

# Focus Group Update February 24, 2012



# Focus Group Update: UCONN Center on Aging Results

- UCONN recruited a focus group sample in collaboration with members of the Complex Care Committee of the Medical Assistance Programs Oversight Council, the Money Follows the Person Steering Committee, and community-based organizations
- Focus Group Domains included; current experience of care delivery; care coordination; consumer protection; and, vision of ideal services and supports
- Diverse participation:
  - Geographic: Covered all 5 areas of the state: Eastern (2), North Central (1), South Central (2), Southwest (2), Western (1)
  - Nursing home residents, Community dwelling individuals (healthy individuals and those with chronic disease or disability)
  - Spanish speakers
  - Family members of individuals with chronic disease or disability
- 77 participants in all

# Focus Group Feedback

- Comments on reports of doctors refusing to take Medicare/Medicaid were widespread and present access problems for many with primary, specialty, and behavioral health needs
- Co-pays cause confusion, even anger, and lead to some foregone medications and other care appointments
- People with care managers and/or Residential Service Coordinators (RSCs) have far more coordinated services, know where to go for help, and have fewer issues than those who do not have such assistance
- Coordination is difficult for those without care managers or RSCs is difficult and confusing
- Pharmacists are frequent, reliable source of information and counseling about medication

# Focus Group Summary of Themes

- **1. *What happens when you go to the doctor?***
  - Most participants consistently see an office-based PCP and have one to four specialists in different practices and locations
    - Some change doctors due to rotation of newer/younger docs
  - Many reported have issues with distance and transportation
  - Where alternatives to using the ER exist, participants are willing to use them
- **2. *If you stayed in the hospital/nursing home in the past year, how did your providers help prepare to go home?***
  - Many described positive transitions BUT some noted insufficient services at home after the transition
  - Communication problems between the nursing home and home services for those transitioning from a nursing home

# Focus Group Summary of Themes

- **3. *What happens when your doctor prescribes a medication?***
  - Most doctors explain the basics (e.g. dosage)
  - Most rely on pharmacists for any medication questions
  - Visiting nurses help educate and
  - A few had interpretation issues due to language barriers
- **4. *Do you think your doctors talk to one another re: your care?***
  - Doctors do communicate -- via fax or EHR
  - Communication between physicians and other healthcare providers is very important
  - Important for a relative to be involved (but not necessarily be involved themselves)
  - Doctors do not communicate with homecare providers (except with visiting nurses)

# Focus Group Summary of Themes

- **5. *Have you seen a written plan for your medical care and other services?***
  - Confusion as to what a care plan was; participants reported seeing documents re: Homecare; Medications, i.e.: schedule; other medical records
  - Opinions on who should be involved in designing a care plan varied from not wanting anyone else involved to wanting at least one relative involved
  - Caregivers want to be involved in their relatives' care plan
- **6. *Who do you rely on most for day-to-day help?***
  - Family, care managers, RSCs to find help that includes VN, companion, ADL/IADL help and housekeeping
  - Persons on CHCPE had more help at home, including LTSS, transportation, medical issues, emergency services
  - Participants noted that “Gatekeepers” (family, RSCs, care managers) can be both helpers and obstacles.

# Focus Group Summary of Themes

- **7. *If you wanted to see a doctor about your mental health, would you know where to go?***
  - Yes, (with many participants indicating they use services)
  - Most people go to their primary care doctor, social worker, or resident services coordinator for referral
  - Some did not know who to approach for emotional care and some participants experienced problems accessing mental health care, e.g., physicians not taking Medicare or Medicaid
- **8. *Complaints about care & patient rights***
  - Many don't know how to make a complaint or would change docs instead of complaining
  - Some would talk to health care provider directly; others mentioned specific people they would ask
  - While some reported they have been told about their patient rights, many others have not

# Focus Group Summary of Themes

## ■ **9. Are you able to choose your doctors?**

- Participants reported a wide range of experiences re: choice
- Specialists were generally identified through PCP referrals without choices, but many trusted PCPs to identify specialists
- Others reported lack of choice in LTSS providers, and denial of requests to change
- A *significant* number had been turned away by providers who don't accept Medicare or Medicaid

