Medical Considerations for Adults with Intellectual and Developmental Disabilities

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Objectives

- Identify 3 common behavioral presentations of pain in an individual with communication challenges
- List 2 Resources available in New Mexico which can assist with Complex tube feeding regimens
- List 3 resources in New Mexico which can assist teams/caregivers of individuals with Intellectual and Developmental Disabilities

Case 1 - Carlos

- 27-year-old male with a long history of mental illness
- He has been in and out of many behavioral health facilities, UNM Mental Health, NM BHI
- Repeated interactions with the legal system, currently in jail
- TEASC was contacted by the psychiatrist at the prison facility who had concerns that Carlos had undiagnosed developmental disability
- The psychiatrist has noted that Carlos does well in the structure of jail, and “falls apart” when released into the community
- History of violence, triggered by fear
- Self-calming techniques –rocking and odd hand gestures which look like psychosis and trigger medical personnel to try to inject him with antipsychotics, which further terrifies him

Case 1 - Carlos

- TEASC Evaluation done at the prison facility
- Through interviews with family, psychiatrist, medical providers and police CIT team who know him
- In infancy, did not like to be held or touched, frequently rocked and banged his head against hard objects
- He had no friends, would retreat from other children, would not approach other children for interaction or play
- He would scream when touched
- He had poor eye contact, eye contact was uncomfortable for him
- Walking at one year of age, frequently rocked and paced back and forth
- Speech volume has always been poorly modulated, loud and monotone

Case 1 - Carlos

- Long history of Developmental delay, odd behaviors which began to exhibit around 12 months of age
- Recurrent seizures associated with a high fever in the first year of life
- In school, diagnosed with ADHD, developmental articulation disorder, conduct disorder and learning disability prior to age 9. IQ was in low normal range
- Suicide attempt at age 5 years, not manageable at home, vulnerable with other kids
- Lived in group homes/treatment facilities most of the time from 8 years due to unmanageable behavior

Case 1- Carlos

- He did not exhibit imaginative play on his own
- He had action figures but he would only arrange them
- From eight months until 18 months, he would get into his diaper and “paint” with his feces
- He also had Star Wars books and comic books which he kept in a certain order, covered, and no one could touch them
- He had a silky cloth that he needed to rub to fall asleep
- As a teen he developed hand gestures which looked like “gang signs” as a way to keep people at a distance
- This coping mechanism led to increased police intervention as he looked aggressive and dangerous

Case 1 - Carlos

- TEASC team completed a comprehensive medical, psychiatric and developmental evaluation with IO testing and an evaluation for autism spectrum disorder

Neuropsychological Assessment

- FS IQ measured 76, composite score 81, nonverbal 82, working memory 71

Diagnosis:

- Autism Spectrum Disorder
  - Requiring very substantial support for social communication
  - Requiring very substantial support for restrictive/repetitive behaviors
  - Without accompanying intellectual impairment
- Schizophrenia, Onset after the Developmental disability
- Posttraumatic Stress Disorder

Case 1 - Carlos

- His case was given to DDSD for consideration of Emergency allocation of DD waiver services
- With intensive supports from the prison system, he is finally able to be released from prison to a specialized DD waiver supported living facility with intensive behavioral supports
- Once receiving appropriate DD services, behavior supports, ongoing medical and psychiatric care, he is reported to be thriving in more appropriate community setting

Common Behavioral Presentations of Pain/Illness in Individuals with Communication Challenges

Common Behavioral Presentations of Pain/Illness

- Behavior change
- Self Injurious behavior
- Aggression
- Isolation
- Refusals
- Change in memory or concentration, unable to follow usual routines
- Elopement
- Agitation
- Pacing
- Grimacing
- Food seeking/gulping drinks
- Screaming/Moaning/Crying/Whimper
- Breath holding or air swallowing
- Arching
- Sweating
- Weight loss
- Tachycardia
- Tachypnea
- Increased muscle tone / muscle spasms
- Lethargy
- Insomnia
- Loss of Appetite, Increase in appetite
- Change in eyes or facial expression
- Color Change

