



Strengthening Support for Family Caregivers: Policy Solutions & Resources

with Heather Sachs and Rachel Starr

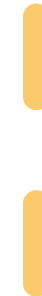
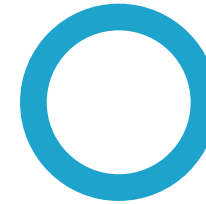


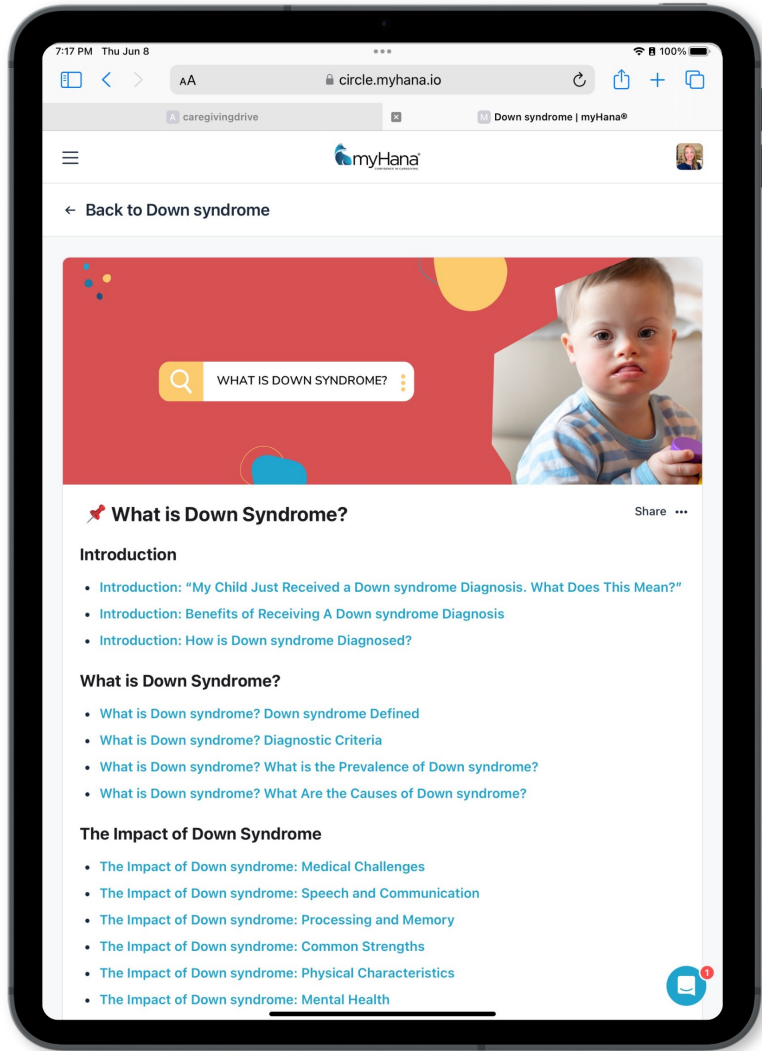
**CAREGIVING IS A
JOURNEY.
LET US PROVIDE
YOU AND YOUR
FAMILY WITH A
ROADMAP.**



Welcome and Introduction of Facilitators

- Rachel Starr, myHana® COO
- Heather Sachs, myHana® Content Director





What is myHana®?

Your Caregiving Companion



COMMUNITY



EDUCATION




DOCUMENT
STORAGE



CARE
MANAGEMENT



Overview

- 
- Understanding family caregivers
 - Importance of supporting family caregivers
 - Current policy environment
 - Advocacy and action
 - Resources for family caregivers
 - Next steps and Q&A
 - Feedback

Embracing the Power of Care: Caregiving and Healthcare Trends



“There are only four kinds of people in this world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers. Caregiving is a universal.”

