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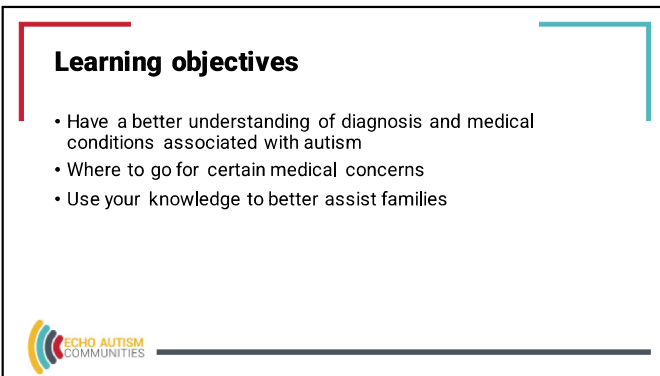
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**Knowing how to navigate helps to:**

- Provide quality health care
- Provide quality behavioral care
- Provide quality mental health care
- Provide access to specialists
- To give a diagnosis to open the door to treatments



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**What is a medical system?**

- Providing health care through various means
  - Hospitals/clinics
  - Primary care providers
  - Nurses
  - Specialists
  - Therapists



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### Whose Who

- Physician
  - 4 years of medical school
    - 2 years in a classroom, learning and groups, testing
    - 2 years in rotation (1 month or 4 weeks each)
      - Family Medicine, pediatrics, internal medicine, specialties
  - After medical school, additional training (residency)
  - Residency also has rotations as well
  - Most primary care residencies are 3 years
    - Family Medicine, Pediatrics, Internal Medicine




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### Nurse Practitioner (NP)

- Obtain a Bachelors in Nursing- Will obtain RN status
- Masters or Doctor of Nursing Practice- around 3 years
  - Obtain clinical hours while in program
- May not need to practice on a physician in some states

### Physicians Assistant (PA)

- Master of Physician Assistant Studies (MPAS) degree from a medical school or medical center
- minimum of 2,000 clinical hours
- Need physician oversight




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### Specialist

- Continued training after residency in a certain area
  - Can even further specialize
    - Medical School to IM Residency to GI Fellowship to Hepatology Fellowship
- Gastroenterology
- Neurology
- Developmental
- Orthopedic Surgery
- Physical Medicine and Rehabilitation
- Psychiatrist
- Sleep Specialist
- Genetics




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The slide features three circular diagrams. The top diagram shows a person with silhouettes of others, surrounded by boxes for 'Engagement in learning', 'Social and emotional wellbeing', 'Physical health', 'Safety & material wellbeing', and 'Supportive relationships'. The middle diagram is a four-quadrant circle labeled 'Holistic Care' with quadrants for 'Physical', 'Spiritual', 'Psychological', and 'Social'. The bottom diagram is a larger circle labeled 'Whole Person Development' with segments for 'Cognitive', 'Emotional', 'Social', 'Physical', 'Behavioral', and 'Developmental'.

### Treating the Whole Patient

- Those with autism should be no different
- Best outcomes
- Greatest benefits to patients

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### Neurologic

- Seizures
  - Inc risk for autism among youth with epilepsy
  - Inc risk of seizures in those with autism
    - 7-23% of people with ASD
    - Increased for females, being born earlier and intellectual disability\*
- What this looks like
  - Tonic-clonic
    - Stereotypical shaking
  - Staring episodes
  - Complete collapse

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### Neurologist

- 3 years of fellowship training after 3 years of residency
- Specialize in all things nerve and/or brain related
  - Seizures, read EEGs
  - Muscle tone
  - Headaches
  - Sensation issues
  - Autism (not all)
  - ADHD

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**Looks can be deceiving**

Noah has not been eating well for the past 3 days. The chicken nuggets he usually gobbles down are left cold on his plate. He seems more easily frustrated and it is harder to get him to focus on his therapy. What is going on?



**ECHO AUTISM COMMUNITIES**

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**GI: Top to bottom**

- Numerous symptoms
  - Abdominal pain, constipation, diarrhea, reflux, feeding problems
- Noticed as early as 6 to 18 months age
  - Avoidance a whole food group
- 75% can have problems eating
  - Due to texture, color, temperature
- Delayed oral motor skills
- Restricted eating causing constipation?
- Poor diet ——— Poor nutrition



**ECHO AUTISM COMMUNITIES**

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**Gastroenterologist**

- Most have 3-year fellowships after 3 years of residency
- Hand medical and some surgical GI related issues
  - Constipation
  - GERD
  - Inflammatory Bowel Disease (IBD)
    - Crohn's and Ulcerative Colitis
  - Celiac Disease
  - Irritable Bowel Syndrome (IBS)
  - Esophagogastroduodenoscopy (EGD)
  - Colonoscopies
  - Liver, gallbladder

