Mini-Module: Caregiver Mental Health

Lesson 1 of 7

Introduction

Focusing on Caregiver Mental Health, this mini module is designed to reach a broad audience. Learners may include social workers, therapists, physicians, mental health providers, healthcare providers, students, and other individuals who work with those serving as caregivers in any capacity.

The content in this lesson can also be found in **Module 3: Mental and Behavioral Health**.

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Thomas Jefferson University

Pennsylvania Developmental Disabilities Council

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Note: If you do not complete all of the learning material at one time and would like to pause and return at a later time, you may do so. The system will not save your progress. Make a note of where you stopped and you may return at any point.

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Lesson 1: Family caregiver mental health

According to a caregiver survey by The Arc in 2017, **80%** of individuals with IDD live with a caregiver who is their family member.
54% of caregivers reported they **do not** have a plan for the future. [1]

For many individuals with disabilities, assistance falls to their family members. These are most often people who are not trained medical professionals.

Over time, family members who support an individual's care become experts in supplies, their family member's condition, technology to support, assistive devices, medications, and more.

A family's ability to care for someone is dependent on many factors. Things like the timing of care needs, the physical ability of the potential caregiver, and the stage of an individual's disability all can change what caregiving looks like across the lifespan.

There are different adjustment periods for caregivers of someone who is born with a disability versus someone who becomes a caregiver after a family member experiences an acquired disability.

When someone is a caregiver, their own medical care, employment, physical, and mental health are impacted. This can have a lifetime effect.

Hear from a family of caregivers:

YOUTUBE

An intimate look at the life of a young caregiver | Caring fo...

An intimate look at the life of a young caregiver | Caring for Tor

Stephane Alexis, 24, has put his own goals and aspirations on hold to help his parents care for his younger brother Torence, who has cerebral palsy. Young caregivers are an often-overlooked population - too tired from the day-to-day to advocate for more resources and support.

VIEW ON YOUTUBE ›

When connecting with a caregiver, consider those who are part of the **"sandwich generation"** - those caring for a child (with or without IDD) and also caring for an aging parent.

Read the full Family & Individual Needs for Disability Supports (FINDS) report from The Arc here. [1]

READ MORE

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Many individuals have a nurse or team of nurses who provide care at home. Having a stranger in the home can be difficult and increase feelings of vulnerability but is often a necessity for the care an individual may need.

It is difficult for individuals to find external long-lasting caregivers in their home. Our project consultants shared some challenges in staffing. This included finding care for the appropriate number of hours, consistent care, quality care, and the difficulty of having someone in your home.

Based on the needs of an individual's care, they may require nursing care with higher licensure or qualifications. This can make it more challenging to find the right provider, and turnover may be high.

One consultant shared that in 14 years of providing care for her daughter, they have worked with over 600 caregivers and in-home support. The process of finding and maintaining care is incredibly time consuming. Each new caregiver and staff support needs to be trained to the individual's needs and takes time to acclimate.

Hear from a collection of family caregivers about the difficulties in finding assistance and the amount of care they provide. This video highlights the perspectives of parents caring for their adult child with IDD, and children caring for their aging parent.

No One to Hire

When Parents Age Out of Caregiving: New Mobility Magazine

Read about the experiences of two families of care partners and the realities of managing care and the future with an aging parent.

READ MORE

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Transition planning

Providers working with patients with disabilities who have a family member as their primary caregiver need to begin conversations about transition planning as their caregiver ages. This is a very difficult conversation. Bringing it up periodically is important, as the process has many parts, is complicated, and emotionally charged.

Some families who are the primary caregiver of an individual with IDD are trying to start the transition process well in advance, so the individual can find a place that suits their needs, acclimate, and still be able to engage with family in a meaningful way.

In some instances, a family may have other siblings who are not currently caregivers. These family members may become an individual's primary caregiver when a parent or grandparent is no longer able to fill the role.

A sibling may not be familiar with the individual's level of care or daily routine or may have difficulty accessing necessary finances. Conversations about transition planning should include inquiring about access to account passwords and banking.

YOUTUBE

Caring for an adult child with disabilities in retirement

Caring for an adult child with disabilities in retirement

Hundreds of thousands of people with intellectual and developmental disabilities in America are living and receiving care at home. But their aging caregivers, many of whom are parents or siblings, are worried about who will continue to care for their loved ones when they are gone.

