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Caring for aging patients with IDD/ASD/SPMI

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Caring for aging patients with IDD/ASD/SPMI



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Drs. Herge, Rene and Stephens
September 10, 2020

Disclosures. . . None officially. . . But we just wrote a chapter together and. . . meet Callie again!



Outline and Objectives

- What are we talking about?
- Prevalence and associated co-morbidities
- Healthy aging pearls for special populations
- A case: Dr. Herge. . . . From the OT perspective
 - Best practices for referral and resources
- A case: Dr. Rene. . . . From the behavioral health perspective
 - Best practices for referral and resources

Language Guidelines

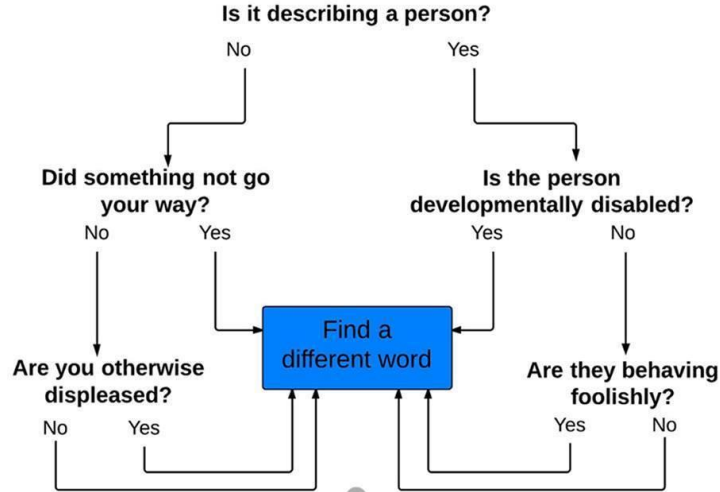
So, for example. . . .Down syndrome 101

- Person-first language
 - An adult with Down syndrome vs. “He has Down’s” or Down syndrome adult
- Cognitive or intellectual disability, not mental retardation

It doesn’t always flow smoothly off the tip of the tongue. . . that’s ok, keep trying.

SPREAD THE WORD TO END THE WORD

When is it okay to use the word
retarded?



MILITARY SPECIAL
NEEDS NETWORK

Developmental Disability

- A severe, chronic disability in someone 5 years or older
- Onset before age 22
- Affects 3 or more areas of life activities
 - Self-care, receptive/expressive language, learning, mobility, self-direction, capacity for independent learning, economic self-sufficiency

Intellectual disability

- Significantly reduced ability to understand new or complex information and to learn and apply new skills
 - Which impairs ability to cope independently
- . . .and begins before adulthood

ASD

- The name keeps changing
 - And it's a relatively new-ish diagnosis (1940s)
- Autism Spectrum Disorder
 - Asperger's syndrome
 - High or low functioning
 - PDD
 - Childhood disintegrative disorder

ASD

- First recognized formally in the 1940s
 - Complex neurodevelopmental condition
 - Characterized in 2013 in DSM-5
 - Persistent deficits in social communication and social interaction across multiple contexts
 - Social-emotional reciprocity
 - Deficits in nonverbal communicative behaviors
 - Deficits in developing, maintaining and understanding relationships
- Ask your patient how they want you to address them
 - May be exceptions to the person first language rule here
 - Autistic adult or an Aspie

SPMI

- Severe and Persistent Mental Illness
 - Schizophrenia
 - Schizoaffective disorder
 - Treatment refractory depression
 - Bipolar d/o

Aging

- Keys to successful aging
 - Avoiding disease
 - Maintaining high cognitive and physical functioning
 - Maintaining engagement in life
 - Rowe and Kahn

Aging

- The WHO and others recognize adults with disabilities as a vulnerable population
 - Risk for secondary conditions/co-morbidities
 - Age-related conditions
 - Higher rates of premature death
- Adults with disabilities AND ID/DD are at an even greater risk

Social Determinants of Health

- Think about a “cascade effect”
 - Starting with co-morbidities/underlying condition and key social determinants
 - Access to care
 - Access to quality care
 - Challenges with screening and detection of disease
 - Communication barriers
 - Validated scales?

