PADDC Module 3: Mental and Behavioral Health

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Conclusion

Introduction

This project is funded by the Pennsylvania Developmental Disabilities Council (PADDC). Dr. Mary Stephens and Karin Roseman from the Jefferson FAB (For Adolescents and Beyond) Center for Complex Care were recipients of a grant from PADDC to fund their project: **Increasing Access to Quality Healthcare for People with Disabilities: A Co-Designed Educational Curriculum for Family Medicine Residents.** Please contact Rosemary Corcoran (rosemary.corcoran@jefferson.edu) with any questions about this project.

Thomas Jefferson University

Pennsylvania Developmental Disabilities Council

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This is Module 3 of a 4-part learning series. Additionally, a Disability Education Module for physicians, trainees, and students is provided in the Mini-Modules and Resources section of our project website. The additional learning materials, resources, and a discussion board can be accessed here: Increasing Access to Quality Healthcare for People with Disabilities.

This module serves to provide background education on mental health and primary care for adults with intellectual and developmental disabilities and uses case studies to support integration of knowledge. Interactive knowledge checks are included throughout the module to allow for reflection, understanding of materials, and provide opportunity for self-assessment. Further discussion related to course topics can be found on the program website's interactive discussion board, also linked at the end of the module.
Discussion board

At the end of this module, learners should be able to:

- Identify barriers to behavioral health treatment for people with intellectual and developmental disabilities (IDD)
- Identify the ways in which behavioral health concerns can manifest in people with IDD
- Discuss the role of medication management in the primary care setting
- Discuss the role of family caregivers and healthcare transitions

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.

CONTINUE

Lesson 1: Disability and mental health overview

People with IDD have higher rates of mental health conditions and behavioral support needs. [1]

- It is difficult to determine the actual rate of these conditions and needs because there are not quality diagnostic tools available for people with IDD.
- Limited availability of appropriately validated screening tools for this population.
- At baseline, it can be difficult to identify people with IDD in population studies.

Under recognition and undertreatment of mental health conditions in people with IDD are impacting their overall quality of life. [2]

- For a long time, the medical field did not believe people with IDD could have mental health conditions.
    - These conditions then went unnoticed and therefore untreated.
- Anxiety and depression are now considered more common diagnoses in individuals with IDD.
- Schizophrenia and post-traumatic stress disorder (PTSD) are overrepresented in this population.

Barriers to mental and behavioral health care for people with IDD

- *Note: Even people who do not have complex conditions can have a difficult time finding mental health care.*
- It is difficult to find a provider who can understand the challenges and nuance of the lived experience of IDD.
- Very few providers have a disability themselves.
    - Only 1.5% of members of the social psychology professional society with a doctorate in psychology able to provide care self-identify as having a disability. [3]

Further reading...

Co-occurring mental illness and behavioral support needs in adults with intellectual and developmental disabilities. [1]

READ MORE

Learn more from a 2018 CDC report highlighting mental distress in people with disabilities. Recall the elements of the social determinants of health in

this report. [4]

LEARN MORE

CONTINUE

Lesson 2: Mental health medications and autism

Recall from Module 1: 1 in 31 eight-year-olds meet the criteria for autism spectrum disorder (ASD) as of 2022. The need for primary care providers who are able to manage care needs for adults with ASD is growing.

Individuals with ASD face elevated rates of co-occurring medical, psychiatric, and behavioral conditions compared to those without. [5]

- Sleep disturbances
- Depression, anxiety, OCD
- Irritability, aggression
- Attention deficit hyperactivity disorder (ADHD)

When trialing and prescribing medications, consider the following elements: [5]

Start low and go slow

- This recommendation is closely aligned with best practice for prescribing medication for older adults.
- Start treatment at the lowest practical dose, then gradually titrate up to most effective dose for the patient.
- This allows for observation of an individual's response to medication and tracking side effects more accurately.

Mode of medication

- Can the patient swallow pills?
- Does an individual require liquid medication?
    - If yes, what does this liquid taste like?
- Is there an alternative form of the medication?
    - Think about sprinkles, crushable, or chewable forms.
- Does a medication require additional elements to monitor, such as regular blood draws?
    - If yes, does this patient tolerate a blood draw well?
    - If not, does the benefit of the medication outweigh the functional elements of its management?
    - Patient adherence, safety, and satisfaction are important treatment elements.

Re-evaluate over time

- Was there an event that happened to cause a new behavior such as a change in environment or circumstance? Has that circumstance resolved?
    - For example, agitation and aggression may naturally improve for a teen with autism who is now in their 20s.
- The efficacy of medication can wane at the same dose over time.
    - Sometimes the answer is to increase a dose...but sometimes the answer is to go **down** instead of **up**.

Track side effects

- Document behaviors, comments about the patient's mood from themselves or a caregiver. Put them directly into notes to be able to refer back.
- Sometimes, a side effect can impact a person's abilities, or they are diagnosed as a new condition altogether.
- Medications for unrelated comorbidities might also have an impact on behavior.