Case 2- Danny

- 24-year-old male with Autism, intellectual disability, visual impairment, seizures, hip dysplasia. He has limited verbal communication, loves routine, loves to play with his dog, loves calculators, and thinks racecars are cool!
- He loves day program and outings, especially to see racecars, visit animal shelter and the zoo
- 6 months ago began with aggressive behavior, self injurious behavior (head banging), pacing and agitation
- Increased thirst, drinking fast in large gulps, seeking drinks, grabs food, risky eating
- In the car, he is no longer allowed to wear shoes because he uses them as a projectile weapon at the driver whenever they pass a McDonald's and don't stop

Case 2- Danny

- Change in personality: Isolation, withdrawn, yells at his dog and his Mom
- Forgot how to do previously learned activities, unable to perform usual routines, requires frequent cues in ADLs
- Spending more frequent and prolonged time in bathroom- rocking on toilet, possibly pain with urination, possibly slow stream, hesitancy
- No change in usual constipation on Miralax with BM every 1-2 days
- He has had several episodes of urinary incontinence which are very distressing to him. When he has an “pee” accident, he “loses it”, Bangs head and has required forehead sutures 3 times
- Cannot attend outings with Day program due to aggression, yelling , rectal digging

Case 3- Danny

- Long history of challenging behavior, tantrums, but has escalated severely in past few months
- Lives at home, day program staff have been stable, no new change in environment
- Seen in the ER 5 times in past 6 weeks for severe behavioral outbursts, aggression and self injury
- Neurology work up – EEG and Head CT negative
- Referred to psychiatry who Started on Seroquel with no change
- PRN Lorazepam which is mildly helpful but lasts <1 hour
- Referred to Adult special needs clinic for evaluation of possible “Rage Seizures” vs medical illness vs pain

