

# Caring for Those Who Care: Supporting the Family Caregiver's Needs

2017 HCBS Conference  
Tuesday, August 29<sup>th</sup>, 2017

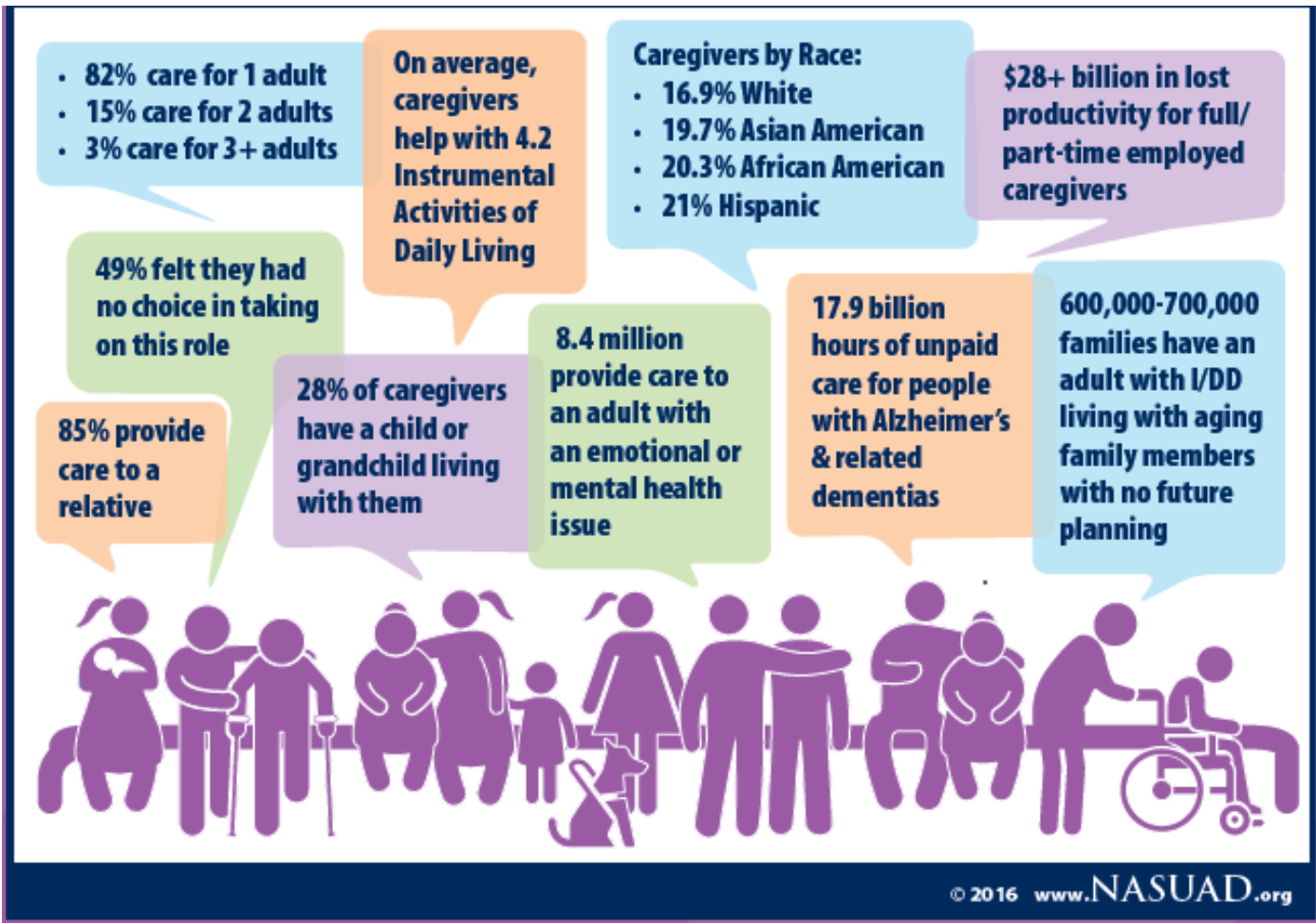


# Caregiving Trends & Challenges

**Martha Roherty**

**National Association of States United for Aging &  
Disability**

# Caregivers in America



# Caregivers- who are they and what do they do?

### CAREGIVERS: WHO THEY ARE

**Prevalence**

**39.8 MILLION** ARE CAREGIVERS

**6 IN 10** ARE EMPLOYED

**Compensation**

**90%** of all caregivers who provide long-term services and supports are **UNPAID**

**Gender**

**60% FEMALE 40% MALE**

**Age**

**1 in 10** Caregivers are **75 or Older**

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### CAREGIVERS: WHAT & WHERE