IDD and aging

- Maybe 1 - 4 % of the adult population
- Growing population
- Life expectancy lower than average (66) but improving
- More health disparities and poorer health than peers

IDD and aging

- Comorbid conditions
 - Vision and hearing
 - Obesity
 - Skin conditions
 - Dental caries and disease
 - GI conditions
 - Thyroid disease
 - Osteoporosis
 - Mental health diagnoses

IDD and aging

- What about dementia?
 - In general, same as the risk for the general population except for Down syndrome
 - Average age in DS is in the 50s
 - Can occur in 40s but really question in younger adults and always look for reversible causes/look-alikes
 - NTG-Early Detection and Screening for Dementia tool

ASD and aging

- Prevalence probably around 1 - 2%
- ? Growing vs more recognized population
- Decreased life expectancy and increased risk of premature death
 - Worse if associated with more severe degrees of ID
 - Epilepsy, sudden unexplained death and injury
 - Increased rates of mortality when hospitalized

ASD and aging

- Comorbid conditions and unmet health needs
 - Epilepsy
 - CVD
 - Endocrine conditions
 - Obesity and feeding/nutritional deficiencies
 - Sleep disorders
 - Depression/anxiety/PTSD

ASD and aging

- Lower general and chronic condition self-efficacy
- Higher odds of unmet physical and mental health needs
- Lower rates of Td and paps
- Greater use of the ED

SPMI and aging

- Growing segment of the population
 - ? 4 - 6 %
 - Mortality gap is widening
 - Death 10-20 years earlier than general population

SPMI and aging

- Suicide and unintentional injury are common
- Tobacco and obesity contribute to excess mortality
- Unrecognized medical diagnoses
 - Substance abuse
 - High risk sexual behavior
 - HIV
- Symptoms of disorganization and anticholinergic side effects

Pearls for the family doc

- Remember the interprofessional team!
- Understand who the decision maker is and re-evaluate over time. . . But never forget the patient
- Review the med list
 - For those with IDD, 20-40% on at least 5 meds
- Manage pain. . . Not just with meds!
- Start early!

Thank you. . . We know it's early and a lot to think about!!!



Jefferson Elder Care

E. Adel Herge, OTD, OTR/L, FAOTA

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Interprofessional Team



Occupational Therapy and Dementia

- Occupational therapy practitioners help people with Alzheimer's disease and other dementias and their caregivers to live life to its fullest by:
 - focusing on what the person can do to maximize engagement in activity (occupation)
 - promoting safety
 - adapting the environment
 - enhancing quality of life

<https://www.aota.org/About-Occupational-Therapy/Patients-Clients/Adults/Alzheimers.aspx>

Wellness Programs

Falls Prevention

- Modifying environment



https://img.thrfun.com/img/079/892/throw_rug_1.jpg

CG education

- Promoting stress management



<https://www.mindandmovement.com.au/mbsr-perth/>

Health Promotion

Health promotion

- Facilitating engagement in preferred activities
- Maintaining habits and routines



<http://seniors.lovetoknow.com/mental-activities-senior-citizens>

Activity and/or Environment Modification

- Modifications
 - Adapting environments to promote safety
 - Providing supports to increase participation in activity



<https://www.afb.org/afbpress/image>



<http://www.signaturehardware.com/media/catalog/product/>

<https://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/MH/Facts/Dementia.pdf>

Jefferson Elder Care



Jefferson Elder Care is committed to improving the lives of individuals who have memory loss, Alzheimer's disease or other dementias and intellectual disabilities



Jefferson Elder Care

Clinical and Consultative Services

- Home Safety Assessments
- Skills2Care® and Skill2Care®-ID
- Agency Consultation



<https://starklab.wustl.edu/i-hope-kit/>

Occupational Therapy Dementia Service

Service is provided in the living space of the person with dementia

- Comprehensive evaluation
 - Sensory, motor
 - or, cognitive functions
 - ADL performance
 - Home Environment
- Plan of care
 - Goals
 - Treatment plan



Skills2Care®

- **Skills₂Care®** is an evidence-based program
- Occupational therapists trained in Skills₂Care® provide hands-on-education to caregivers
- Strategies are tailored to the unique needs and environments of the person with dementia and caregiver

- **Outcomes:**
 - improves well-being and skills of the caregiver
 - reduces challenging behaviors
 - slows decline in daily functioning of the person with dementia

Skills2Care®

- **Assessment:**
 - Caregiver identified problems and needs
 - Caregiver readiness to change level
 - Caregiver management and communication
 - Caregiver depressive symptoms
 - Home environment for safety and support of activity
- **Education:**
 - Alzheimer's disease and other dementias
 - Caregiver stress management techniques
 - Problem-solving approach and brainstorming

