SIDNEY KIMMEL MEDICAL COLLEGE

Mental and Behavioral Health

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Jefferson
Thomas Jefferson University

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Increasing Access to Quality Healthcare for People with Disabilities: A Co-Designed Educational Curriculum for Family Medicine Residents

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We'd Like to Thank Our People With Lived Experience!

- To help in the planning and design of these didactic sessions, we have hired individuals with lived experience with disabilities, as well as some caretakers, as advisors.
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Objectives

- Identify barriers to behavioral health treatment for people with IDD and neurodiversity
- Identify the ways in which behavioral health concerns can manifest in people with IDD and neurodiversity
- Discuss the role of medication management in the primary care setting
- Discuss the role of adult protective services and how to make a report

Background

Disability and Mental Health

People with intellectual and developmental disabilities (IDD) have higher rates of mental health conditions and behavioral support needs

- Hard to say what the rate is because there aren't good diagnostic tools!

Anxiety and depression are very common but schizophrenia and post traumatic stress disorder (PTSD) are also overrepresented in this population

For a long time, the medical field didn't believe that people with IDD could have mental health conditions and so their conditions often went unnoticed and untreated

Barriers to Finding Mental Health Care

Even people without complex conditions have trouble finding care when they are neurodivergent

- Finding and scheduling with a mental health professional can be complicated

People with disabilities find that providers without disabilities don't understand the challenges they face

There are not enough providers with a disability

- Only about 1.5% of members of the social psychology professional society with a doctorate in psychology and able to provide care have a disability

Case Study: Patient CT

Case Study: Patient CT

At initial visit, presents with:

- increased agitation
- incontinence
- aggression with family
- poor safety awareness

- elopement behavior
- marked decline in function and mood
- spitting and drooling
- *remote history of seizure

How do you approach this patient in the office?

What's in your differential?

How would you approach the complex behavior?

Let's pause to discuss mental health medications and autism.

Medications for mental health and complex behaviors

- **Start low and go slow!**

- Re-evaluate over time
  - Has the trigger or circumstance resolved?
  - Agitation and aggression may naturally improve with time so think about lowering doses periodically
  - Effectiveness of certain medications may be lost over time at the same dose
    - Sometimes the answer is less!

- Track side effects
  - Sometimes side effects can affect people's abilities or be diagnosed as something new

Wait...

- Have we considered medical conditions that could be causing complex behaviors?
  - Think head to toe... and don't forget the teeth!

Medications to consider from a Primary Care perspective

- For irritability and aggression*
  - Risperidone- FDA approved
    - Watch for abnormal movements, weight gain, fatigue and anxiety
  - Aripiprazole- FDA approved
    - Weight gain, nausea and vomiting, fatigue, abnormal muscle movements
  - Maybe Sertraline- an SSRI

*LeClerc 2015, Doyle 2012

Medications to consider from a Primary Care perspective

- For depression/ anxiety/ OCD
  - SSRIs
    - May help with inattention, repetitive behaviors
    - Start with sertraline, escitalopram, or citalopram
    - Fluvoxamine with repetitive behaviors, aggression
  - Buspirone+ for anxiety and stereotypical behaviors

+Palumbo 2018

Medications to consider from a Primary Care perspective

- For sleep
  - Mirtazapine
    - May help with depression, anxiety, and irritability
    - May cause weight gain
  - Melatonin
    - 3-6mg – higher doses may contribute to anxiety
    - 30-60 minutes before bed
  - Trazodone

+Palumbo 2018

Back to our case study

Case Study: Patient CT

At second visit:

- Patient has aged out of education system and moved into a group home
- Marked weight loss and withdrawal
  - (BMI 17.1 to 13.8 in 1 year)
- Hands in mouth, chewing them all the time
  - Check for dental issues

Case Study: Patient CT

Currently:

- On Ativan and Zoloft
  - (Anti-epileptic drugs work as mood stabilizers but can cause irritability)
- verbal
- speaking multiple words in sentences
- goes out in the community
- plays with dogs at the dog park
- spending a lot of time with family
- active in his own self-care
- able to tolerate a full physical exam

Case Study: Patient CT

CT was diagnosed with **Phelan-McDermid Syndrome**, a de novo mutation. CT's family had a lot of questions, especially as sister is considering starting a family of her own and was worried about risks. Ultimately, family was happy to have a diagnosis.