Other conditions causing complex behaviors...back to basics

Note: Sometimes a complex behavior needs to be addressed immediately for safety reasons before other possibilities can be considered.

- Is there a medical cause triggering a new behavior?
- Think head to toe, and do not forget teeth.

- Common causes may be gastrointestinal, dental, kidney or bladder, and thyroid.

Recall from Module 1: Poor dental health is the most common chronic condition in people with IDD

Medications to consider from a primary care provider's perspective [5, 6, 7, 8]

Note: This is not a comprehensive guide for all medications to consider. It can be used as a quick reference and learning guide. For additional information on best practices in prescribing medications for co-occurring conditions in individuals with ASD, read more in the references highlighted at the end of this page.

SLEEP	DEPRESSION, ANXIETY, AND OCD	IRRITABILITY AND AGGRESSION

• Melatonin, 3-6 mg - Higher doses may contribute to anxiety.
  ◦ Remember that melatonin is for **falling asleep**, not for staying asleep
• Mirtazapine - May help with sleep, depression, anxiety, and irritability.
  ◦ May cause weight gain
• Trazadone - Less popular but benefits some patients.		

A general note about sleep: If the patient is not sleeping, that means other household members are not sleeping either.

SLEEP | DEPRESSION, ANXIETY, AND OCD | IRRITABILITY AND AGGRESSION

- SSRIs - A good first line treatment. They may help with inattention and repetitive behaviors. Recommendation to start with sertraline, escitalopram, or citalopram. Fluvoxamine can be supportive for repetitive behaviors with aggression.
- Buspirone - For anxiety and stereotypical behaviors.

Remember to observe behaviors. Behavior is communication!

SLEEP | DEPRESSION, ANXIETY, AND OCD | IRRITABILITY AND AGGRESSION

- Risperidone - FDA approved. Watch for abnormal movements, weight gain, fatigue, and anxiety.
- Aripiprazole - FDA approved. Watch for weight gain, nausea and vomiting, fatigue, and abnormal muscle movements.
- Consider adding an SSRI - recommend sertraline to start.

When evaluating patients with disabilities, what is often missing?

A lack of validated scales, functional outcomes, and a baseline for comparison.

- Consider functional outcomes and patient centered goals - what is important to the patient is not necessarily the same as what is important to the provider.
- Gather as much baseline data as possible. Often, change is small and incremental.
- Prioritize care based on patient and caregiver input, with a key focus on patient safety.

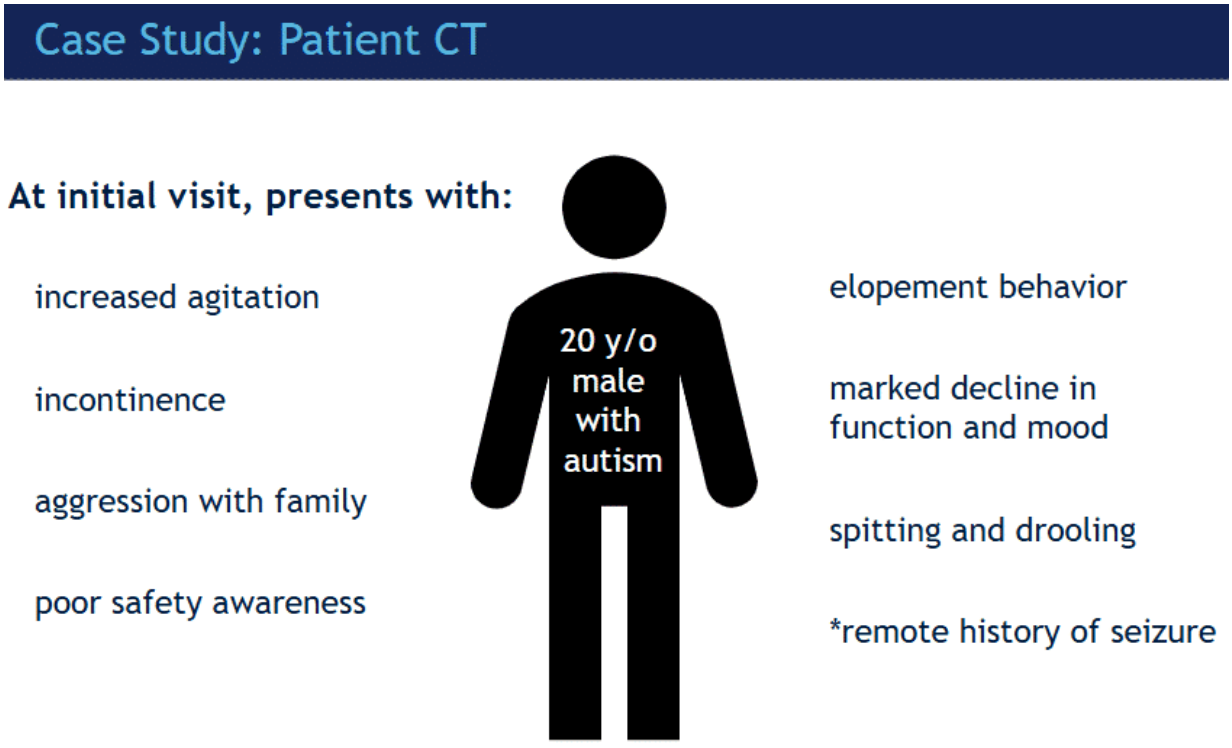
CONTINUE

Lesson 3: Case study 1 - Patient CT

This is a case study of a patient who received care from the Jefferson FAB Center for Complex Care. Patient information has been de-identified.