**ECHO AUTISM COMMUNITIES**

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## Behavioral Health

- Seen in 70-80% of those with autism
  - ADHD
  - Anxiety
  - Depression
  - OCD
- Sleep problems
  - 50-80%
  - Behavior vs differences in melatonin, changes from "normal" nervous system




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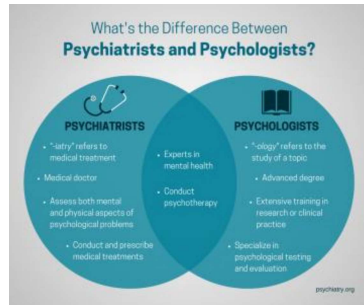
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## Psychiatrist and psychologist

- Psychiatrist has 4 years of residency
  - Peds- 5years of psych training total




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## Miscellaneous

- Dental issues
  - Decreased visits due to avoidance
  - Restriction in wanting to brush
  - Restricted diets
- Pica
  - Eating/swallowing toxic items
- Motor disorders
  - Tic disorders




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### Therapies

- Speech and Language Therapist
  - Bachelors and then Masters and then Clinical Training
  - Assist with speech, eating, swallowing
- Occupational Therapist
  - Bachelors and then Master with training
  - Assist with fine motor movements, daily skills, sensory issues
- Physical Therapist
- Board Certified Behavioral Analyst




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### Therapies

- Physical Therapist
  - Bachelor's, then 3 years of specialty school and then training
  - Help with large muscle movement and ambulation
- Board Certified Behavioral Analyst
  - Bachelor's, then Masters and then clinical training
  - Assist with behavior analysis and set up structure of Applied Behavior Analysis (ABA) therapy




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### How to manage all of it?




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## Navigating the Medical System

- You need:



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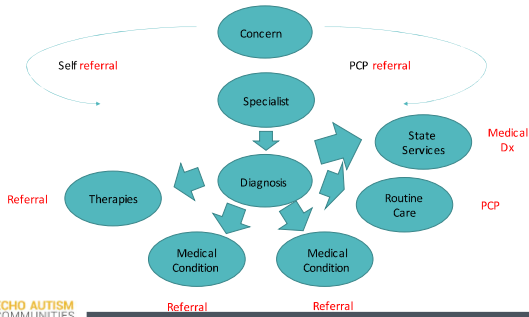
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## Choosing a provider

- Find someone who works with you and makes decisions jointly
- Has knowledge about patients with autism
  - May not know all, but willing to learn
- Ask, "How many children do you see who have autism?"
- Look providers trained in STAT evaluations



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### Tips

- For answers to certain questions
  - For accuracy, contact the team associated with the plan
  - If concerned, reach out to the primary provider if no response
- When possible, send updates of plan to team
  - Sign release of information at all clinics
- Have goals or a treatment plan set in place
  - Allows for continuity from all involved with care
  - Allows all to see the care being provided
- Some insurance programs have health coordinators
  - Can assist with appointments, follow up on concerns, assist with prior authorizations




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### The Times They Are A-Changin

- Telehealth
- Station MD (<https://stationmd.com/>)
  - *“StationMD is a physician service that is dedicated to individuals with intellectual and/or developmental disabilities (I/DD) and other vulnerable populations. Our mission is to provide the highest quality of medical care for individuals with I/DD, fostering independence and improving quality of life for our patients and those providing their care.”*




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### Advocating in the Medical System

- What does this look like
  - Ensuring access to care
  - Navigating the system
  - Mobilizing resources
  - Addressing health inequities
  - Influencing health policy
  - Creating system change




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### Resources for help

- ECHO Autism
  - <https://echoautism.org/>
- Autism Speaks
  - <https://www.autismspeaks.org/>
- Missouri
  - <https://dmh.mo.gov/dev-disabilities/autism/centers>




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### Resources:

- Hyman, SL, Levy SE, Myers SM; American Academy of Pediatrics, Council on Children With Disabilities and Section on Developmental and Behavioral Pediatrics. *Clinical report: identification, evaluation, and management of children with autism spectrum disorder. Pediatrics.* 2020; 145 (1): e20193447
- Hubinette M, Dobson S, Scott I, Sherbino J. Health advocacy. *Med Teach.* 2017 Feb;39(2):128-135. doi: 10.1080/0142159X.2017.1245853. Epub 2016 Nov 21. PMID: 27866451.




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**U** Pediatrics  
School of Medicine  
University of Missouri

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