Case 2- Danny

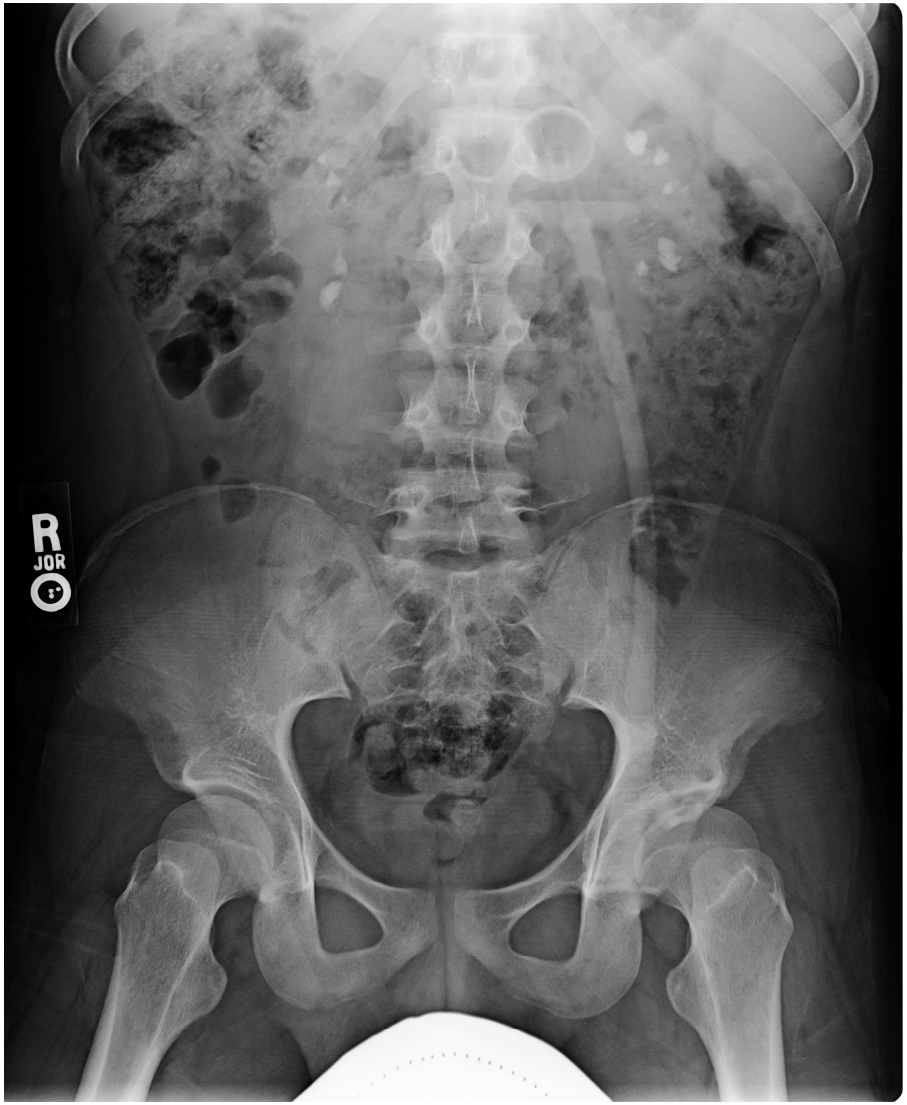
- On physical exam: He is in constant motion around the room. He did sit for a few minutes on the exam table. He is without shoes, he is talkative in his own language pattern, He holds a calculator in each hand
- Head with sutures in the center of forehead. Dysmorphic facial features, thick glasses, obvious visual impairment
- Eyes, ears , throat and teeth with no signs of infection or injury.
  Heart and lung exam normal
- Abdomen is soft and mildly distended, not really tender, but he gets up and moves away quickly when it is touched
- Back may be tender to percussion over the kidneys – He gets agitated with this exam.
  Gait is mildly clumsy but steady, he walks quickly around the room
- Good strength, well nourished, amazing projectile accuracy
  He is hyper-motor and sensitive to sound: He and his mom had to leave the clinic quickly when a baby is heard to cry in order to prevent a “meltdown”

Case 2- Danny

Basic screening labs , urine ordered

Lab results:

- UA – Moderate blood, Negative nitrite, trace Leuk Esterase, pH 7, glucose 100
- CBC Basic Chemistry, B vitamins, thyroid and LFTs normal
- X rays of Hips, Spine and Abdomen ordered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Case 2- Danny

- Findings of Bilateral kidney stones and significant constipation
- He was immediately started on bowel regimen with magnesium citrate with large amount of stool out over a 2 day period
- Behavior improved somewhat with treating constipation, but agitation and aggression continue while waiting for Urology
- He is treated with Flomax, pain medication and fluids until urology appointment with gradual improvement
- After Pain medication, fluids and tamsulosin to help pass stone and then Urology lithotripsy procedure his behavior returned to baseline

Case 3 – Megan

- 30 year old woman with Down syndrome, hypothyroidism, intellectual disability
- She loves to dance, go shopping and have her nails done
- Team notes gradual loss of function and weight loss
- She can no longer perform basic activities of daily living
- Memory concerns- getting lost in familiar surroundings, cannot remember were silverware/dishes go, doesn't remember how to turn a doorknob or turn on the faucet, loss of verbal abilities
- Progressive lower extremity edema over the last year
- Evidence of psychosis- distressing auditory/visual hallucinations- very anxious, interacting with someone who isn't there, randomly cries and hides, fearful of familiar people
- She has recently started acting very strangely- notably she has a new habit of wearing underwear on her head, and no one can convince her otherwise