Adult Protective Services

Contacting Adult Protective Services

PA Statewide Abuse Hotline (24/7): 1-800-490-8505

- To report elder abuse or abuse of an adult living with a disability
- State investigations
- Helped parents find home health aides when Patient CT had to be kept at home

  *APS is not just for reporting suspected abuse or neglect, they can help families when they need support or resources

Act 70 PA Mandatory Abuse Report

pennsylvania DEPARTMENT OF AGING | pennsylvania DEPARTMENT OF HUMAN SERVICES

MANDATORY ABUSE REPORT

Date of Report:	Time:

Name of victim/recipient/consumer (Last, First, M.I.):		Facility name:
Address:		Address:
City:	State: Zip Code:	City: State: Zip Code:
Phone:		Phone:
Date of birth:	Sex:	Facility type: (NH, PCH, DC, CLA, etc.)
Date and time of incident: Date: / / Time: ____ : ____ A.M. / P.M.		Facility licensing agency: / Facility licensing number:
Date and time of report to licensing agency: Date: / / Time: ____ : ____ A.M. / P.M.		Licensing agency contact and telephone number: Name: Telephone # :

OAPSA (OVER 60)

Abuse type: (check one)

- ☐ ABUSE not Involving sexual abuse, serious bodily injury, serious physical injury or suspicious death
- ☐ SEXUAL ABUSE (rape, involuntary deviate sexual intercourse, sexual assault, statutory sexual assault, aggravated indecent assault, indecent assault or incest)
- ☐ SERIOUS BODILY INJURY ☐ SERIOUS PHYSICAL INJURY
- ☐ SUSPICIOUS DEATH

APS (UNDER 60)

Abuse/Neglect type: (check one)

- ☐ ABUSE, NEGLECT, EXPLOITATION or ABANDONMENT not Involving sexual abuse, serious injury, serious bodily Injury or suspicious death
- ☐ SEXUAL ABUSE (rape, involuntary deviate sexual intercourse, sexual assault, statutory sexual assault, aggravated indecent assault, or incest)
- ☐ SERIOUS BODILY INJURY ☐ SERIOUS INJURY
- ☐ SUSPICIOUS DEATH

Date/Time oral report to AAA: Date: / / Time: ____ : ____ A.M. / P.M.	Name of AAA contacted:	*AAA/APS Agency use only* Date/Time oral report to county coroner: (If applicable) Date: / / Time: ____ : ____ A.M. / P.M.	*AAA/APS Agency use only* Name of coroner: (If applicable)
Date/Time oral report to local law enforcement: (If applicable)	Name of law enforcement agency: (If applicable)	Date/Time oral report to PDA/DHS: (If applicable)	

Contact information: (Please check appropriate block) ☐ Guardian ☐ Attorney-in-fact ☐ Next of kin	Alleged perpetrator name:	Relationship to victim:
Name:	Address:	
Address:	City: State: Zip Code:	
City: State: Zip Code:	Phone number: / Age: / Sex:	
Phone: Relationship:	Type of position: (RN, LPN, CNA, etc.) / Work shift: / Date of hire:	

PLEASE COMPLETE REVERSE SIDE

PA 1943 5/16

Details and description of abuse: (attach additional sheets if necessary)	
Actions taken by facility, including taking of photographs and X-Rays, removal of victim and notification of appropriate authorities: (attach additional sheets if necessary)	
Other pertinent information, comments or observations directly related to alleged abuse incident and victim:	
Name and title of reporter: (Please type of print) Name: Title:	Signature of reporter:
Reporter contact information: Telephone number: Email address:	Date:
Name and title of person preparing report: (Please type of print) Name: Title:	Signature of person preparing report:
Person preparing report contact information: Telephone number: Email address:	Date:

PA 1943 5/16

Retaliatory Reporting

Families that have nurses and case workers coming to their home are vulnerable and can be judged without having the whole picture

These people also have a lot of power over a family

- Retaliatory reporting can and does happen after a nurse or aide is reprimanded or fired
- Adds a lot of unnecessary stress and distress

Celebrate Success!