Background information

CT is a 20-year-old male with autism. Review his symptoms at his initial visit, then follow the progression of care.



Initial symptoms of patient CT, case study 1

Stop and think: How do you approach this patient in the office? What is your differential diagnosis? How would you consider this set of complex behaviors?

After reflecting, flip the card below to see what steps were taken in the office for patient CT at his initial visit.

1

Steps taken at first visit:

Click to flip the card.

- Medications prescribed to address agitation and aggression toward family
- Treated for potential reflux to address drooling and spitting

2

Review the changes to patient CT at his second visit, 6 months later:

- CT has aged out of the education system and has moved into a new group home. CT completed his education at a residential school and greatly benefited from this format, so a group home was the next step for this family after graduation.
- He has marked weight loss and new withdrawn behavior.
    - BMI decreased from 17.1 to 13.8 over one year.
- Hands in mouth, frequent chewing on hands and fingers.
    - Dental issues were checked

and ruled out.

Think, then click to flip this card.

What is the most pressing medical concern at this time?

Significant decrease in BMI

1 of 1

3

Next steps taken for patient CT:

- Medical: Engaged with psychiatry for a consult due to continued behaviors and new withdrawal.
    - Psychiatry recommends lorazepam and sertraline.

- Psychosocial: Group home was changed to better suit CT's needs.

4

With these interventions, CT is now:

- Verbal and speaking multiple words in a sentence
- Going out into the community
    - He enjoys playing with dogs at the dog park
- Spending a lot of time with his family
- Active in his own self care
- CT is now able to tolerate a full physical exam

5

During the time of this case study, CT underwent genetic testing. He was diagnosed with Phelan-McDermid syndrome, a de novo mutation.

How was this helpful to the family?

- Provided information to family members, including CT's sister, who was looking to start a family of her own.

- This syndrome often causes psychosis in the late teens or early 20s. This could have been helpful information to know about the behavioral changes which were being observed in CT during his initial visits.

Genetic testing can be a helpful tool for individuals diagnosed with ASD. Genetic syndromes or chromosomal abnormalities are present in up to 40% of individuals with ASD. [9]

Impact of genetic and genomic testing on the clinical management of patients with autism spectrum disorder. [9]

It can be difficult to have genetic testing covered by an insurer. Learn more about genetic testing and its benefits for individuals with ASD.

READ MORE

Learn more about Phelan-McDermid syndrome. [10]