- Rosalynn Carter, *Former First Lady of the United States*




Understanding Family Caregivers

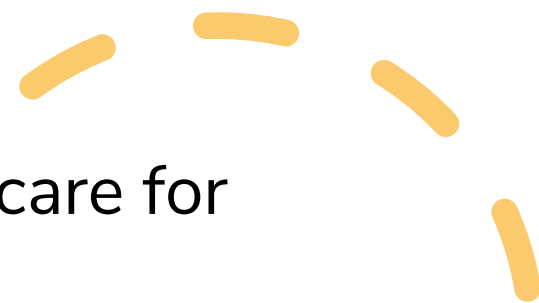
- Definition of family caregivers
- The role of family caregivers in the healthcare system
- Common challenges faced by family caregivers

Definition of Family Caregivers: The Extraordinary Support Squad

- **Professional Caregivers: The Extraordinary Experts who provide specialized care and support.**
 - Home health aides, direct support persons, and more, armed with compassion, skills, and dedication.
- **Informal/Family/Unpaid Caregivers: The Unwavering Champions who provide care from the heart.**
 - You! The unsung heroes who selflessly attend to the needs of others within the comfort of their homes.



Are You an Everyday Hero?

- 
- Do you provide unpaid care for others in your home?
 - Are you responsible for attending to the daily needs of another person?
 - Do you provide physical, emotional, and/or financial support to someone unable to care for themselves due to disability, illness, or injury?

The role of family caregivers in the healthcare system



Illuminating Daily Living: Providing support in essential activities such as bathing, mobility, and bathroom use.

Nurturing a sense of comfort, independence, and well-being.



Masters of Medical Care: Skillfully performing complex medical tasks, including wound care, injections, and managing medical equipment.

Ensuring the child's health and safety with compassion and expertise.



Navigating with Limited Support: Often receiving little instruction or formal assistance in managing healthcare tasks.

Expertly navigating health insurance claims, coordinating care among providers, and advocating for comprehensive support.



Journeying Together: Providing transportation to medical appointments, therapies, and other vital services.

Ensuring access to specialized care and supporting the child's healthcare needs.

Embracing Challenges

Everyday Heroes, Extraordinary Challenges:

- Family caregivers of children with Down Syndrome conquer unique obstacles with love and resilience.

Nurturing Beyond the Norm:

- Supporting the child's development, including speech, motor skills, and cognitive abilities.
- Adapting to individual learning styles and providing tailored care.

Balancing Acts:

- Juggling multiple responsibilities, including caregiving, personal commitments, and family dynamics.
- Navigating time management and self-care amidst demanding routines.

Emotional Triumphs and Struggles:

- Navigating emotional ups and downs, such as managing stress, anxiety, and feelings of uncertainty.
- Celebrating milestones and achievements, fostering resilience, and cultivating a positive outlook.

Allies in the Journey:

- Seeking support systems, connecting with communities, and accessing resources for guidance and encouragement.
- Embracing the power of support networks and sharing experiences with fellow caregivers.





Importance of Supporting Family Caregivers

- Statistics and facts about family caregivers
- Impact of caregiver stress on their physical and mental health
- Benefits to society, the healthcare system, and individuals when caregivers are supported



Caregiver Diversity: The Sandwich Generation in Action

- The Mighty Sandwich Generation:
 - Juggling responsibilities as caregivers, parents, and professionals with grace and determination.
 - 48% of caregivers are between 18-49, embracing the challenges with energy and resilience.
- Leading the Way:
 - Caregiving is predominantly female, with 61% female caregivers and 39% male caregivers.
 - Caregivers come from diverse racial and ethnic backgrounds:
 - 61% white, 17% Latinx/Hispanic, 14% black, and 5% Asian.

Nurturing the Nurturers: Impact on Caregivers' Health & Well-being

Caring Hearts, Caring for Themselves:

- Caregivers selflessly provide care, but their own well-being is equally important.



Balancing Care and Finances: Impact on Caregivers' Financial & Professional Lives

- **Caregivers' Dual Roles:**
 - Caregivers courageously navigate the challenges of balancing caregiving with their financial and professional lives.
- **Employment Disruptions:**
 - 70% of family caregivers work outside the home but face regular disruptions, such as arriving late, leaving early, or taking time off to fulfill caregiving duties.
 - Many caregivers have had to turn down promotions or increased responsibilities due to their caregiving responsibilities.
- **Financial Setbacks:**
 - 10% of caregivers report retiring early or leaving the workforce entirely, resulting in significant loss of wages and retirement savings.
 - Caregivers often incur high out-of-pocket costs for medical equipment and paid caregiving services, adding to their financial burden.
- **The Cost of Care:**
 - Caregiving responsibilities lead to an estimated annual loss of \$522 billion in income for caregivers.