Skills2Care[®]

- **Practice:**
 - Customized *Action Plan*
 - Practice and reinforce strategies that address caregiver identified problems
- **Generalization:**
 - Apply knowledge and skills with other care situations
 - Modify strategies as disease progresses

ID and dementia

Behavioral Changes

“Behavioral excesses”

Aggression

Anxiety

Restlessness

Personality Changes

Social Withdrawal

Apathy

Stubbornness / uncooperative



Other Changes

Disturbed sleep

Low mood/affect

Difficulty with self care

Adams et al, 2008; Ball, et al, 2006; Prasher & Filer, 1995

Skills2Care[®]-ID

- **Carrie**
 - 77 y o female
 - Moderate ID, anxiety, depression, dementia symptoms
 - Lives with her sister; niece provides care for both
 - Supported by full time DSP; behavioral specialist
 - Attends day program 2-3 days per week; community outings
 - Home
 - LR and bedroom; shares bathroom with sister

Skills2Care®-ID

- Obsessive behaviors (cleaning, laundry)
- Agitation and anxiety; outbursts
- Refusal behaviors
- Increased fall risk
- Enjoys doing paperwork
- Coloring/drawing
- Listening to music on CD player
- Minimal assist with ADLs

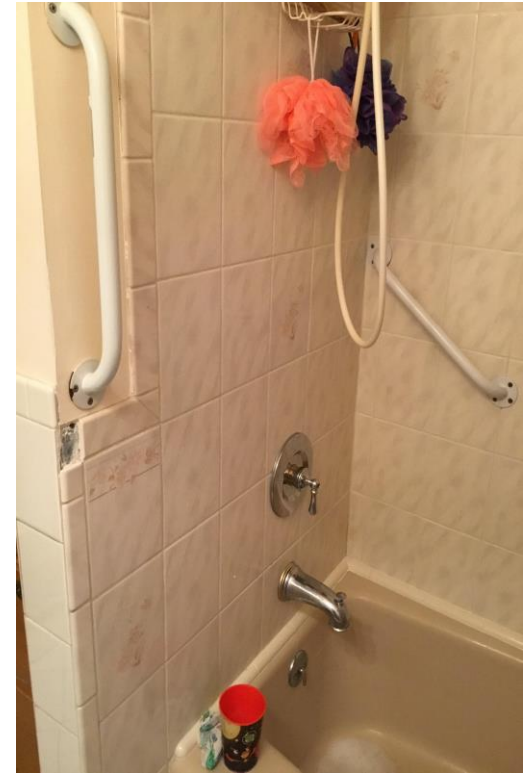
Occupational Therapy-Carrie

Goals:

- Reduce dementia related behaviors to maintain participation in self care
- Use compensatory strategies and adaptive equipment to transfer safely
- CG will be skilled in using compensatory strategies to maintain pt participation in self care
- CG will be skilled in using compensatory strategies to maintain pt safety during transfers

Occupational Therapy-Carrie

- Bathroom
 - Adaptive equipment



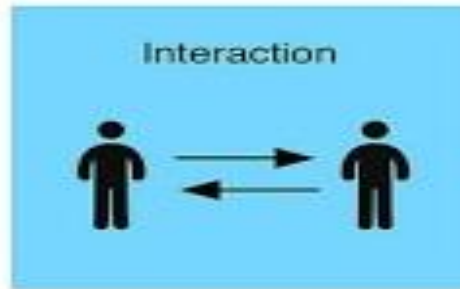
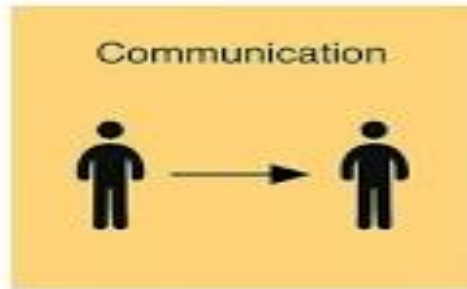
Skills2Care®-ID--Carrie

- **Problem areas:**
 - Aggression
 - Anxiety
 - Refusals
 - Leisure participation



Skills2Care[®]-ID--Carrie

- 6 visits completed
- Collaborated with DSP; behavioral specialist
- Maintained communication with the niece (phone, email)



Skills₂Care.

Action Plan Agitation or Anxiety

Name: C Date: 7-18-2018

Description of the problem: C sometimes becomes anxious or agitated about activities or situations that arise.