**Where Care Recipients Live**

**48%** his/her home

**35%** caregiver home

**11%** nursing facility, assisted living, retirement community

**6%** memory care home

**Hours of Caregiving**

**24.4 HOURS AVERAGE PER WEEK**

**Caregiver Tasks**

**57%** assist with medical/nursing tasks

**78%** who provide medical/nursing tasks are managing medications, and administering IVs, injections, and medications

**42%** perform medical/nursing tasks without any training

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### CAREGIVERS: THE STRESSORS

**Emotional**

**55% FEEL OVERWHELMED** BY THE AMOUNT OF CARE FAMILY MEMBERS NEED

**Health**

**1 IN 5** REPORT PHYSICAL STRAIN DUE TO CAREGIVING DUTIES

**Financial**

**FAMILY CAREGIVERS ARE 2.5 TIMES MORE LIKELY TO LIVE IN POVERTY**

**1 IN 5** RETIREES LEFT WORKFORCE EARLY TO CARE FOR FAMILY

**\$303,880** LOST INCOME and BENEFITS ON AVERAGE OVER LIFETIME FOR FAMILY CAREGIVERS 50+

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### CAREGIVERS: LIMITED SUPPORT

**Services for Caregivers**  
The National Family Caregiver Support Program\*

**INFORMATION SERVICES** 12,600,435 SERVED

**RESPIRE CARE** 69,450 SERVED

**COUNSELING** 117,530 SERVED

**ACCESS ASSISTANCE** 779,359 SERVED

**CASH & COUNSELING** 1,902 SERVED

**SUPPLEMENTAL SERVICES** 32,904 SERVED

\*CAR SERVED IN 2013

**Services Unable to Meet Demand**

**8 OUT OF 10** COULD USE MORE INFORMATION AND SUPPORT

**The Growing Value of Caregiving**

UNCOMPENSATED Family & Friend Caregiving\* **>** TOTAL Medicaid Spending

**\$470** BILION Economic Value **\$449** BILION

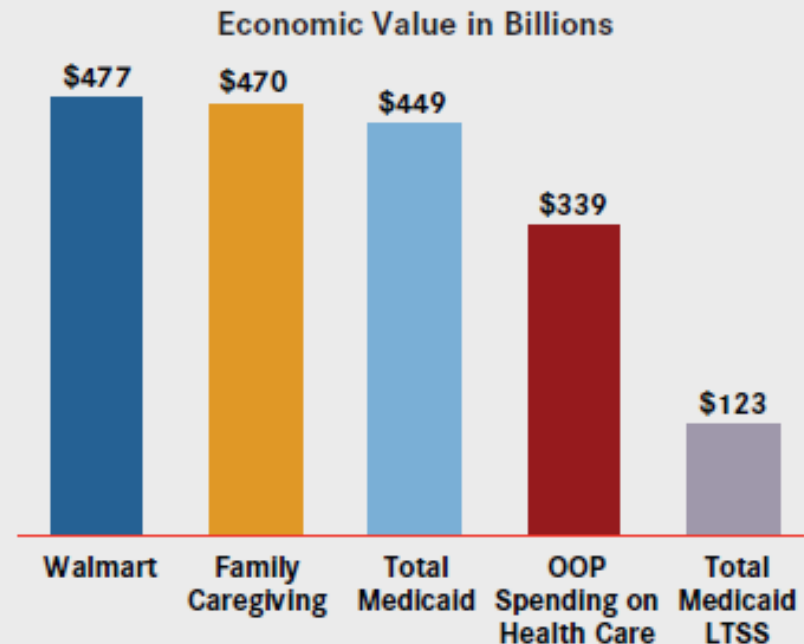
\*CAREGIVERS IN 2013

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# Importance of Caregiving

- The economic value of family caregiving to the United States economy was estimated at \$470 billion in 2013, more than the total federal and state Medicaid spending of \$449 billion for medical and long-term care in the same year
- The importance of caregiving is compounded by the aging of Baby Boomers and slowing of population growth to replace them

The economic value of family caregiving is as big as the world's largest company, and bigger than Medicaid and out-of-pocket (OOP) spending on health care.



# Challenges for the Family Caregiver

- Family Caregiving today is more complex, costly, stressful, and demanding than at any time in human history.

Financial Impacts

Impact on  
Caregivers'  
Physical and  
Emotional Health

Family Care is  
Expanding and  
Increasingly  
Complex

Work/Family/Caring  
Balance

# Trends in Medicaid and Federal Policy

## Medicaid Policy:

- In 2014, CMS released a new rule on community living for HCBS programs, for the first time CMS formally recognized the importance of assessing the needs of family caregivers when caring for someone with a disability.
- The Balancing Incentive Payments Program (BIPP) established under ACA encourages states to make greater use of HCBS and recommends assessment of the family caregiver and recognizes common challenges including: caregiver stress, need for info/referrals, support groups and respite care.