Case 3 - Megan

- Physical exam: Short, thin woman with typical facial features of Trisomy 21
- Heart, lung and abdominal exam with no significant findings except lower extremity edema
- Normal skin exam, thyroid not enlarged, no lymphadenopathy
- Minimally verbal, speaks 1-2 word phrases, flat affect, normal strength, wide based gait, negative primitive reflexes, normal DTRs, no tremor
- Head CT Negative, Cervical spine X rays normal, Brain MRI negative
- Initial trials of Depakote and antipsychotic medications were not helpful
- Initial labs were normal- CBC, Chem 7, TSH, CRP, T. pallidum, HIV

Case 3 - Megan

- After basic lab work up was negative and symptoms still worsening, vitamin levels are ordered
- Folate and B12 Normal
- **Vitamin B1 level showed very low levels**
- Celiac Testing is ordered
- Initial blood testing positive for Celiac disease

Thiamine (B1) Deficiency

- Thiamine is a vitamin essential for brain and heart health
- Thiamine deficiency (BeriBeri) symptoms can include: Shortness of breath, rapid heart rate, weakness especially in the legs, tingling or loss of feeling in the feet and hands, pain, mental confusion, difficulty speaking, vomiting, eye movement disorders
- Wernicke-Korsakoff syndrome most common in alcoholism, but can also occur in patients who have malabsorption, severe GI disorders, blood cancers, drug use disorders, or AIDS
- Wernicke encephalopathy- an acute life threatening neurologic illness
- Korsakoff psychosis – due to chronic thiamine deficiency, is associated with severe short-term memory loss, disorientation, confusion between real and imagined memories, dementia

Groups at Risk of Thiamine Deficiency

- People with alcohol dependence
- Older adults- Up to 20%–30%, higher in elderly people who reside in an institutional setting
- Diabetics
- People with Malabsorption syndromes or severe gastrointestinal disease, chronic diarrhea
- Dialysis Patients
- Certain medications- Chronic Lasix may be a risk factor
- HIV/AIDS
- People who have undergone bariatric surgery

Celiac Disease or Gluten-sensitive Enteropathy

- Celiac disease, AKA celiac sprue or gluten-sensitive enteropathy
- Genetic autoimmune disorder triggered by consuming a protein called gluten, which is found in wheat, barley and rye
- Symptoms classically include diarrhea, abdominal pain and distention and weight loss
- Involvement of the small bowel can lead to water-soluble (B12, folic acid) and fat-soluble (A, D, K, E) vitamin malnutrition and calcium deficiency. Thiamine deficiency is less common but does occur
- Neurologic manifestations can include neuropathy, ataxia, seizures and impaired cognitive function or dementia have most often been described
- Neurologic symptoms may be due to vitamin deficiency or in some cases an immune-mediated process

Incidence and Risk factors for Celiac Disease

- Celiac disease occurs primarily in whites of northern European ancestry
- Studies in the 1950s reported between 1 in 4000 and 1 in 8000. However, this diagnosis was based upon classic symptoms of malabsorption
- In the 1970s we began to recognize the wide symptoms complex, and with better testing found closer to 1in 300 people with the disease
- A newer study found prevalence of 1:70 to 1:300 in most countries
- **In Down Syndrome, the prevalence is 1 in 6 individuals**

Case 3 - Megan → Follow up

- She was started on a strict Gluten free diet
- Vitamin B1 therapy was initiated
- After 6 weeks, she began talking more and was able to help with her showers and dressing
- Psychotic and odd behaviors slowly resolved
- Gait improved
- Her smile and the mischievous sparkle in her eyes returned
- Unfortunately, she continued to have short term memory problems and never quite returned to baseline function

Case 4 – Maria

- 69 year old woman, with a great smile, she adores Elvis and has a great sense of humor
- PMH includes intellectual disability, non verbal, hypothyroid, seizure disorder, severe kyphoscoliosis, Parkinsonism (due to long term psychiatric medication), hypernatremia, GERD, hip arthritis and remote history of behavior issues
- She had a G-Tube placed about a year ago due to progressive swallowing dysfunction due to her Parkinsonism
- She does some eating for pleasure as tolerated. Most of her nutrition is given through her G-tube
- She presents to Special Needs Clinic with progressive change in behavior, not smiling anymore, progressive fatigue, leaning to one side and inability to hold her head up