Why the problem may occur:

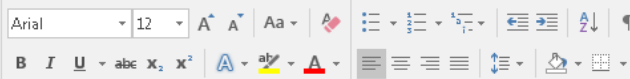
- Being told "no"
- Overstimulation (too noisy, too many people) or under-stimulation (boredom)
- Feelings of failure or sense of rejection
- Feelings of fear

How I want the problem to change: C will be more relaxed and less agitated about activities or events.

STRATEGIES

Simplifying the way you communicate

DO:	DON'T:
<input type="checkbox"/> Provide 1 to 2 step simple verbal instructions. Say: "Let's go to the bathroom"	Avoid using long sentences or abstract words. Avoid asking questions.
<input type="checkbox"/> Provide simple direct statements. Distract and re-direct to reduce	Avoid asking questions. Avoid long explanations or continuing to talk about



Arrow down time and breaks. Provide several shorter activities rather than one longer one. Avoid expectations for the ability to do one activity right after another. Avoid long complicated activities.

Specific recommendations:

1. C has been asking for "coffee" more frequently recently. Instead of saying "no, you had two cups already" provide a warm drink that could be a small amount of coffee with lots of milk OR other drink that can be served warm (ie. a nutritional Boost). It appears she enjoys a warm drink with dairy so something similar might satisfy her.
2. When C becomes tearful or agitated and is not easily calmed with a hug or comfort, take her to the bathroom. Her need to use the bathroom may be showing as sadness. Do not ask her if she has to use the bathroom, cue her directly (and gently) "Let's go to the bathroom."
3. Create an activity box with new paperwork/activities that are familiar to C. Keep this box in the closet and offer her a new, fun activity each day. Be sure the activities are familiar (ie papers to color, books, pictures of kittens).
4. Try to incorporate an outing on each day that C does not go to the day program (weather permitting). Introduce the destination using the picture card

We may make some changes over the next few sessions, based on how these strategies work.

Eileen Herge OTD, OTR/L, FAOTA

7-18-2018

Occupational Therapist

Date

3

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Jefferson Elder Care

- Direct occupational therapy services
 - Funded by PEW grant
 - Available until April 2021
- Skills2Care-ID available virtually

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Behavioral Health Consultant (BHC) Approaches to Treating Patients with ASD

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Clinical Assistant Professor

September 10, 2020



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“The most challenging component of management lies in assessing and interpreting the presenting symptomatology, and considering medical conditions among the possible underlying causes.” (Smith et al., 2012)

Case Example: “Johnny”

- 34 y/o male
- History of ASD, mixed hyperlipidemia, obesity, bullying as a child/adolescent, major depressive disorder
- Per mother has Asperger, low functioning in some areas
- Lives at home with mother
- Works PT
- No medical/physical health visit in 3-4 years
- Mother called practice seeking mental health support for son
 - Concerned about his behavior; “he shoved something up his urethra”
- Stressors compounded by pandemic
- PCP referred to Behavioral Health Consultant (BHC)

First Things First

- Consult w/PCP to rule out any underlying medical conditions
 - Need for immediate attention / Ongoing sxs / ER visit
 - Address ways to approach and communicate with mother and patient
- Rule out safety concerns (i.e. SI risks, etc.)
- Resource gathering for possible community referral
- Contact family

BHC Assessment

- Guarded
- Negative history with mental health providers in school
- Felt blamed & targeted for instances of upset
- Underreported symptoms of depression & anxiety (PHQ9, GAD7)
- Strong family connection; two other siblings
- Challenging family dynamics
- Chronologically 35 y/o; developmentally 16 y/o
- Higher end of ASD spectrum; language comprehension
- Socially - low to moderate functioning
- Limited social support
- Enjoys dressing in drag
- Disclosed sexual orientation and presentation
- Lots of shaming behavior

Treatment Goals

- BHC Goals:
 - Goal setting
 - Reduce level of distress; safe space, harm reduction
 - Connect to specialty mental health program for ongoing care
 - Encourage visit with PCP for physical

BHC Interventions

- Rapport building
- Establish trust
- Listen, listen
- Acceptance & non-judgmental approach
- Self-acceptance / Self-love
- Harm reduction / creating sense of safety
- Normalization & Reframing
- Psychoeducation
- Visualization
- Expand Network of Care
 - Weekly Care Team consults & updates
 - Family engagement
- Encouraged own research & learning
- Affirmed strengths & needs

