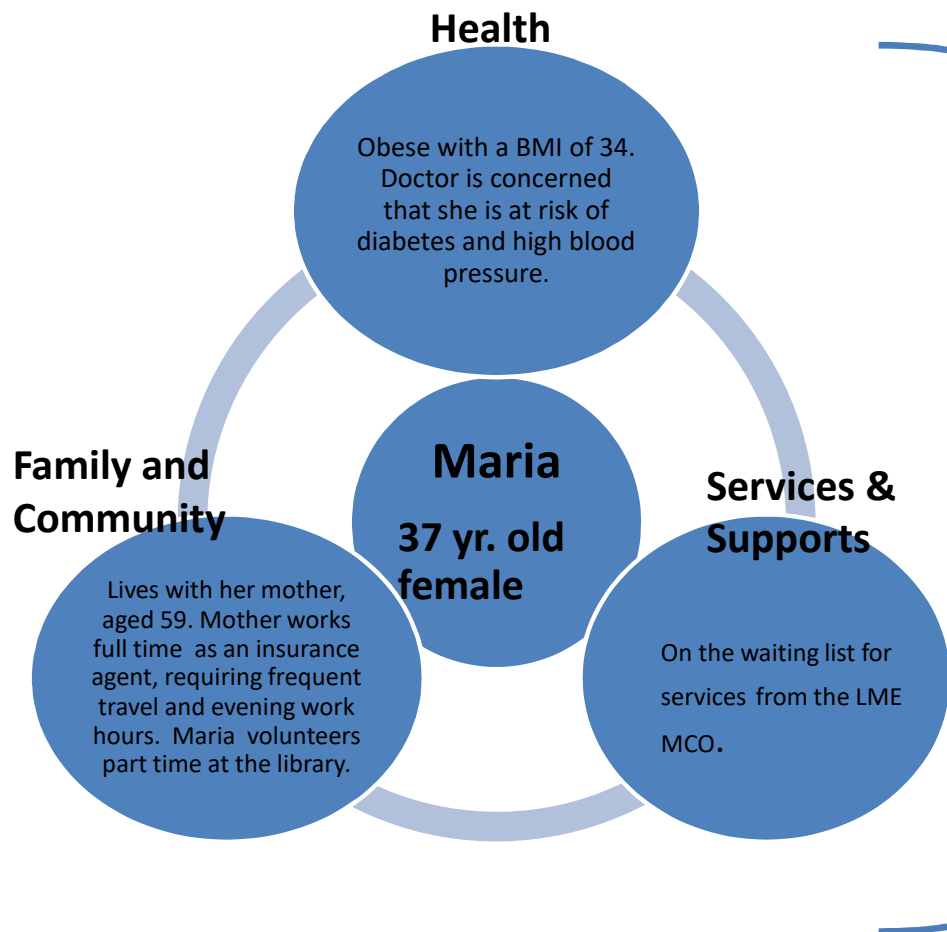
# Getting Started

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- Engaging individuals & families in health, wellness and healthcare: *What matters to you?*
- Conducting comprehensive health assessments on a regular basis
- Providing health education for individuals, families, staff
- Establishing relationships with primary care, specialists, BH, dentists, health educators
- Establishing relationship, agreements, protocols, documents
- Sharing health and disability information with primary care and other providers
- Educating healthcare partners on how to care for individuals with I/DD

*“The annual health check is one of the single most important investments in the primary healthcare of people with I/DD.”* Walmsley 2011

# A Snap Shot of Maria



## Challenges

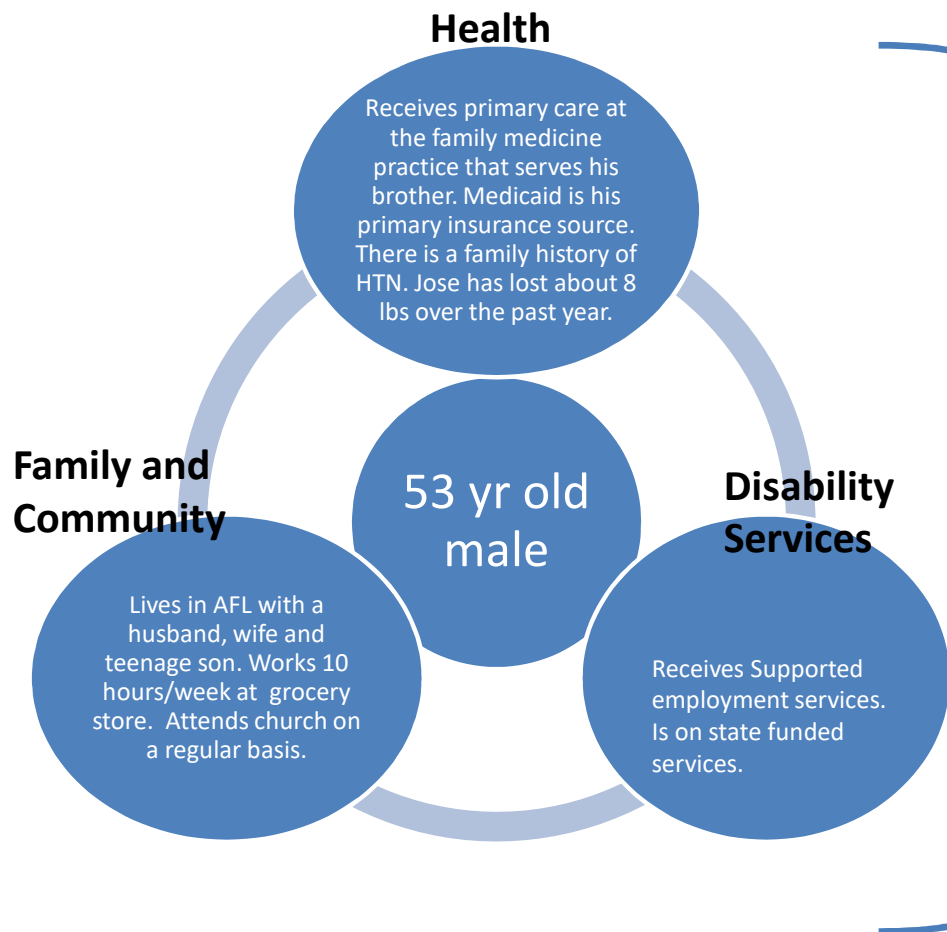
1. Maria is a 37 year old woman with a moderate intellectual disability, history of anxiety. Currently being treated with psychotropic medications.
2. Her weight has been increasing over the past three years. At her last annual physical her BMI was 34.
3. There is a family history of obesity, diabetes, HTN and heart disease. Maria's mother is being treated for diabetes. Her father died of a heart attack five years ago at the age of 62.
4. Maria has experienced anxiety attacks during medical appointments. This has been traumatic for Maria and mother.
5. Mother thinks her daughter is worried and unhappy about her weight. She is not sure how to help Maria lose weight. Maria is often alone at home, has difficulty with cooking healthy meals and sometimes overeats.

