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

2017 HCBS Conference
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Caregiving Trends & Challenges

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National Association of States United for Aging & Disability
Caregivers in America

- 82% care for 1 adult
- 15% care for 2 adults
- 3% care for 3+ adults

On average, caregivers help with 4.2 Instrumental Activities of Daily Living

49% felt they had no choice in taking on this role

85% provide care to a relative

28% of caregivers have a child or grandchild living with them

8.4 million provide care to an adult with an emotional or mental health issue

17.9 billion hours of unpaid care for people with Alzheimer’s & related dementias

Caregivers by Race:
- 16.9% White
- 19.7% Asian American
- 20.3% African American
- 21% Hispanic

$28+ billion in lost productivity for full/part-time employed caregivers

600,000-700,000 families have an adult with I/DD living with aging family members with no future planning
Caregivers- who are they and what do they do?
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.
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

LeadingAge®
National Council on Aging
NACDD
National Association of Councils on Developmental Disabilities
NAMI
National Alliance on Mental Illness
CTD
Coalition of Texans with Disabilities
EJC
National Council on Independent Living

ncba
The National Caucus and Center on Black Aging, Inc.
Texas Parent to Parent

NATIONAL ALLIANCE for CAREGIVING
Advancing Family Caregiving Through Research, Innovation, and Advocacy

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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 of 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
“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

Daniel Martin Wiederhold

Southwestern Texas Synod
Evangelical Lutheran Church in America
God’s work. Our hands.
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
  - Other children at home
  - Grandchildren
  - 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....

- 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
  - Physicians/specialists
  - DME companies
  - UnitedHealthcare – Case Managers!
  - Private Insurance
  - Medicaid
  - Medicare
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!
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.
Many thanks to Immanuel Lutheran Church to saying “YES”! in supporting us, and donating the space for us to use.
• 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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