Case 4- Maria

- On physical exam, non dysmorphic features, diminished movement of the muscles of facial expression, mask-like facies
- Cardiac exam is normal, lungs are clear, normal thyroid
- Abdomen is soft, non tender and she has a MicKey G tube in place
- On neurologic examination, she has diffuse rigidity and coarse resting tremor of the hands, cogwheel rigidity in the upper extremities bilaterally
- She leans towards the right and during the 2 hour meeting, she progressively more fatigue, needing pillows to prop her upright. She falls asleep repeatedly during the evaluation

Case 4- Maria

- UA normal
- CBC, C-Reactive Protein and Sed Rate normal
- Vitamin B12 Folate, Thiamine, Vitamin D all normal
- Normal Chemistry, LFTs, NH3
- Thyroid studies normal
- Testing for syphilis, TB and HIV negative
- Brain and Cervical MRI, EEG all normal
- Thoracic spine and Abdominal Imaging all negative except for arthritis in the spine

Case 4- Maria

- Medication review done and she is only taking Levothyroxine, Miralax, Colace, and Acetaminophen (PRN)
- Supplements include Multivitamin, Calcium, Vitamin D
- G tube feeding regimen: Jevity 1.0, 1 can 7 times a day, and free water 250 mL 2 times daily
- Each 250 mL can of Jevity is given over 45 min, each water flush over 30 minutes
- She is to remain upright at 90 degrees for 45 minutes after each formula and water flush

Case 4- Maria

Given the Tube feeding regimen, how many hours is Maria required to remain upright at 90 degrees?

- Formula 7 times a day→ 7 X 45 = 315/60 = 5.25 hours upright
- Water 2 times a day → 2 X 30 = 1 hour upright
- 45 minutes after each feeding and water flush →9 X 45 = 405/60 = 6.75 hours
- Total hours per day upright at 90 degrees: 13 hours daily
- Her CARMP indicates that she is to sleep at 45 degrees
- Maria is not getting any rest. This may be why she has had fatigue, sleepiness, leaning to one side and progressive behavior change

Case 4- Maria

Tube feeding regimen changed as follows:

- Jevity 1.0 changed to Jevity 1.5, decreased from 7 cans daily to 5 cans daily
- This brings the total volume down from 2250 mL to 1750 mL per 24 hours
- Initiate pump feeds at 85 mL per hour for 18 hours a day
- Change the Water to 120 ml flush before and after the pump feed, and the remaining 260 mL given during the pump feeds
- With feeds via pump at slower rate, she does not need to remain upright. (Upright 90 degrees not indicated on original regimen)

Consultative Multidisciplinary Team Models Providing Services for Adults with Complex Needs The New Mexico

- UNM Transdisciplinary Evaluation and Support Clinic (TEASC)
- UNM Adult Special Needs Clinic
- UNM Adult Cerebral Palsy Clinic
- UNM Adults Special Needs Rural Outreach Clinics
- UNM DDMI- Developmental Disability/Mental Illness- Rural Outreach
- NM DOH *SAFE* Clinic- **S**upports and **A**ssessment for **F**eeding and **E**ating