LEARN MORE

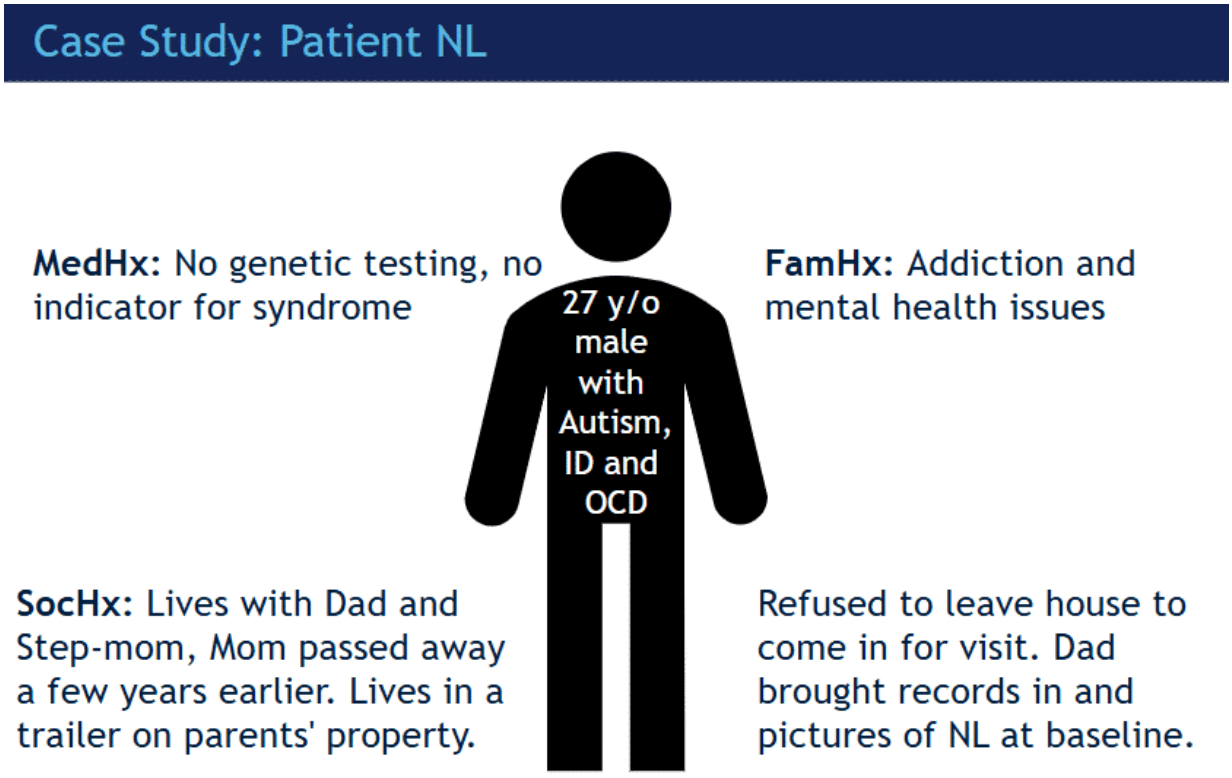
CONTINUE

Lesson 4: Case study 2 - Patient NL

This is a case study of a patient who received care from the Jefferson FAB Center for Complex Care. Patient information has been de-identified.

Background Information

Patient NL is a 27-year-old male with autism, ID, and OCD. Review his relevant medical history, then follow along to his initial visit.



NL histories

Additional background information:

- NL's autonomy is very important to him and his family. He has some past history of refusing to come inside the house where he sits outdoors and rocks, sometimes wearing clothing inappropriate for weather conditions.
- NL would not come to initial office visit. His father drove to the appointment himself and brought pictures of NL from about 1 year prior.

Initial visit - via telehealth

- Since NL did not come to the office for his initial visit, the next day the first visit took place via telehealth with NL's dad as the primary informant.
- During the visit, NL was sitting outside and rocking.
    - Physical appearance was vastly different than the photos which had been shown to providers when NL's dad came in-person the day before. He appeared disheveled and does not look like the smiling man from the photo 1 year prior.
- Primary complaints from NL's father:
    - NL has gained a lot of weight.
    - He sits outside most of the day, even when it is raining or cold.
- Important to note: NL had a recent unremarkable trip to the emergency department for an unrelated behavioral escalation.
    - Clear lab results
    - Unremarkable neuroimaging

Jefferson
HOME OF SIDNEY KIMMEL MEDICAL COLLEGE

Behavioral intervention alone is not effective at this point in time for NL. What are possible differential diagnoses?

Consider possible medical interventions.
Flip this card over to see what treatment was used for NL.

- Failed trial of citalopram
- Stabilized mood using aripiprazole and considered adding fluoxetine

Very frequent visits were elected to monitor NL's condition. All of these visits took place via telehealth.
Review NL's progress with his new medication regimen:

Week 1

NL's father indicates NL was more positive and interactive as well as calmer in demeanor.

Week 2

NL is less irritable and more talkative. He took a shower, shaved, and went for a haircut.

Month 2

(Note time jump)

NL's father says changes were "amazing" and was noticing a "200% difference"

Month 4

(Note time jump)

NL comes in-person to an office visit. He communicates clearly. NL has gained a significant amount of weight at this point; at this point, decreasing the aripiprazole is recommended due to weight gain.

3

Successes

- Dramatic change in NL after 4 months of treatment.
- NL is engaged in his daily life in a way that is meaningful for him and his caregivers.

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As a provider, what else should you consider when monitoring this patient? Which labs might you order? (Hint: Think about risks associated with use of aripiprazole)

CONTINUE

Section 1: Knowledge check

Instructions

This knowledge check is a case scenario. You will review the information provided, then engage with the interactive scenario format to answer questions and provide care for the patient, Max.

CONTINUE

Background information

Max is a 24-year-old man with ASD, ID, and anxiety. His care is being managed in a general primary practice. Max lives at home with his parents and grandmother. He has a sibling who he is very close with, who has recently moved out of state for work.

Max has a history of dental complications, which are now well managed by a specialty dentist who he sees 3 times a year. He has a behavioral history of elopement; however, this behavior has decreased greatly since he is no longer in the education system and finds meaning in the community activities he is involved with.

Max currently takes medicine for seasonal allergies.

Visit information

Max and his mother arrive at the office. They are familiar with this practice and have attended visits in person before. The staff are accommodating to Max's needs, and he is able to come into the office and is escorted directly back to a quiet exam room. Once he is acclimated to the space, Max typically allows providers to complete their exam.

Max had an annual physical exam 6 months ago. There were no remarkable findings, and all of his lab results were in the normal range.

To the provider, Max self-reports he has been very tired recently. He says it is hard to go to sleep.