## ■ **10. Do you think some health care providers treat people differently?**

- Most reported no problem with discrimination
- Others had perceived discrimination based on: Race/ethnicity; Age; use of Medicaid (or Medicare)
- Others reported poor treatment, with no clear cause
- A few felt they receive better treatment due to their age

# Focus Group Summary of Themes

- ***11. How would you describe an ideal health care and service program for you?***
  - Most agreed that they want more doctors to accept Medicaid and Medicare patients
  - A holistic approach to health care with their primary care and specialists located in one town, or in one location
  - Access to a navigator or health care advocate
  - A streamlined, easy process for submitting medical/prescription claims to DSS
  - Better information about why some people have to pay co-pays is needed to avoid confusion regarding this issue

*It's hard to get a doctor these days... if you don't have the right insurance, you don't always get the doctor you want. ....  
So a lot of people hang on to their doctors knowing that he or she is better than not having a doctor at all.*

*I would like for it to be like what I have, everything in the same place, the cancer center and there is psychological help, you know, everything.*

*I have [skipped a doctor's visit] because I could not pay...the co-pay is a stop-wheel because they asked for the co-pay and [I say:] "I don't have it" [and they say:] "sorry, but without co-pay we can't see you"*

*One thing is the mental health system is over taxed, like there is such a great need to have a consult, and someone to prescribe the meds, and interventions and home care and it's very difficult to find people also who would take the insurance and it's a long wait to get in and also the funding and payment from insurance companies gets reduced so that need to be improved and be taken more seriously*

*I think the secret too is if you can find a doctor who has a holistic approach and care about all of you and not just about that little piece that he specializes in...*

# Focus Group Caveats

- 65+ population may not represent experience and concerns of under 65 population
  - Focus groups planned in March with individuals with SPMI and developmental disabilities
- Some generational/attitudinal differences affect results
  - “The doctor is always right”
  - “I’m in a wheelchair so I can’t live at home”
- Dementia experience was largely unexplored in focus groups

# Focus Group Results

Issue	Programmatic Consideration
<p>When docs unavailable, most people head straight for ER</p>	<ul style="list-style-type: none"><li>• Develop clear access standards (after hours care, non-visit based contact) for MMEs with incentives in the Health Neighborhood to see people when necessary</li></ul>
<p>Many doctors refuse MMEs as patients and are unwilling to accept Medicare and/or Medicaid</p> <ul style="list-style-type: none"><li>• Some MMEs have been dismissed by long-time providers</li></ul>	<ul style="list-style-type: none"><li>• Work toward improved access within Health Neighborhoods and ASO systems with incentives to see the population</li></ul>
<p>Co-pays for Part D services cause confusion and anger</p> <ul style="list-style-type: none"><li>• Some people forego drugs (or medical visits) because they can't afford co-pays</li></ul>	<ul style="list-style-type: none"><li>• Re-examine cost-sharing for individuals over 200% of FPL for HCBS</li><li>• Re-examine Part D co-pays for budgetary flexibility and cost-effectiveness</li></ul>
<p>Transportation issues for medical care exist</p>	<ul style="list-style-type: none"><li>• Ensure stronger access to transportation through Health Neighborhoods and the ASO</li></ul>
<p>Missing services including dental, high quality hearing aids, interpreters</p>	<p>Review options to provide these services and supports</p>

# Focus Group Results

Issue	Programmatic Consideration
Care provision & coordination for those without care managers or Residential Service Coordinators is difficult and confusing	Written care plans viewed favorably; involve family members <i>when desired by consumer</i>
Most people don't know where/how to make consumer complaint	Create an Ombudsman for the ASO/Health Neighborhood; provide clear information as part of the enrollment process for MMEs to facilitate the complaint and resolution process
Families need information & support	Ensure that MMEs and their families (where appropriate and desired by the MME) can obtain information regarding options for services and supports
Age, racial/ethnic and other types of discrimination highlight the need for cultural sensitivity	Develop measurement and improvement opportunities to decrease racial and ethnic disparities
Pharmacists were seen as a major information sources at the point of service	Include a counseling role for pharmacists on the Health Neighborhood team