Stronger Society:

Unleashing the Power of Support: Benefits of Caregiving Support



A Cycle of Support

- When caregivers receive the support they need, they can continue to provide exceptional care and support to their loved ones.
- This creates a positive ripple effect, fostering resilience and empowering future caregivers.





Overview of Current Policy Environment

- Biden Roadmap
- Paid family and medical leave, paid sick time
- Fair and flexible scheduling
- Anti-discrimination protections

Shining a Light on Family Caregiving: Response to the COVID-19 Pandemic

- **National Conversation:**
 - The COVID-19 pandemic has brought the challenges of family caregiving to the forefront of national discussion.
 - Recognition of the essential role caregivers play in supporting vulnerable populations.
- **Expanding Support:**
 - Numerous federal and state initiatives have been implemented to expand caregiver supports.
 - Over \$1 billion allocated to caregiving through various funding streams.
- **State Action:**
 - States are taking proactive measures to support caregivers and recognize their invaluable contributions.

Vital Supports



Empowering Family Caregivers: National Strategy and Action

- National Strategy: Supporting Family Caregivers
- Biden Administration's 2022 National Strategy to Support Family Caregivers, codified in the RAISE Family Caregivers Act (P.L. 115-119).
- A comprehensive framework to address the needs and challenges faced by family caregivers.

5 Main Goals

01

Increase awareness of and outreach to family caregivers.

02

Advance partnerships and engagement with family caregivers.

03

Strengthen services and supports for family caregivers.

04

Ensure financial and workplace security for family caregivers.

05

Expand data, research, and evidence-based practices.



Collaboration and Action:

Medicare & Medicaid Response during COVID-19

- **Public Health Emergency (PHE) Acute Hospital Care at Home Waiver**
 - Allows hospitals to receive payments to provide care outside of hospital setting
- **Medicare Advantage plans added supplemental benefits** such as in-home support services and adult day health services
- **American Rescue Plan Act of 2021 (ARPA)** increased state Medicaid HCBS funding
 - 30 states included funding to support family caregivers
 - Many states increased respite care options, training and education for family caregivers, and direct payment to family caregivers
- **Spousal impoverishment protections**
 - Extended through 2027 so that the spouse of a person receiving Medicaid HCBS isn't required to spend down all of their assets in order for spouse to receive services

Other Successful Federal Initiatives

- **Expanded supports for caregivers of veterans (VA MISSION Act expanded)**
- **Reauthorization of Older Americans Act of 1965**
 - Extends RAISE Family Caregiver Act and provides tools to states for caregiver assessments
- **Lifespan Respite Care Program Reauthorization Act of 2020**
 - Increased funding for accessible, community-based respite for caregivers
- **Caregiving volunteer program (in Consolidated Appropriations Act)**
 - National Volunteer Care Corps – volunteers to deliver nonmedical services to older adults and individuals with disabilities

Some current legislation to support caregivers

Autism Family Caregivers Act (HR 2965) – grants to enhance caregiver training (bipartisan)

Social Security Caregiver Credit Act (S. 1211) – credit caregivers with “deemed wages” for up to 5 years caregiving service

Supporting Our Direct Care Workforce and Caregivers Act (S. 1298/S.1332) – grants through the Administration on Community Living to support direct care professionals and caregivers

Child Care for Working Families Act (S. 1354/HR 2976) – increase quality and supply of childcare and lower childcare costs

HCBS Access Act (S. 762/H.R. 1493) – make HCBS mandatory entitlement under Medicaid

Elizabeth Dole Home Care Act (S. 141) – changes to Veterans Affairs programs to support caregivers

State-Level Initiatives

- **Caregiver Advise, Record, and Enable (CARE) Act** – 45 states and territories
 - Supports family caregivers when their relatives go into the hospital and then transition back to home care
- **Financial relief for family caregivers**
 - Grants of \$2000 to family caregivers to access respite care (ME)
 - Tax credit of up to \$500 for family caregiver (MO) and \$2000 (ND) for eligible expenses such as adult day care, home health care, respite, etc.
- **Paid family leave that covers caregiving** – 11 states + DC
- **Paid sick leave** – 14 states