On the flip side, it's great for family and caregivers to be acknowledged when they are providing good care and support for someone! It's nice to be seen!

Case Study: Patient NL

Case Study: Patient NL

MedHx: No genetic testing, no indicator for syndrome

FamHx: Addiction and mental health issues

SocHx: Lives with Dad and Step-mom, Mom passed away a few years earlier. Lives in a trailer on parent's property.

Refused to leave house to come in for visit. Dad brought records in and pictures of NL at baseline.

Case Study: Patient NL

NL's First Visit with the FAB Center:

- March of 2022
- Telehealth as he refused to leave home
- Did not want to engage with providers during visit
- Complaints from dad:
  - NL gained a lot of weight
  - Sits outside most of the time, even when raining or cold
- Provider noticed:
  - NL looked disheveled
  - Significant change from the photo from the year before where he was dressed up and smiling
- Recent unremarkable trip to ED

Case Study: Patient NL

Medication and Treatment:

- Failed trial of Celexa
- Stabilized mood with Abilify and considered adding Fluoxetine

Case Study: Patient NL

Treatment Progress from Initial Visit:

1 week
- Dad indicated NL was more positive and interactive as well as calmer

2 weeks
- Less irritable, more talkative
- Took shower, shaved, went for a haircut

2 months
- Dad said changes were "amazing" and there was a "200% difference"
- NL going bowling, out to eat, hugging dad
- Improved hygiene and appetite

4 months
- NL able to come into office and communicate clearly
- Gained a significant amount of weight*

*At this point, consider decreasing Abilify because of weight gain.

Case Study: Patient NL

- Successes:
  - Dramatic change in NL in 4 months of treatment
  - Parents are both patients of the FAB Center now too and are up to date on preventative visits

What's often missing when evaluating patients with disabilities?

	Validated scales
	Functional outcomes
	A baseline for comparison

Down Syndrome Regression Disorder

Down Syndrome Regression Disorder Background*

- In the past has been referred to as or considered:
  - late onset autism
  - Down syndrome disintegrative disorder
  - Unexplained regression in Down syndrome
- Typically occurs in individuals with DS between 10 and 30 years of age*

*Important to note that DSRD is different from early onset Alzheimer's which is common in individuals with Down syndrome around age 50

*Stephens & Roseman, 2023: https://www.myodp.org/mod/book/view.php?id=47289&chapterid=1041

Down Syndrome Regression Disorder Background

- Features include:
  - Subacute loss of skills including:
    - Language
    - Communication
    - Cognition
    - executive function
    - behavioral and adaptive skills
  - New onset stereotypes
    - Rocking
    - hand-flapping
    - waving
    - and other autistic features

Down Syndrome Regression Disorder Background

- This disorder, while similar to autism, is a distinct diagnosis from autism
- Efforts are underway to understand etiology, treatment, and diagnostic criteria
- The role of psychological stress is unclear but common in patients with DSRD
- One hypothesis is neuroimmunology dysfunction given the responsiveness to IV immunoglobulin in some cases

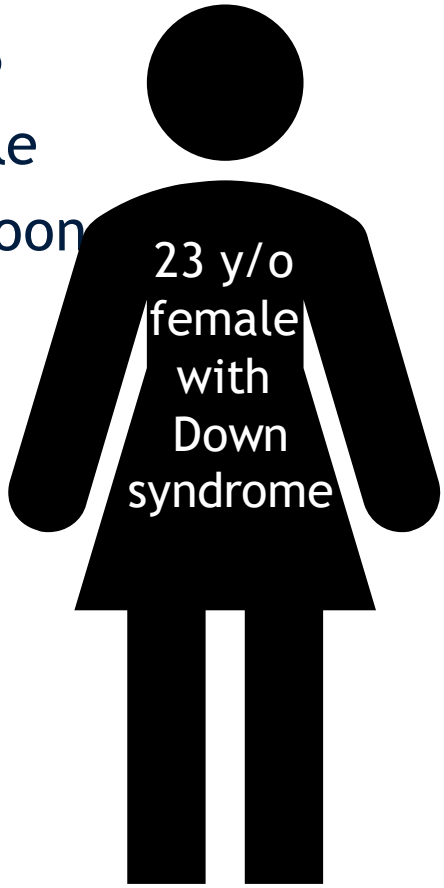
Case Study: Patient LN

Case Study: Patient LN

- Appointment in office in April 2023
  - LN about to start a program out of state
  - Totally independent with things like showering
  - Anxious but able to settle self
  - Able to have Pap and labs done in the office