VIEW ON YOUTUBE ›

ⓘ **Note: Some people with disabilities do not have any family involvement in their care. These individuals may manage all of their own outside care or have help from their support coordinator. Do not assume a person's support network. It is always best to ask the patient what support looks like for them.**

Transition planning conversations should occur early, and often. Explore these resources made for individuals and caregivers to help.

Got Transition - Parents and Caregivers [2]

Got Transition offers a variety of educational and medical support transition resources for individuals and their supporters.

LEARN MORE

Got Transition - Youth & Young Adults [3]

LEARN MORE

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Lesson 3 of 7

Lesson 2: Caregiver health services

Caregivers of individuals with IDD have their own health needs which they may push aside to support the person they are caring for. It can be difficult for a caregiver to find a provider who understands their unique circumstance.

Mental health needs

- Similar to the way individuals with disabilities struggle to find therapists or counselors who understand the challenges they face, caregivers often struggle to find people who understand what their daily experience is like.
- Caregivers can join support groups, but often end up providing others with the services they need
  - Many support groups are for caregivers of an aging parent, not for a parent of an adult with IDD
  - It can feel nearly impossible for caregivers to find a provider who "gets" the unique experience of caring for an adult with IDD

The Ontario Caregiver Association conducted roundtable discussions with caregivers of what they would like from healthcare providers. These are their top takeaways: [4]

- Greater empathy and respect for caregiving
- More help to navigate the system and a reduction of "silos" between services and providers
- Hands-on support for caregivers to manage their own needs
- Access to the right information at the right time - it is difficult to read and understand so much information when you are tired and stressed
- A better understanding from providers of the caregiver's role
- An overall understanding that anyone could become a caregiver at any time
- Engage in self-care, whether for 5 minutes or a full day

Primary care needs

- As a provider, it is important to know if you have a patient who is a full-time caregiver. This can impact aspects of their own care. [5]
    - For example, telling someone not to lift anything for 6 months to heal a back strain is not possible for someone who needs to physically assist someone in their daily tasks.
    - Telling someone to get more sleep is not always possible for a caregiver who needs to provide care through the nighttime.
    - Encouraging a person to get out of their home for regular activities or exercise can be difficult for someone who may be the sole provider of care for someone who needs consistent care.

- At the Jefferson FAB Center for Complex Care, family caregivers are able to receive primary care at the same location as the individual with complex care needs.
    - Providers are familiar with complex care needs and IDD, and the realistic needs of a caregiver.

- **Caregivers have little time to look for resources, funding, and finding help. How can you support as a provider?**

Learn more about some online support networks for caregivers:

Our Parallel Paths Podcast

A podcast from different caregivers of adults with disabilities as they embark on the transition planning journey.

LISTEN HERE

The Global Tracheostomy Collective [6]

Online forums for family caregivers and individuals with tracheostomy.

LEARN MORE

Assocation for Autism and Neurodiversity [7]

Offer a wide variety of virtual support groups for individuals with ASD and their supporters.

LEARN MORE

Parents Helping Parents [8]

Hosts support groups for parents of individuals with IDD across the lifespan. They offer a parent of adults with developmental disabilities online connection and Facebook group.

LEARN MORE

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92% of family caregivers surveyed by The Arc reported they have difficulty finding respite care. [1]

What is respite care?

Respite care provides short-term relief for caregivers, typically family, inside or out of the home. Respite can last a few hours or over the course of multiple days.

Respite care is **not covered** by Medicaid and is only covered by Medicare under Part A hospice services. Respite can be covered by some Medicaid waiver programs or is paid out of pocket by an individual.

Care can take place in the home, at an adult day center, a community center, or a program like a camp.

Respite care, when available, can help to reduce feelings of caregiver burnout and provides a break for caregivers.

Socializing as a caregiver

Providers and others recommend social time for caregivers to take a break. This can be difficult for caregivers. Our project consultants shared some things that can be difficult as a caregiver when attending social events:

- Limited time - Caregivers have limited time and opportunity for self-care. When given the opportunity to socialize or go out to an event, they are still feeling "on" in their role and know there is a time when their break ends.
- Connections - When caregiving full-time, a caregiver can become quickly disconnected from local events, popular culture, the news, and other common conversation topics. This can cause difficulty in figuring out what to talk about with others.
    - When others find out someone is a caregiver, the topic of conversation frequently drifts to this subject.
- Fatigue - A planned social event does not account for the other things going on in a caregiver's daily life, or the needs of the individual they are providing care for. Sometimes, an event comes around and a caregiver may feel too tired to go or would rather spend time "off" in their own space.