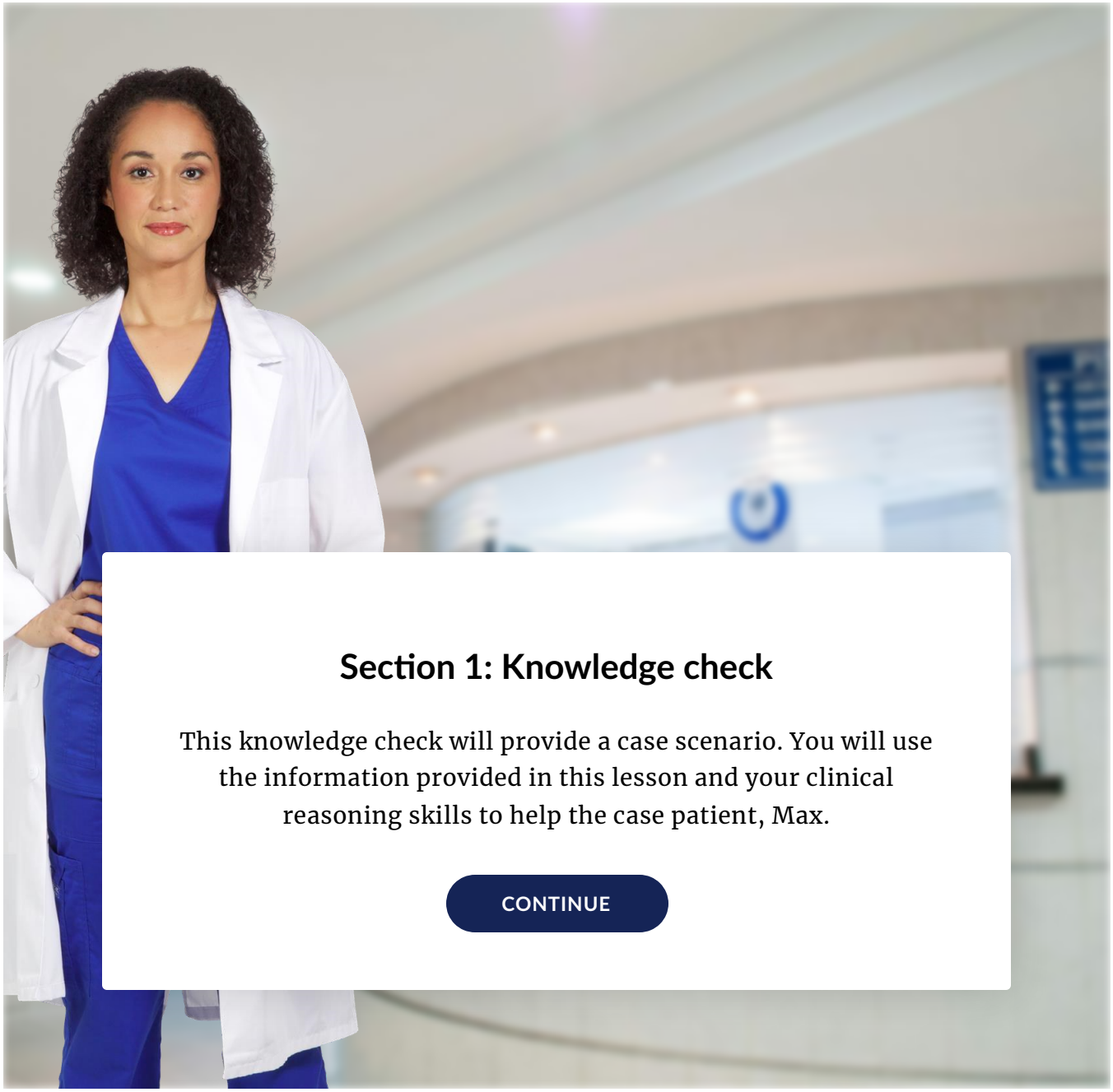
Max's mom provides support to Max's statement that his sleep patterns have changed. Max used to wind down around 9:30pm and fall asleep by 11:00pm. Now, Max is having difficulty winding down at night. He wanders through the house, sits on various furniture for short periods of time, then keeps moving. For the past month, Max won't get to bed until around 2:00 or 3:00am. Max always wakes up by 6:30am no matter the time he goes to bed, so this is a drastic change from his typical routine.

Because he is sleeping much less, Max's parents have noticed an increase in irritability. Once last week, Max fell asleep at work. This prompted the office visit, as Max's employment is very important to him and his family.

Max's daily routine

Max has a consistent weekly routine. Three days a week, he works at a local nursing facility on their dining team. The other two days of the week, Max helps with chores around the house and participates in seasonal Special Olympics sports. His favorite is basketball.

Max and his sibling would spend a lot of time together on the weekends. Max would join in on hanging out with friends and really looks up to his sibling. He is having a very difficult time adjusting to the change since his sibling has moved away.