Case Study: Patient LN

- Telehealth appointment in mid-May 2023
  - Extreme anxiety, self-talk, imaginary people
  - Crying, wanting to be a baby, only using spoon
  - Recently saw therapist who recommended starting meds
    - LN distressed by visit
    - Started on Sertraline and Melatonin



Case Study: Patient LN

- Message from Mom in end of May:
  - Started to see improvement but then LN reverted to previous behaviors
  - Would not have contact with other people
  - Wanted to eat like a baby

Case Study: Patient LN

- In office appointment August 2023
  - Significant behavior changes
  - Tried to start program out of state but exhibited further regression- unable to participate in any activities
  - Returned home unable to complete self-care activities or feed herself
  - Therapist concerned about depression

Case Study: Patient LN

- Evaluations
  - Brain MRI, abdominal and pelvic MRI, labs
  - Sedation for other procedures like lumbar puncture
  - Considered ovarian pathology
- Results
  - No evidence of active inflammation
  - Positive TPO antibodies
  - Thyroglobulin pointed towards some inflammatory process
  - Considering Hashimoto's encephalopathy as opposed to DSRD

Case Study: Patient LN

- Admitted to hospital in August
- IV Ig
- Seen at FAB once a week and now once a month
- Doing much better now

Caregiver Mental Health

Caregiver Burnout

- Assistance for someone with disabilities often falls to their family who are usually not trained medical professionals
  - There are a lot of things to learn, supplies to acquire and store, and technology/ devices to adjust to!
  - Family's ability to care for someone is dependent on the timing, ability of person, and stage of disability. Sometimes it has to be a nurse providing home care.
- Medical care, employment, physical, and mental health are all impacted when someone is a caregiver
- Different adjustment periods for caregivers for someone born with a disability versus someone with an acquired disability

Vulnerability

When someone is medically complex, there are a lot of people in their life that they didn't invite into it

- Doctors, social workers, home health nurses, etc.

- People come into their home and judge them without really knowing them

Strangers are involved in very intimate aspects of a person's life and that is difficult to adjust to

- At the same time, this is necessary as it is difficult to find a family member/ friend who is comfortable caring for someone who is medically complex.

Caregiver Mental Health Services

- Similar to the way that people with disabilities struggle to find therapists or counselors that understand the challenges they face, caregivers also struggle to find people who understand their situation

- Caregivers can join support groups but often end up providing others with the support that they need themselves
  - Support groups are still very necessary though!

Hear from Marie, who is the caregiver for her daughter who suffered a traumatic brain injury

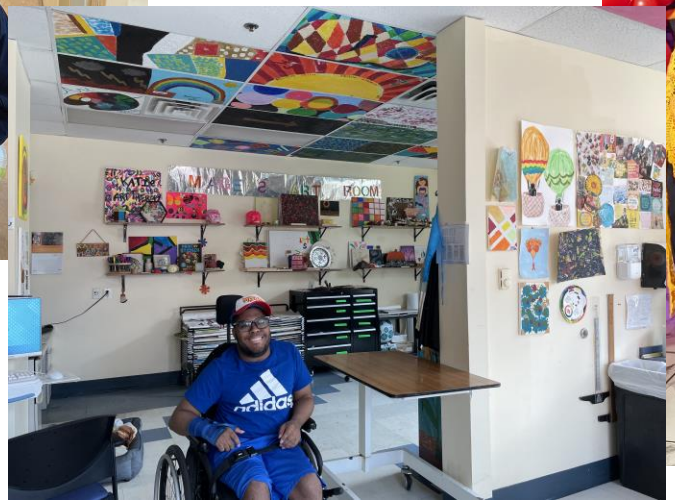
Primary Care Providers

- It’s important to know if you have a patient who is a full time caregiver as it can affect aspects of their own care
- When working with patients with disabilities whose parents are their caregivers, it’s important to think about a transition plan early as the caregivers age
- Please note that not everyone has family that can help them. Some people with disabilities hire and manage all of their own outside care