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Lesson 4 of 7

Lesson 3: Retaliatory reporting

An individual with a disability living alone or in a family home may have nurses, case workers, therapists, and support staffs coming into their home frequently. This places the individual with a disability into a vulnerable position where they may be judged prematurely and creates a complex power dynamic between the patient and the staff.

Retaliatory reporting happens when one of the people who comes to an individual's home puts in a report to Adult Protective Services (APS) because they are upset, they have been reprimanded or fired by the family.

This adds a lot of unnecessary stress and distress to the individual and the members of their home to manage the follow up of a false report.

Individuals receiving care can help to set expectations with caregivers in advance. Recall that it is very intimate to invite someone into your home.

Don't forget: Family and caregivers are so often doing a wonderful job! Be sure to acknowledge when caregivers are providing good care and support to their loved one. It means a lot to be seen.

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Lesson 4: Community crisis & caregiver resources

These organizations exist to support individuals in need. Please save these numbers for your future use. You can also access them in the Resources page at the conclusion of this module and linked on the project website.

- **Suicide and Crisis Lifeline**: 988
    - Available 24/7 via phone call or text
    - Options for individuals who are deaf or hard of hearing
- **Einstein's Crisis Response Center**: 215-951-8300
    - 24/7 support for acute psychiatric needs
- **National Domestic Violence Hotline**: 1-800-799-7233 (SAFE) or text START to 88788
    - Available 24/7
- **Einstein Intellectual Disability Services Emergency Line**: 215-829-5709 and 215-685-6440 (after 5 pm)
    - Emergency placement or to report a missing person with IDD
- Pennsylvania counties each have individual contacts for mental and behavioral health, as well as a crisis line

- **Philadelphia Crisis Line**: 215-685-6440
    - 24/7 behavioral health emergency services system
    - Ability to dispatch mobile emergency team for mental health crisis

    - Each county's direct numbers can be found in the document below

PDF

Pennsylvania by County Crisis Services List.pdf

229.9 KB

Additional supportive resources:

Adult protective services [9]

- In Pennsylvania, APS exists to protect older adults and people with disabilities from abuse, neglect, exploitation, and abandonment.
- A report can be made on behalf of an individual whether they live at home or in a care facility such as a nursing facility, group home, or hospital.
- The APS hotline can be contacted 24/7 at 1-800-490-8505 to make a report.

National Task Group (NTG) on Intellectual Disabilities and Dementia Practices [11]

- NTG supports family caregivers and healthcare professionals who care for individuals with IDD and dementia.
- NTG is a central resource offering family support committees, online events and webinars, diagnostic resources, publications, research, and trainings.
- Caregivers and healthcare professionals can refer to NTG and utilize their resources to support individuals with IDD as they age.

Smart911 [10]

- This service allows individuals to register and provide important health and tracking information to first responders in the event that 911 is called.
- Individuals can sign up to share medical conditions, allergies, vehicle make and model, emergency contacts, precise GPS locations, and other information which can be shared easily with first responders in an emergency situation.
- You can learn more and sign up here.

Emergency alert tags

- In an emergency situation, it is important for first responders to have additional information about someone with complex care needs.
- Consider recommending wearables like a medical alert bracelet or necklace if an individual can tolerate its wear.
- In a vehicle, an emergency alert band can be added to a seatbelt.
- Medical tags (similar to identification on luggage) can be filled out in advance and secured onto backpacks, wheelchairs, or other devices which travel with a person.

Health passport [12]

- A "health passport" helps provide healthcare professionals with information about an individual's health history, medications, preferences, and behavioral needs prior to a provider visit or an emergency health situation.
- This health passport can be particularly helpful for when an individual is receiving care from someone who is not part of their regular care team.
- There are a variety of different templates available for health passports based on an individual's needs.
- Review one health passport from the University of South Florida and Florida Center for Inclusive Communities below.