Scene 1 Slide 1

Continue → Scene 1 Slide 2

Scene 1 Slide 2

0 → Scene 1 Slide 3

1 → Next Slide

Scene 1 Slide 3

0 → Next Slide

1 → Scene 1 Slide 5

Scene 1 Slide 4

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Scene 1 Slide 5

0 → Next Slide

1 → Next Slide

2 → Next Slide

Scene 1 Slide 6

Continue → Scene 1 Slide 7

Scene 1 Slide 7

Continue → End of Scenario

CONTINUE

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. [11]

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.

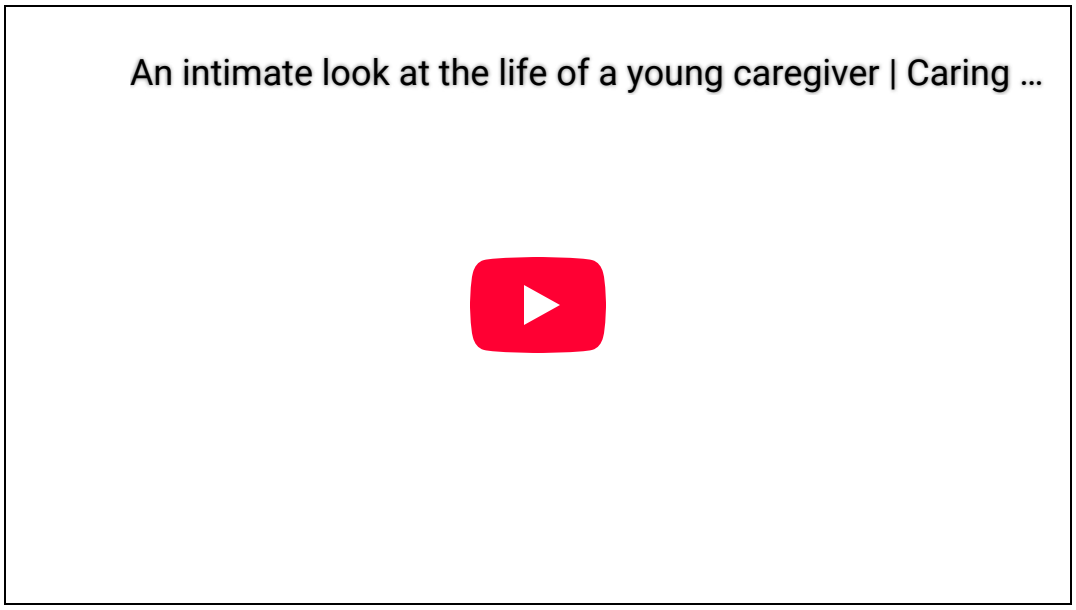
A family's ability to care for someone is dependent on many factors. Things like the timing of care needs, the physical ability of the potential caregiver, and the stage of an individual's disability all can change what caregiving looks like across the lifespan.

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 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. [11]

READ MORE

CONTINUE

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.
Recall from module 2: In-home nursing support can be covered by Medicaid Waiver funds.

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.

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

CONTINUE

Transition planning

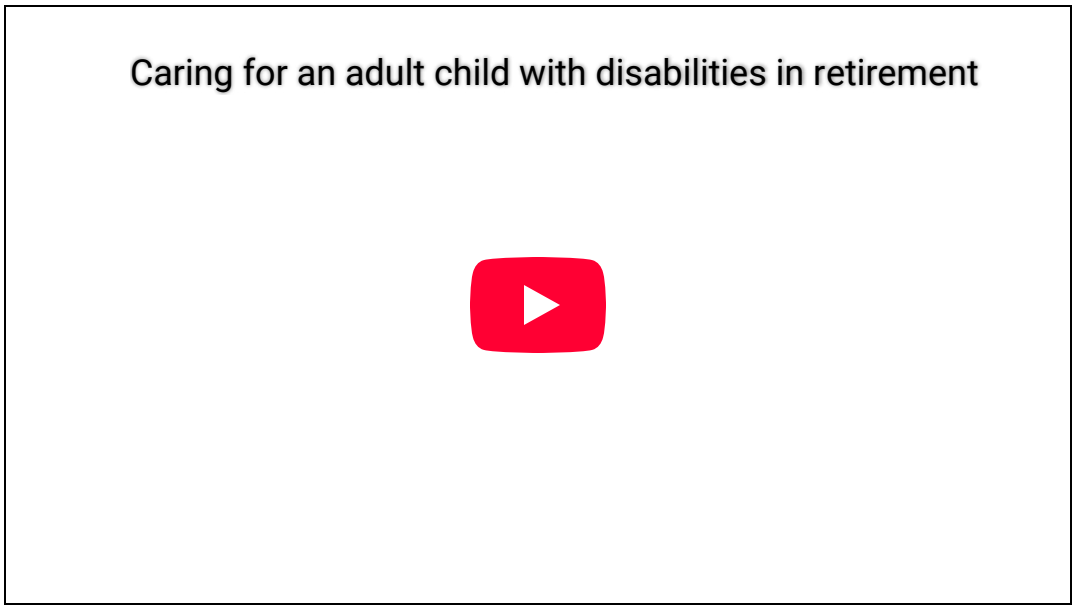
Providers working with patients with disabilities who have a family member as their primary caregiver need to begin conversations about transition planning as their caregiver ages. This is a very difficult conversation. Bringing it up periodically is important, as the process has many parts, is complicated,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

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 [12]

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

LEARN MORE

Got Transition - Youth & Young Adults [13]

LEARN MORE

CONTINUE

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: [14]

- 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. [15]
    - 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 [16]
Online forums for family caregivers and individuals with tracheostomy.