TEASC Evaluation

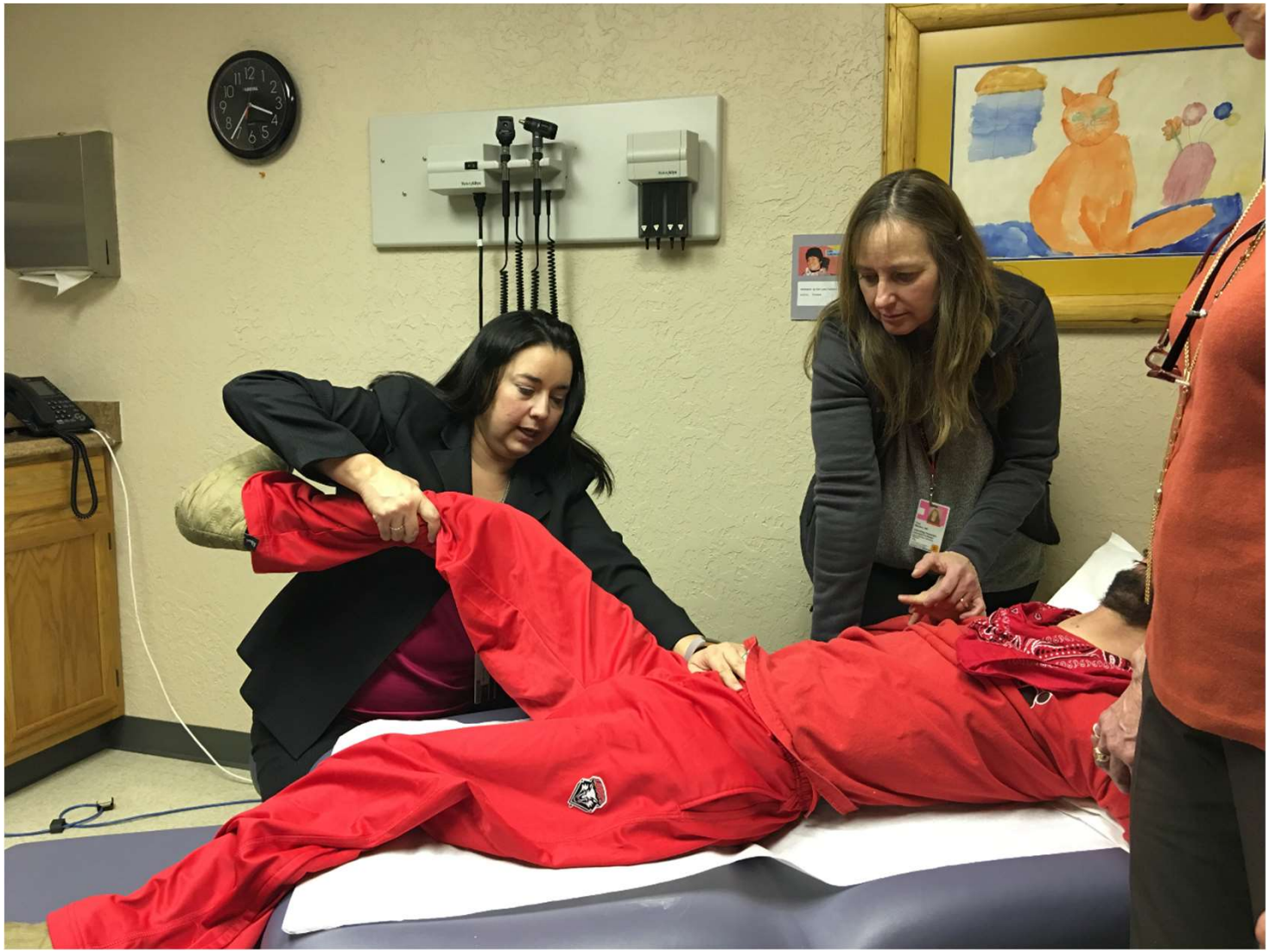
- Comprehensive, multidisciplinary evaluation
- Complex medical, psychiatric, pharmacologic, behavioral, psychosocial concerns
- Comprehensive review of client's medical, psychiatric and therapy records
- TEASC Team travels to the individual's community
- 2 hour face to face evaluation
- Review of medications- historic and current medications as well as response to those medications
- Comprehensive report and recommendations follow the evaluation
- Follow up after the evaluation

Adult Special Needs Clinic (ASNC)