## Federal Initiatives:

- Congressional Caucus on Family caregiving
- Institute of Medicine Study – Committee on Family Caregiving of Older Adults
- Commission on Long Term Care

# **Medicaid Managed Care & Caregiving**

**Catherine Anderson**

**UnitedHealthcare Community & State**



# National Advisory Board Representation



# 2016-2017 National Advisory Board Focus

In 2016 after the launch of the MLTSS and ID/DD Quality Frameworks the C&S National Advisory Board made the decision to shift their focus to addressing the needs of caregivers.

## Family Caregivers

- There are an estimated **43 million family caregivers** nationwide providing support or assistance for loved ones. The **economic value** of family caregiving to the U.S. is an estimated **\$470 billion**.
- The **number of family caregivers** in the United States is **expected to decline** as more than half of the family care recipients today are under age 75, and almost one-third under age 50, **the demand for caregivers will only increase** over the coming years\

## Direct Service Workers

- The **quality of life** and healthcare for those accessing LTSS is **largely dependent** on the performance of **Direct Service Workers, more than any other health care professional**.
- The **demand for DSWs** currently **outpaces the supply** of individuals working in the profession,” and **as family caregivers age out**, there will be an **increase in the importance of paid LTSS services**.

# Family Caregiving Challenges



**Despite acknowledged social and economic advantages that family caregivers provide to society, family caregivers often face many challenges including:**

- Emotional & Financial Difficulties
- High Expectations and Few Formal Supports
- Lack of Work Family Balance
- Family Caregivers Are Aging
- Caring for Persons with Mental Illness or Psychiatric Disabilities
- Caring for Persons with Intellectual and/or Developmental Disabilities
- HIPAA
- Lack of Acknowledgment for the Role of Family Caregiver

# NAB Proposed Solutions



Promote Targeted and Culturally Appropriate Caregiver Education, Training & Resource



Promote Peer-to-Peer Networking and Respite



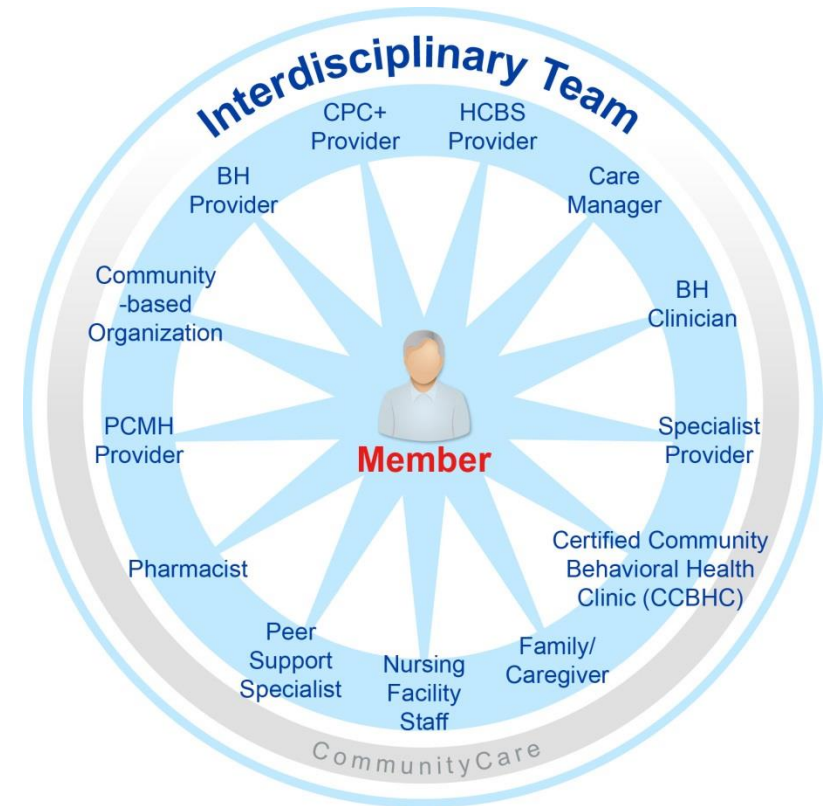
Implement Targeted Pilots to Leverage Ongoing UHC Initiatives for Family Caregivers



Promote Telehealth and Remote Patient Monitoring to Provide Additional Supports for Family Caregivers

# Collaboration with MCOs to Improve Caregiving Supports

- Managed care programs can drive improvements to the care delivery system, such as more care coordination and support services focused on the individual and family
- Person-Centered Care should include the family caregiver at the member's discretion
- Care Coordinators should work with family caregivers to facilitate referrals and trainings.