Treatment Outcomes

- 7 visits with BHC via JeffConnect / Telemedicine*
- Established visit with PCP for Medicare wellness
- Change in PHQ9 / GAD7 scores
 - Initial PHQ9: 3 Final PHQ9: 1
 - Initial GAD7: 4 Final GAD7: 5* (expressed upset about country reopening)
- Improved management & understanding of sensory experiences
- Declined referrals to specialty mental health services for ongoing care
- Felt BHC was helpful and no longer needed to continue with services

“Care providers should be aware that problem behaviors in patients with ASDs may be the primary or sole symptom of the underlying medical condition...” (Buie et al., 2010a)

Treatment Outcomes: Benefits of Cognitive Behavioral Therapy (CBT) Intervention

- Increased level of emotional awareness
 - Patience
 - Flexibility
- Decreased impulse to escalate emotions
- *Telemedicine may have helped fast track treatment outcome and rapport with BHC

What is Cognitive Behavioral Therapy (CBT)?

- One of many psychotherapy approaches
- Based on the idea that how we feel, think, and behave are naturally intertwined.
- Goal of CBT is to help patients identify the relationships between unhealthy thinking patterns, disruptive behavior, and negative emotional responses in upsetting or impairing situations.
- More concerted efforts to adapt CBT for people presenting with varying degrees of clinical complexity (i.e. ASD / SPMI)
 - Good outcomes reported for adults with psychosis (Lincoln and Peters 2019)
 - Bipolar affective disorder (Chiang et al. 2017) and
 - Co-occurring physical and mental health conditions (e.g. Kew et al. 2016).

Adjusting, Adapting Psychotherapy to the Population

- 1) Language
- 2) Frequency of Sessions
- 3) Shorter Sessions
- 4) Duration of Therapy
- 5) Utilize a More Structured & Directive Approach
- 6) Communication with Collaterals
- 7) Modify Complexity of Interventions
- 8) Therapist needs to be supportive
- 9) Therapist needs to be flexible
- 10) Therapist needs to be part of a team approach

CBT and ASD

- CBT will not change ASD diagnosis nor is it meant to
- ASD
 - unique cognitive and behavioral styles; varies with the severity of ASD symptoms.
- CBT intervention is adapted, adjusted and focused on patients strengths and needs
 - Generally, resonates well with people in this population who often have difficulties with abstract concepts
 - Discussions in CBT tend to be semi-structured and detail-focused
 - Potentially more understandable for people

Cognitive Behavioral Therapy

- Short-term goal-focused ‘talking therapy’, based on several central premises:
- (1) there are interdependent relationships between what and how we think, how we feel physiologically and emotionally, and what we do
- (2) unhelpful thoughts and thinking styles and particular coping strategies can indirectly perpetuate negative affect; and
- (3) negative affect and physiological anxiety and arousal can reinforce the use of less helpful responses and encourage negative thoughts and ways of thinking.

CBT - How We Focus Our Attention

- Your thoughts are not the real problem
- Meaning making machine: importance/meaning attached to thoughts
- Steering your attention to improve mood and reduce anxiety

Common Beliefs of People with ASD

- *"I must stay in control because there may be danger"*
- *"If I try to fit in, I'll fail"*
- *"If I stay away from people, I won't get hurt"*
- *"I can't understand what is going on in [my] world" or*
- *"Everyone takes advantage of me"*
- *"I'm flawed"*
- *"I'm weird"*
- *"I'm out of control"*
- *"I'm incompetent" or*
- *"I'm vulnerable"*

Treatment Considerations

- Cognitive conceptualization
 - identifying key cognitions and behaviors to target in treatment
- Engagement and the therapeutic relationship are key
- These common beliefs may pose serious challenges to reaching a person's individualized goals, and often these beliefs can become self-fulfilling prophecies.
- Helping people to shift to more accurate and more helpful cognitions is a powerful tool in helping them realize their goals and potential.