LEARN MORE

Assocation for Autism and Neurodiversity [17]
Offer a wide variety of virtual support groups for individuals with ASD and their supporters.

LEARN MORE

Parents Helping Parents [18]

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

CONTINUE

92% of family caregivers surveyed by The Arc reported they have difficulty finding respite care. [11]

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.

CONTINUE

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.

CONTINUE

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 [19]

- 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 [21]

- 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 [20]

- 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.
- Learn more and sign up: Smart 911

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 [22]

- 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.

USF Health Passport.pdf

539.1 KB

CONTINUE

Section 2: Knowledge check

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

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

CONTINUE

Lesson 1: Emerging trends: Medical cannabis and ASD

Medical cannabis and ASD

- Conventional medical management of ASD shared earlier in this module highlight a variety of antipsychotics, SSRIs, stimulants, and anxiolytics to address behavioral symptoms of ASD.
- 40% of individuals with ASD do not respond well to these standard treatments. [23]
- Therapeutic alternatives are part of ongoing research, with one path focusing on a component of *Cannabis sativa*, Cannabidiol (CBD).
    - CBD and other components in the cannabis plant are being explored in the way they may affect cognition, socioemotional responses, susceptibility to seizures, pain perception, and overall neuronal plasticity.
- Systematic reviews highlight a wide range of response to CBD for symptoms of ASD. [23, 24, 25]
    - Benefits included decreased hyperactivity, increased sleep, decreased aggression and irritability, restlessness, and some changes in language.
    - Mild to moderate side effects were observed in certain individuals; sleep disturbance, restlessness, changes in appetite, and fatigue were most common. However, the effects were not as severe as noted with other medicinal interventions.
    - Note the similarities between the benefits to treatment and the side effects observed. This highlights the individual variance in response for

participants.

- There is evidence that cannabis intoxication in adults may induce acute psychiatric symptoms with higher doses. [25]
- At this point, randomized and double-blind placebo-controlled clinical trials, as well as longitudinal research, will need to be conducted to better understand and clarify the effects of cannabis and CBD on symptoms of ASD.
    - This is a treatment avenue that can be explored for individuals with ASD beyond traditional pharmacological and behavioral interventions. Research is evolving.

- A medical cannabis card can be provided in Pennsylvania for individuals with diagnosed ASD with a physician recommendation.

Learn more about medical cannabis in research:

Safety and efficacy of medical cannabis in autism spectrum disorder compared with commonly used medications. [25]

READ MORE

Cannabis and cannabinoid use in autism spectrum disorder: A systematic review. [23]

READ MORE

The evolving role of cannabidiol-rich cannabis in people with autism spectrum

disorder: A systematic review. [24]

READ MORE

CONTINUE

Lesson 2: Down syndrome Regression Disorder

Down syndrome regression disorder (DSRD) is newly recognized diagnosis categorized by a set of symptoms including neurocognitive regression and loss of previously acquired skills. [26]

This condition is observed in individuals with Down syndrome age 10-30. It had previously been considered a late-onset autism or unexplained regression in Down syndrome. Past research has largely been based on individual case studies. In 2022, a team of experts in Down syndrome care and research established a common nomenclature and set of symptoms for what is now known formally as DSRD. [26] Current research including best practice for diagnostic criteria, treatment, and recommendations continues to evolve.

Symptoms of DSRD are as follows:

- Subacute loss or deterioration of previously acquired developmental skills in categories of language, communication, cognition, executive function, behavior, and adaptive skills.
- Neuropsychiatric symptoms including catatonia, agitation, hallucination, and depersonalization.
    - Whispering is a common onset feature.
- New onset stereotypies: Rocking, hand-flapping, waving, crying, etc. which were not present earlier in life.

- New changes in sleep or instances of aggression.

It is important to note that DSRD is **different from early onset Alzheimer's Disease**, which is common in individuals with DS around 50 years of age.

Santoro et al. [27] investigated the most successful therapeutic advances for DSRD. IV immunoglobulin (IV ig) is currently being investigated as an effective treatment option for the condition. Other successful treatments at this time include antidepressants, antipsychotics, electroconvulsive therapies, and benzodiazepines. Success in treatment supports an individual to reach a psychological baseline and start to regain lost skills.

DSRD is considered a diagnosis of exclusion at this time. There is a role of psychological stress frequently identified as a predecessor to symptoms, which is still unclear but common in patients with DSRD. One primary hypothesis to the etiology of DSRD is a neuroimmunology dysfunction.