Paid Leave

- US is the only industrialized nation in world that provides ZERO days of PAID leave for its workers
- Family and Medical Leave Act (FMLA) (1993)– up to 12 weeks job-protected family leave but unpaid and very limited
- New legislation pending in Congress
 - Family and Medical Insurance Leave (FAMILY) Act (S. 248/HR 804) – national paid leave insurance fund
 - Caring for All Families Act (S. 242/ H.R. 789) – expands who can take family and medical leave and provides additional leave
 - Healthy Families Act of 2023 (S. TBD)- guarantees 7 days paid sick leave per year; access to preventative care
 - Comprehensive Paid Leave for Federal Employees Act (S. 274/HR 856) – 12 weeks family and medical leave for federal employees
- States continue to pass paid family leave laws – CA, CT, DC, MA, NJ, NY, RI, VA, WA, CO, DE, MD, NH, OR, MN

Discrimination against caregivers

- **“Caregiver” is not a protected status under federal law**
 - Some states and localities have stronger protections
- Examples of discrimination
 - Caregiving worker is harassed, reassigned to lower paying job, hostile work environment, fired
- **Little protection from discrimination based on caregiving status**
 - Family Medical Leave Act – protects workers who request leave but unpaid and limited
 - Americans with Disabilities Act – illegal for employers to discriminate against workers who are caregivers for disabled family members
 - Civil Rights Act – forbids discrimination based on sex, which is often a de facto outcome of caregiver discrimination
- **Equal Employment Opportunity Commission has issued guidance against discrimination for caregiving (but non-binding)**

Advocacy is
needed for
policy
change!

- **Stay informed**
 - Follow NDSC, The Arc (national and state), AARP for information and calls to action
- **Respond to Action Alerts**
- **Tell your story** – reach out to your state and federal elected officials and share your personal experiences
 - Bring a one-page leave behind with photos, contact info, and your story



Resources for Family Caregivers

- Introduction to available resources for family caregivers, such as financial, respite care, training, etc.
- Care Plan Exercise
- myHana® - Your Caregiving Companion

Introduction to Available Resources for Family Caregivers

Financial Resources:

- Explore financial assistance programs, grants, and resources specifically designed to alleviate financial burdens for family caregivers.

Respite Care Services:

- Access respite care options that provide temporary relief and support for caregivers, allowing them to take much-needed breaks.

Training and Education:

- Take advantage of caregiver training programs and educational resources to enhance caregiving skills and knowledge.

Support Groups and Counseling:

- Connect with support groups and counseling services to share experiences, receive emotional support, and gain valuable insights.

Caregiver Support Organizations:

- Discover national and local organizations dedicated to providing guidance, resources, and support for family caregivers.

Online Resources and Apps:

- Access digital tools and mobile apps that offer information, tips, and practical tools to assist caregivers in their daily tasks.

Community Services:

- Explore community-based services such as adult day centers, home health agencies, and meal delivery programs that can provide additional support.

Accessible Caregiver Resources



Caregiver Resources by State:

How myHana Can Help?



MYHANA®
COMMUNITY



MYHANA®
KNOWLEDGE HUB



MYHANA® CARE APP

Care Plan Exercise



Comprehensive Care Plan

Note: This form is to be completed about the *PERSON RECEIVING CARE*

First Name:	Last Name:	Date of Birth:
_____	_____	__/__/____
Age:	Phone Number:	Email Address:
__	() _____	_____
Street Address:	City/State:	Zip:
_____	_____	_____

About the Person Receiving Care: Use this section to communicate to other caregivers any relevant information needed to best care for the person receiving care. I.e.- Info. related to family, friends, hobbies, favorite activities, likes/dislikes, strengths, etc.

All about _____ ...

Next Steps

Explore myHana.io:

- Visit myHana.io, a platform dedicated to supporting caregivers.
- Sign up for a free membership to access valuable resources and support.

Stay Informed and Advocate:

- Register for e-newsletters and action alerts from advocacy groups such as NDSC, The Arc, AARP, and other caregiver-based organizations.
- Stay informed about policy changes, advocacy efforts, and opportunities to make your voice heard.

Prioritize Self-Care:

- Remember to prioritize your own well-being and practice self-care.
- Take breaks, engage in activities that bring you joy, and seek support when needed.



Conclusion, Q&A Session, Feedback

As a caregiver, you play a vital role in the lives of your loved ones.

By accessing resources, connecting with others, and practicing self-care, you are better equipped to provide the care and support needed.

Thank You