# Considerations for States

- Leverage the available Medicaid authorities to target caregiving supports
  - 1915c
  - 1915i
- Encourage caregiver assessments as part of the LTSS program
  - systematic process of gathering information
  - helpful and non-threatening
  - structured to best determine what types of assistance may be needed
- Reduce administrative burden
- Evaluate strategies that offer support – what is most impactful

# **Family Caregiving Lessons & Challenges**

**Debbie Wiederhold, Family Caregiver, United Partners**

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**“Caregiver” by definition is a noun, but  
it is definitely an “action” word!**



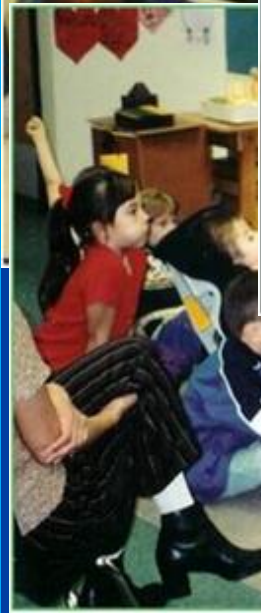
# The Beginning - LIFE in the NICU



# HOME!

(14 months later and a mini NICU  
in our Dining Room!)







High School happens!



2012  
Nomination for  
Bishop's Award  
for Outstanding  
Senior High  
Youth



# Community Involvement



**Leading Central Texas  
Walk-n-Roll Fundraiser for  
Texas Parent to Parent and  
the OI Foundation**

**Texas EMSC  
Champions for  
Children Award**



**Trying to make a  
difference!**



# 2012 High School Graduate!



2014 OIF National  
Conference

# Difficult/Challenging Issues

I wanted, or intended, to just tell you about Daniel, HIS story and how WONDERFUL our life is, and for the most part it is! Daniel is alive and happy.

He's at HOME and out in the COMMUNITY.

As a Family Caregiver, it's easier for me to just leave out the difficult/challenging parts:

- Life vs. planning a funeral
- Home vs. NICU
- Other “Caregivers” in your home - the “Fish Bowl” effect
- Family dynamics
  - Marriage
  - Grandchildren
  - Other children at home
  - Extended family



# Challenges Continued

- Transitioning from Pediatric to Adult care
- Roadblocks in pediatric care:
  - We were home less than a month from a 14 month stay in the Neonatal Intensive Care Unit at the hospital when our then private insurance company came for a visit to see if we were ready to cut back on Daniel's nursing care.
  - All new physicians once he was home
- Roadblocks in adult care:
  - Finding all new physicians again - adult physicians - to “teach” and bring up to speed from the past 21 years; finding physicians willing to take on a new patient with complex health care needs; and in our case, finding a physician or specialists that have some form of crossover with pediatrics as well; finding physicians in-network

# More Issues....

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- Funding
- Transitioning from a Medicaid Waiver to StarPlus (Texas)
- Lack of qualified nursing care
- Medical supplies

# How are issues resolved?



- **Creating relationships!**
- Creating a relationship with Case Managers - whether it be from the MCO, Medicaid, Medicare, etc.
- Creating a relationship with new physicians, office staff, DME companies, and....
- NEVER giving up to get what your loved one needs!

# Vital Supports



- Family
- Other Parents
- Other “caregivers” i.e., nurses in and out of our home (that “fishbowl effect” being a critical part of our son’s existence)
- Friends
- Church family
- Medical Professional “Team”
  - Nursing Agency
  - Private Insurance
  - Physicians/specialists
  - Medicaid
  - DME companies
  - Medicare
  - UnitedHealthcare – Case Managers!

# What's going on now?



- When Daniel aged out of all public school assistance at the age of 22, and he didn't have a job or other activities planned for his day, he started a Program 18 miles away from home. It's a great program, just not as close as we would like.
- When I mentioned the Program to our Youth and Family Director at our Church, and my wish to do something closer, her eyes got big and she said, "I think we could do that here!" And she was right!



**United Partners**

PFLUGERVILLE

## What is United Partners – Pflugerville?

- UP-PF is a Program/Place where individuals can come and feel welcomed, share their God-given gifts and talents and build community partnership. Each and every person that is a part of UP-Pf will know that they have a purpose and that will be celebrated. We create, we work, we produce, we love - all centered in the God who fearfully and wonderfully made each one of us.









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**Many thanks to Immanuel Lutheran Church to saying  
“YES”! in supporting us, and donating the space for  
us to use.**

## UHC Community & State National Advisory Board

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- While employed with Texas Parent to Parent, I was asked to be on a **National Advisory Board of United Healthcare, offering a parent's perspective.** Thank you for this opportunity! I have thoroughly enjoyed being on this Board, meeting new people, sharing ideas and hope my input has been beneficial. I look forward to continuing this partnership!

# On being a Family Caregiver



**It is hard, it never ends, but we keep caring and working towards the best quality of life we, and they, can imagine!**

# 2016 OIF Conference and Disney Trip



# Thank you!



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