# Resources to Consider

- Health Risk Screening Tool
- My Health Passport
- My Health Report
- How Do I Talk to My Doctor
- Today's Visit
- HealthMatters
- Prevent, Understand and Live with Diabetes: a guide for people with DD
- Health Watch Table
- Office Organizational Tips



# A Snap Shot of Jose



1. Jose has not been to the dentist for 4 years. He does not like to brush his teeth.
2. His last dental appointment was very difficult for him, the dentist and staff. Jose has refused to go back.
3. Jose's older brother just completed a course of treatment for severe gum disease.
4. There are a limited number of dentists in their community that accept Medicaid.
5. Jose's Autism makes it difficult for him to communicate when he is in pain.
6. The family physician recently prescribed a new medication to address Jose's hypertension; a potential medication side effect is dry mouth and gum problems.
7. Jose has been eating less, crying during meals, and his clothes are loose.



# Resources to Consider



- Health Risk Screening Tool
- Autism and Health: getting the most out of your health care
- My Health Passport
- My Health Report
- How Do I Talk to My Doctor
- Georgetown University UCEDD Oral Health
- Today's Visit
- Health Watch Table
- Office Organizational Tips

# Resources

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IDD Toolkit: [www.iddtoolkit.org](http://www.iddtoolkit.org)

**Health Services, Video Learning.** General health topics: making the most of medical appointments, provider checklist, caregiver checklist, tools for primary care, behavioral health, seating and positioning, etc. [www.tn.gov/didd/article/health-services-clinical-pearls](http://www.tn.gov/didd/article/health-services-clinical-pearls)

Training for families and other caregivers: [vkc.mc.vanderbilt.edu/healthtraining](http://vkc.mc.vanderbilt.edu/healthtraining)

Health Watch Tables for specific I/DD diagnosis, eg. Autism Spectrum Disorder, Down Syndrome, Prader Willi, Fragile X .

<http://vkc.mc.vanderbilt.edu/etoolkit/physical-health/health-watch-tables-2>

Georgetown University UCEDD Oral Health

<https://ucedd.georgetown.edu/DDA/oral-health.html>

# More Resources

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University of South Florida, Florida Center of Inclusive Communities

- My Health Passport (4 pages)
- My Health Report (2 pages)
- How Do I Talk to My Doctor (2 pages)

**<http://flfcic.fmhi.usf.edu/program-areas/health>**

Health Care Access and Research Developmental Disabilities

**[www.porticonetwork.ca/web/hcardd/healthcareresources](http://www.porticonetwork.ca/web/hcardd/healthcareresources)**

- Today's Health Care Visit: Implementing Health Checks for Adults with DD: A Toolkit for Primary Care Providers (4 pages)

# Embracing Challenges

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“Start where you are, Use what you got, Do what you can.” Arthur Ashe

## *And Look ahead*

Single greatest opportunity to improve health lies in addressing unmet social needs; ***share your expertise.***

Seek out opportunities, don't just focus on problem solving.

Health must be aligned with personal goals, community living, plan of care, and long term services and supports.

Support people and families, your organization and staff, and community to be healthy.

# Key Issues in System Re-Design



Defining the “patient” population to be served	Communication: multi-directional information sharing
Ensuring enhanced access and continuity of care	Use of population data
Defining team composition, roles, and expertise	Outcomes of value and relevance that can be measured
Shared responsibilities	Payment reform and aligned incentives
Standardized screenings and assessments	Workforce development
Integrated plan of care	Innovation

# Some Things We Have Learned



- It is critical that “we” are at table and help set the table, to ensure the needs and concerns of people with disability are addressed as health care and disability services are re-designed
- The landscape is still changing
- There is not ONE model for integrated care, but everyone should have access to primary care, medical home, necessary specialists, community supports
- Process and structures may need to be modified or enhanced to achieve valued outcomes at individual and population levels
- Partnerships and community are essential ingredients



## **MEDICAL HEALTH HOMES**

*Promoting Integrated, Person-Centered Care for  
People with Intellectual & Developmental Disabilities*

### **Key Recommendations**

- Consultation infrastructure with multi-disciplinary team focus
- Navigation services and assistance
- Data analysis and sharing
- Innovative demonstration programs with evaluation

# Thank You

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**MEDICAL HEALTH HOMES**

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