Resources

Magee Rehabilitation

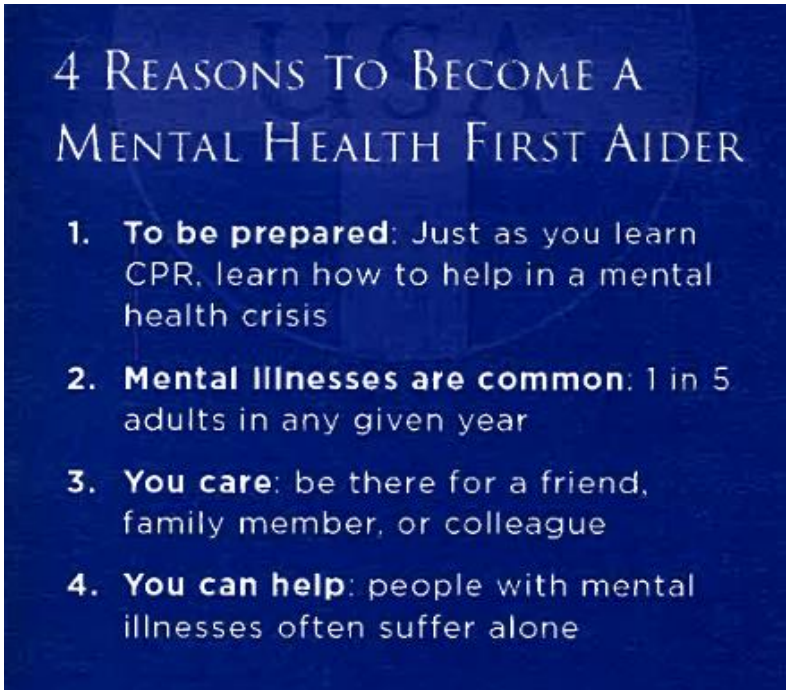
They have great therapeutic options including art therapy, caregiver support groups, and therapy dogs (and 70s parties for patients…)!



Roc and Ms. Donna love it there!