PDF

USF Health Passport.pdf

539.1 KB

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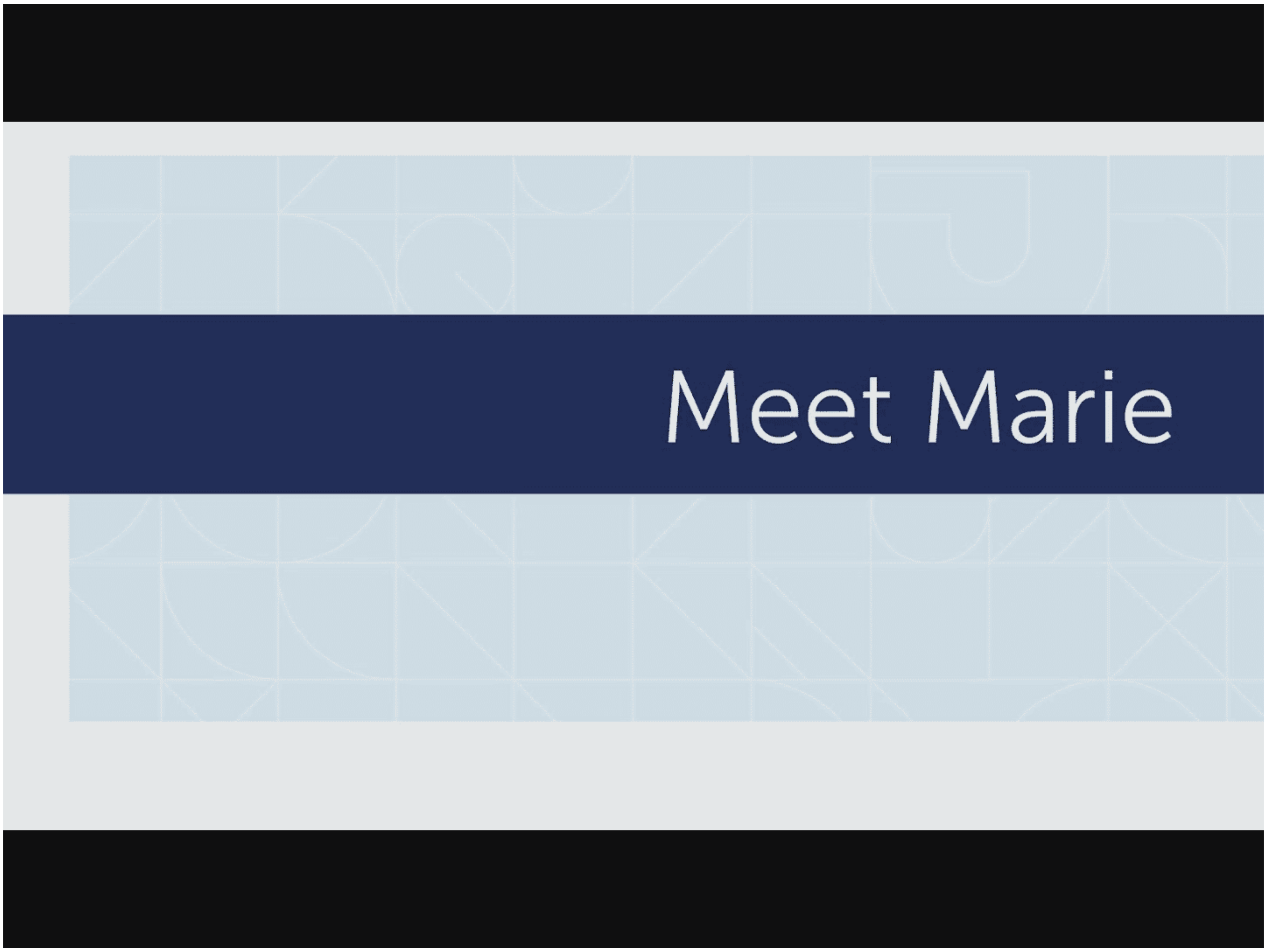
Knowledge Check: Supporting caregivers

Supporting caregivers in practice

Watch the video below to hear from Marie, a project consultant and primary caregiver to her daughter Corey, who has an acquired brain injury from a car accident when she was a teen.

Listen to Marie's experience as a caregiver and her experience with mental health care and caregiver burnout. Then, reflect and answer the question below.



Meet Marie

Jefferson
HOME OF SIDNEY KIMMEL MEDICAL COLLEGE

Think about Marie's experiences and her role as a caregiver to Corey. As a provider, what will you consider when supporting a caregiver as a

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Lesson 7 of 7

Conclusion

Thank you for participating in this **Mini-Module: Caregiver Mental Health.** This is part of an education series funded by PADDC. Additional information related to this project is found on the Introduction page of this website. [Increasing Access to Quality Healthcare for People with Disabilities.]()

Thank you for your support, engagement, and interest in increasing high quality care for patients with IDD. Please review the additional resources below and share this module with your colleagues!

For continued discussion, you may visit our live discussion board page on the Discussion tab of the project website. [Discussion Board]()

PDF **Mini module_Caregiver MH References.pdf**

172.7 KB

PDF

Module 3 Additional Resources__.pdf

147.3 KB