- Meets at the UNM Family Medicine Center
- Comprehensive review of client's medical, psychiatric and therapy records
- Review of medication- historic and current medications as well as response to those medications
- 2 hour Meeting with the individual, family and their IDT
- The Adult Special Needs Clinic team includes:
  - Family Medicine
  - Psychiatrist
  - Neurologist
  - Clinical pharmacist
  - Neuropsychologist
  - Nurse
  - Clinical dental hygienist
  - Social Work/Specialist in DD waiver and systems
- A comprehensive report and recommendations sent to the patient's team, physicians
- Follow up after the evaluation

Adult Cerebral Palsy Clinic

- Comprehensive evaluations include medical and neurological examinations, psychosocial assessment and facilitation of specialist referrals as necessary
- Family Medicine
- Neurology
- Orthopedics
- Social Work/DD Systems Specialist
- Nursing
- Referral questions may include: spasticity management, functional decline, falls, behavioral changes with concern for pain/medical, agitation, unexplained weight loss, wheelchair or equipment assessment, social work needs



Adult Special Needs Rural Outreach Clinics

- Adult Special Needs Team includes Family Medicine, Psychiatrist, Neurologist, Social Worker, Nurse and DD systems specialist
- Team travels to rural community clinic to see patients with the Primary Care Physician in their clinic
- Clinic schedules 5-8 medically and behaviorally complex patients and the team sees the patients with the provider, brainstorms, recommendations, helps formulate a care plan
- Lunch didactic presentation on a clinically relevant topic

Developmental Disability/Mental Illness (DD/MI) Clinics

- Clinics are held at various times and locations around the state of New Mexico
- Individuals with co-occurring developmental disabilities (DD) and mental illnesses (MI)
- DDMI clinics are held on a recurring basis in:
  - Roswell
  - Shiprock
  - Taos
  - SIlver City
  - Las Cruces

NM DOH *SAFE* Clinic
(**S**upports and **A**ssessments for **F**eeding and **E**ating)

- Multidisciplinary consultative feeding clinic for adults with intellectual/developmental disabilities
- Challenges related to oral eating and/or enteral tube feeding
- Focus is on aspiration risk management, oral motor function and swallowing, recurrent aspiration, positioning, assistive technology, nutrition, behavioral supports related to feeding and comprehensive medical management
- SAFE Team: MD, SLP, PT, OT, Nurse, Dietician, Dentist, Behavioral Specialist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Technical Assistance to Families, IDT Teams or Medical Providers

- TEASC Providers are also available for assistance with less complex and/or more immediate issues
- This can consist of phone consultation with an IDT team about a specific medical or psychiatric issue that may be complicated by the client's disability
- Consult by phone or email
- Chart review with discussion, recommendations
- We can also arrange to see the patient in the provider's office as an in-person consult with the physician

Neuropsychological Services

- Through a contract with the UNM Center for Neuropsychological Services, we can refer a limited number of adults for neuropsychological testing
- To establish IQ and adaptive skill levels to support applications for services (such as DD Waiver)
- To test persons with complex cognitive pictures for better understanding of their abilities and needs


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Autism Spectrum Disorder Diagnostic Evaluation for Adults

- A limited number of openings are available in the Adult Special Needs Clinic to evaluate adults for diagnosis of Autism Spectrum Disorder
- Due to limited availability and high need, priority is given to persons in need of significant support services/DD Waiver

New Mexico Resources

TEASC (Transdisciplinary Evaluation and Support Clinic) - UNM Dept. of Community and Family Medicine

- https://fcm.unm.edu/for%20patients/teasc.html
- 505-272-5158

UNM Adult Cerebral Palsy Clinic

- http://coc.unm.edu/clinics/cocclinics/index.html
- 505-925-2383

NM DOH SAFE Clinic

- https://nmhealth.org/publication/view/marketing/4001/
- 505-841-6188 or 1-800-283-8415

UNM Continuum Of Care

- https://coc.unm.edu/
- 505-925-2350

Questions?

SCHOOL OF MEDICINE
DEPARTMENT OF FAMILY & COMMUNITY MEDICINE

How to Refer for
TEASC/ASNC Evaluations or just ask a question…

- Call us …….

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