Common Cognitive-Behavioral Therapy Approaches

- Assessment
- Education
- Advocacy and Resources
- Social Skills Training
- Habit Reversal and Ritual Prevention
- Cognitive Restructuring
- Depending on what the patient needs, various CBT approaches / techniques can be applied
 - skills for problem solving
 - goal setting
 - Assertiveness
 - time management and increasing daily activities
 - sleep hygiene
- MBCT*

Jefferson's Integrated Behavioral Health Program

- 5 year CPC+ program; Began January 1, 2017
 - 50+ primary care practices participating in CPC+ program within Jefferson
 - 31 BHCs across Jefferson enterprise
 - Abington
 - Center City
 - JFMA
 - JIMA / JHAP
 - Navy Yard
 - Jefferson Geriatrics
 - Jefferson Women's Primary Care & Specialty Assoc.
 - Art Museum (*currently vacant*)
 - JIA at Bala Cynwyd (*currently vacant*)
 - Jefferson New Jersey
 - Jefferson Northeast
- * vacant
- Referring to / Accessing a BHC
 - Tiger Text (embedded/assigned to practice)
 - Task
 - Referral in EPIC
 - BHC Access of the Week
 - BHC on call coverage for practices without embedded/assigned BHCs
 - Jeff Be Well Sessions
 - Wellness group sessions for employees

Some of The Ways Our BHC Providers Can Help

- Diagnostic Clarifications
- Behavioral Interventions
- Treatment Planning
- Facilitate Consultation with Psychiatry
 - Medication Management Referrals
- Behavior and Mood Management
- SI/HI Risk Assessment
- Trauma & Anxiety Management
- Interim Check of Psychotropic Medication
- Co-management of somaticizing patients
- Anger Management
- Stress Management
- Weight Management
- Diabetes Behavior Management
- Smoking Cessation
- Insomnia/Sleep Hygiene
- Psychosocial & Behavioral Aspects of Chronic Pain
- Any Health Behavior Change
- Management of inappropriate Medical Utilization

Resources

Center for Autism in Philadelphia

- Offers therapy options; two locations: Ford Rd. and Grant Ave.
- <https://www.thecenterforautism.org/about/>

Center for Autism Research

- Offers info on autism and grief
<https://www.carautismroadmap.org/coping-with-death/>

Indian Creek Foundation in Souderton (*fantastic resource for adults with ASD*)

- <https://indcreek.org/>

Behavioral Health Choices

- Dr. Judith Outten, Psychiatrist
- <https://www.behavioral-health-choices.com/warrington-i-location>

Behavioral Interventions for adults and children

- Michelle Garcia Winner's approach
- <https://autismawarenesscentre.com/speakers/michelle-garcia-winner-ma-ccc-slp/>

Resources

Behavioral Interventions for adults and children

- Michelle Garcia Winner's approach
- <https://autismawarenesscentre.com/speakers/michelle-garcia-winner-ma-ccc-slp/>

Support groups for individuals with autism

- <https://www.ascendgroup.org/>

Robert Naseef, PhD

- Offers Grief counseling
- <http://alternativechoices.com/robert-naseef-phd>
- TEDx talk entitled [“How autism teaches us about being human”](#)

Community Skills Program in Wyomissing, PA,

- Referral options for patients with ASD or SPMI

Resources

Hall Mercer and Horizon House

- Available to patients with Medicaid or Medicaid Medicare
 - <https://www.med.upenn.edu/hallmercer/>

Outside of Philadelphia (*offers outpatient support*)

- Melmark
 - <http://www.melmark.org/>
- Devereux Advanced Behavioral Health
 - https://www.devereux.org/site/SPageServer/?pagename=pa_index
- Elwyn's Philadelphia Special Needs Resource Guide

Resources for Substance Use

- Conversation.zone
 - <https://conversation.zone/>
- Recovery Center of America
 - <https://recoverycentersofamerica.com/>

Resources

YouTube Resources

- Ask an Autistic
- https://m.youtube.com/playlist?list=PLAoYMFsyj_k1ApNj_QUkNgKC1R5F9bVHs/

Bipolar Magazine

- <https://ibpf.org/resource/bp-magazine/>

LifePath

- Offices in Lehigh Valley, Buxmont and Drexel Hill
- <https://www.lifepath.org/drexel-hill-office>

GKSW/Crystal Group

- <http://www.gksw.com/clinical-services/>

Equilibria Psychological and Consultation Services

- <http://www.equilibriapcs.com/>

Alternative Choices *(does not accept insurance- out of pocket cost)*

- <http://alternativechoices.com/>

Choosing Your Focus...



Contact Information

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Thank You



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Jefferson Frankford Hospital | Jefferson Hospital for Neuroscience | Jefferson Methodist Hospital
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Magee Rehabilitation Hospital | Physicians Care Surgical Hospital | Rothman Orthopaedic Specialty Hospital
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