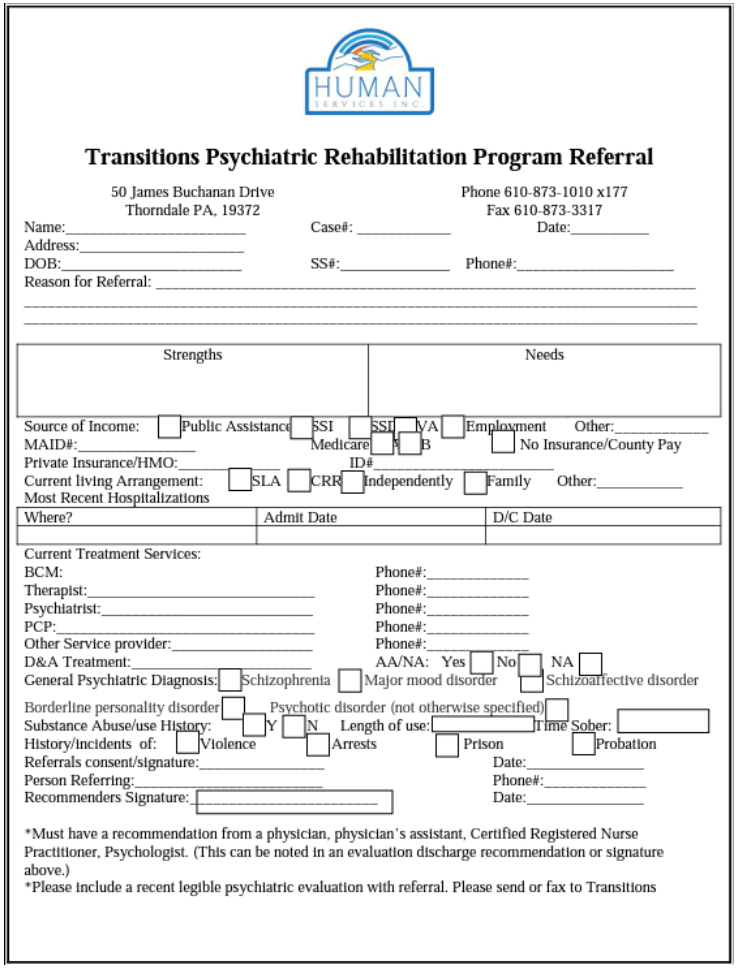
Mental Health First Aid

- The Philadelphia Department of Behavioral Health and Intellectual and disAbility Services sponsors this 8 hour training program
- Go to healthymindsphilly.org for more information!



Transitions

- Transitions is a psychiatric rehabilitation program in Thorndale, PA
- Focus on:
  - Living, learning, working, socializing, and self-maintenance
- Can send referrals and a current psychiatric eval to:
  - Joseph Hickey (jhickey@humanservicesinc.org)
- More info on Canvas!



Transitions Psychiatric Rehabilitation Program Referral

50 James Buchanan Drive
Thorndale PA, 19372

Phone 610-873-1010 x177
Fax 610-873-3317

Name:_____ Case#: _____ Date:_____
Address:_____
DOB:_____ SS#:_____ Phone#:_____
Reason for Referral: _____

Strengths	Needs

Source of Income: ☐ Public Assistance ☐ SSI ☐ SSD ☐ VA ☐ Employment Other:_____
MAID#:_____ Medicare ☐ A ☐ B ☐ No Insurance/County Pay
Private Insurance/HMO:_____ ID#_____
Current living Arrangement: ☐ SLA ☐ CRR ☐ Independently ☐ Family Other:_____
Most Recent Hospitalizations

Where?	Admit Date	D/C Date

Current Treatment Services:
BCM: Phone#:_____
Therapist:_____ Phone#:_____
Psychiatrist:_____ Phone#:_____
PCP:_____ Phone#:_____
Other Service provider:_____ Phone#:_____
D&A Treatment:_____ AA/NA: Yes ☐ No ☐ NA ☐
General Psychiatric Diagnosis: ☐ Schizophrenia ☐ Major mood disorder ☐ Schizoaffective disorder
Borderline personality disorder ☐ Psychotic disorder (not otherwise specified) ☐
Substance Abuse/use History: ☐ Y ☐ N Length of use:_____ Time Sober: _____
History/Incidents of: ☐ Violence ☐ Arrests ☐ Prison ☐ Probation
Referrals consent/signature:_____ Date:_____
Person Referring:_____ Phone#:_____
Recommenders Signature:_____ Date:_____

*Must have a recommendation from a physician, physician's assistant, Certified Registered Nurse Practitioner, Psychologist. (This can be noted in an evaluation discharge recommendation or signature above.)
*Please include a recent legible psychiatric evaluation with referral. Please send or fax to Transitions

Some important crisis lines:

- Suicide and Crisis Lifeline: 988
  - 24/7, call or text, options for deaf or hard of hearing
- Einstein's Crisis Response Center
  - 215-951-8300
  - 24/7 support for acute psychiatric needs
- Einstein Intellectual Disability Services Emergency Line
  - 215-829-5709
    215-685-6440 (After 5 p.m.)
  - Emergency placement or to report missing person with ID
- National Domestic Violence Hotline
  - 1-800-799.SAFE (7233)
    Text "START" to 88788
  - 24/7
- Phila. Domestic Violence Hotline
  - 1-866-723-3014
  - 24/7
- Philadelphia Crisis Line
  - 215-685-6440
  - 24/7 behavioral health emergency services system
  - Ability to dispatch mobile emergency team for mental health crises

Contact Information

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Discussion/ Q&A Time!

Jefferson

Thomas Jefferson University

Jefferson.edu/SKMC