Research and treatment for DSRD are ongoing. Learn more about an active clinical trial and recent case reports below.

Children's Hospital of Los Angeles is leading a clinical trial for individuals with DSRD looking at the effects of three different medication options. [28]

LEARN MORE

Evidence of neuroinflammation and immunotherapy responsiveness in individuals with Down syndrome regression disorder. [29]

READ MORE

Case report: Down syndrome regression disorder, catatonia, and psychiatric and immunomodulatory interventions. [30]

READ MORE

Down syndrome regression disorder, a case series: Clinical characterization and therapeutic approaches. [16]

READ MORE

CONTINUE

Lesson 3: Case study 3 - Patient LN

This is a case study of a patient who received care from the Jefferson FAB Center for Complex Care. Patient information has been de-identified.

Baseline information, April 2023

Patient LN is a 23-year-old female with Down syndrome (DS). She attends an in-office appointment at the Jefferson FAB Center in April 2023.

LN is preparing to start a residential program out of state. She is completely independent in activities of daily living like showering. There is some anxiety at baseline, but LN is able to self-soothe. In the office, LN tolerates procedures such as a Pap test and labs.

1

Telehealth follow up, mid-May 2023

A telehealth appointment is conducted about one month after LN's recent in-office visit due to new concerns.

LN is demonstrating extreme anxiety, with increased self-talk and imaginary people.

She is demonstrating frequent crying, wanting to be a baby, and is now only using a spoon to eat.

A recent visit with a therapist recommended starting medications, thinking that a combination of anxiety and depression were present due to the upcoming transition to LN's new program out of state.

LN was started on sertraline and melatonin for these new behaviors.

2

Follow up, end of May 2023

LN's mother sends a message to the provider that she was starting to see improvement with the medication. Then, another regression was noted over these few weeks. LN has started to not want contact with other people (withdrawn) and continues to want to eat like a baby.

3

In-office appointment, August 2023

A continued significant regression and behavior change is observed. The family tried to start the program out of state for LN over the summer, however, she was unable to complete any of the program activities, complete self-care, or self-feed.

She was returned back home. LN's therapist is concerned about depression.

Now, further testing takes place:

- Brain and abdominal MRI
- Labs and sedation for other procedures including lumbar puncture to look for brain inflammation

Results:

- No active inflammation is present.
- Positive TPO antibodies, which pointed toward some inflammatory processes.
    - Hashimoto's encephalopathy was considered as opposed to DSRD.
    - Some specialists believed a possible DSRD pathology, others did not.

4

Next steps, August 2023

- LN was admitted to the hospital in August 2023 and received Intravenous immunoglobulin (IV ig).
- With this treatment, great improvement was noted in LN's symptoms.

5

Follow up

- After inpatient stay, LN was monitored weekly at the Jefferson FAB Center.
- Visits have decreased from weekly to monthly.
- One year later, in August 2024, LN is doing much better! She is regaining the skills which were previously lost.

CONTINUE

Section 3: Knowledge check

Complete the drag and drop activity below. Then, you will have the opportunity to read more about DSRD and reflect on your knowledge.

Read the card, then decide if it is true or false.
Use your mouse to drag and drop the card into the correct pile.

True

DSRD is a diagnosis of exclusion.

DSRD is considered in individuals age 10-30.

Information and treatment about DSRD are evolving with more research.

False

Someone with DS can get DSRD from another person.

Once an individual has DSRD, they will never recover.

DSRD is well-documented and well-understood in the medical and research fields.

Choose one of the resources below about DSRD. Then, answer the reflection question.

A video from Dr. Jonathan Santoro about symptoms, diagnostic criteria, and testing. (6 min)

WATCH THE VIDEO

Immunotherapy responsiveness and risk of relapse in Down syndrome regression disorder. [32]

Research article from Translational Psychiatry

READ THE ARTICLE

Read about a family's journey with DSRD. [33]

Learn about Amy and her family's experience.

READ MORE

Jefferson

HOME OF SIDNEY KIMMEL MEDICAL COLLEGE

What is one thing you learned about DSRD from the material you chose? How might you support a patient in your clinic who is

CONTINUE

Conclusion

Thank you for participating in **Module 3, Mental and Behavioral Health**. This is part 3 of a 4-part 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.

Please complete the post-module satisfaction survey below in order to provide information to PADDC for reporting purposes.

Thank you for your support, engagement, and interest in increasing high quality care for patients with IDD. Please review the additional resources below after completing the survey 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

References Sheet Module 3__.pdf

151.5 KB

PDF

Module 3 Additional Resources__.pdf

147.3 KB

Please complete the satisfaction survey below from project funders at PADDC.

This survey will take 2-5 minutes to complete.

For each question, please choose the

Learning Objectives from Module 3:

- Identify barriers to behavioral health treatment for people with IDD
- Identify the ways in which behavioral health concerns can manifest in people with IDD
- Discuss the role of medication management in the primary care setting

- Discuss the role of family caregivers and healthcare transitions