



Finding Your Way Home: Managing Inter-specialty Care for Patients with Complex Behavior Needs

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Disclosures

Neither I nor my immediate family members have a personal financial relationship with a manufacturer of pharmaceutical products or services that will be discussed in this presentation.



Case 1

Ms. P is a 45 year old autistic woman with a moderate intellectual disability and minimal verbal communication. She attends a day program and has lived successfully in a group home for 17 years.

New behavior: tantrums including throwing chairs at staff



7 questions

- Who is your patient?
- Who is on your team?
- How do you communicate?
- Do you need services and supports to diagnose and treat?
- How do you formulate a differential diagnosis?
- How do you make the diagnosis?
- How do you monitor the effects of therapy?

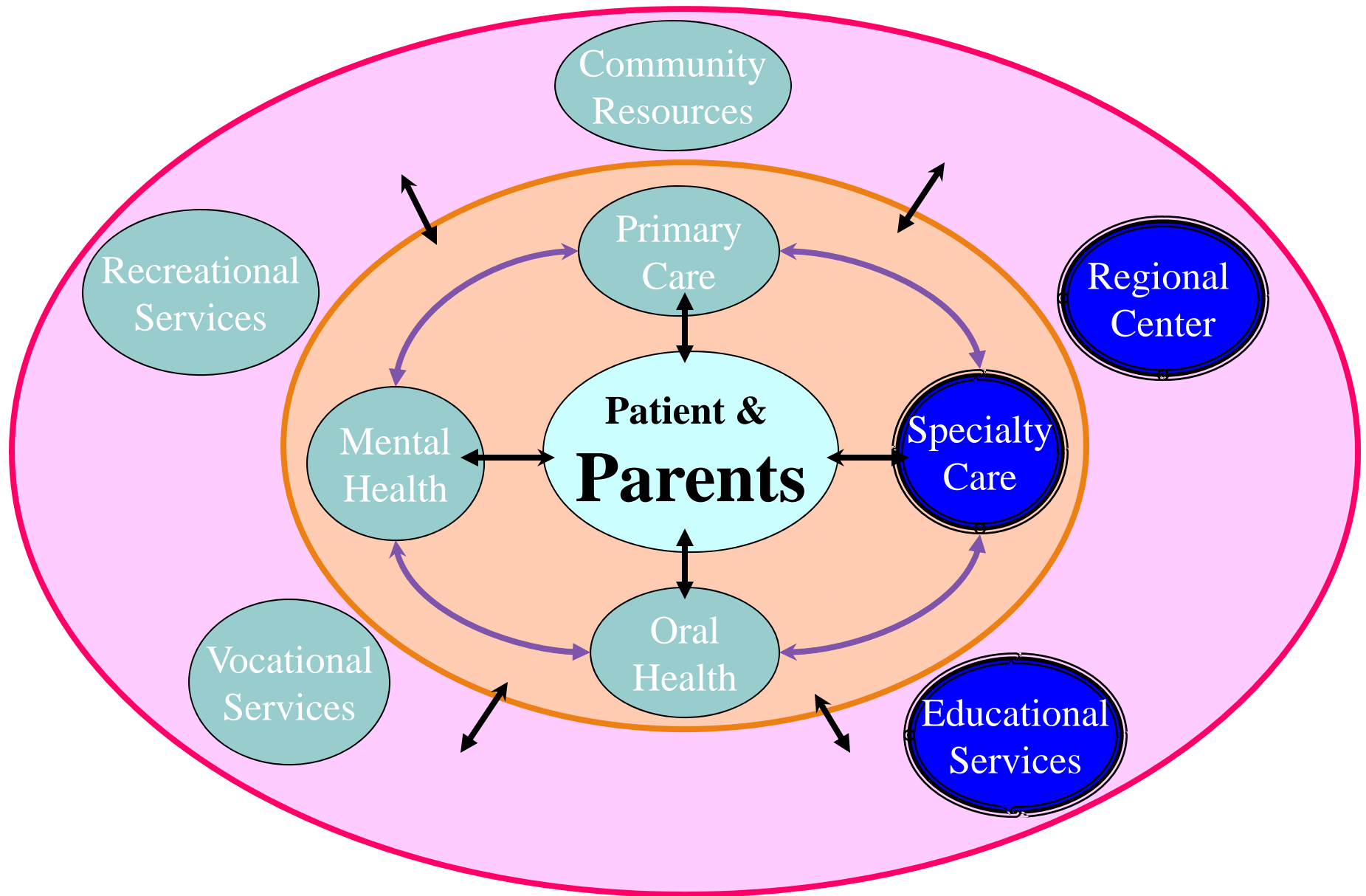


Who is your Patient?

- Neurodevelopmental Profile
 - Diagnosis/etiology
 - Cognitive
 - Neuromuscular
 - Seizure
 - Sensory
 - Mental Health/Behavior

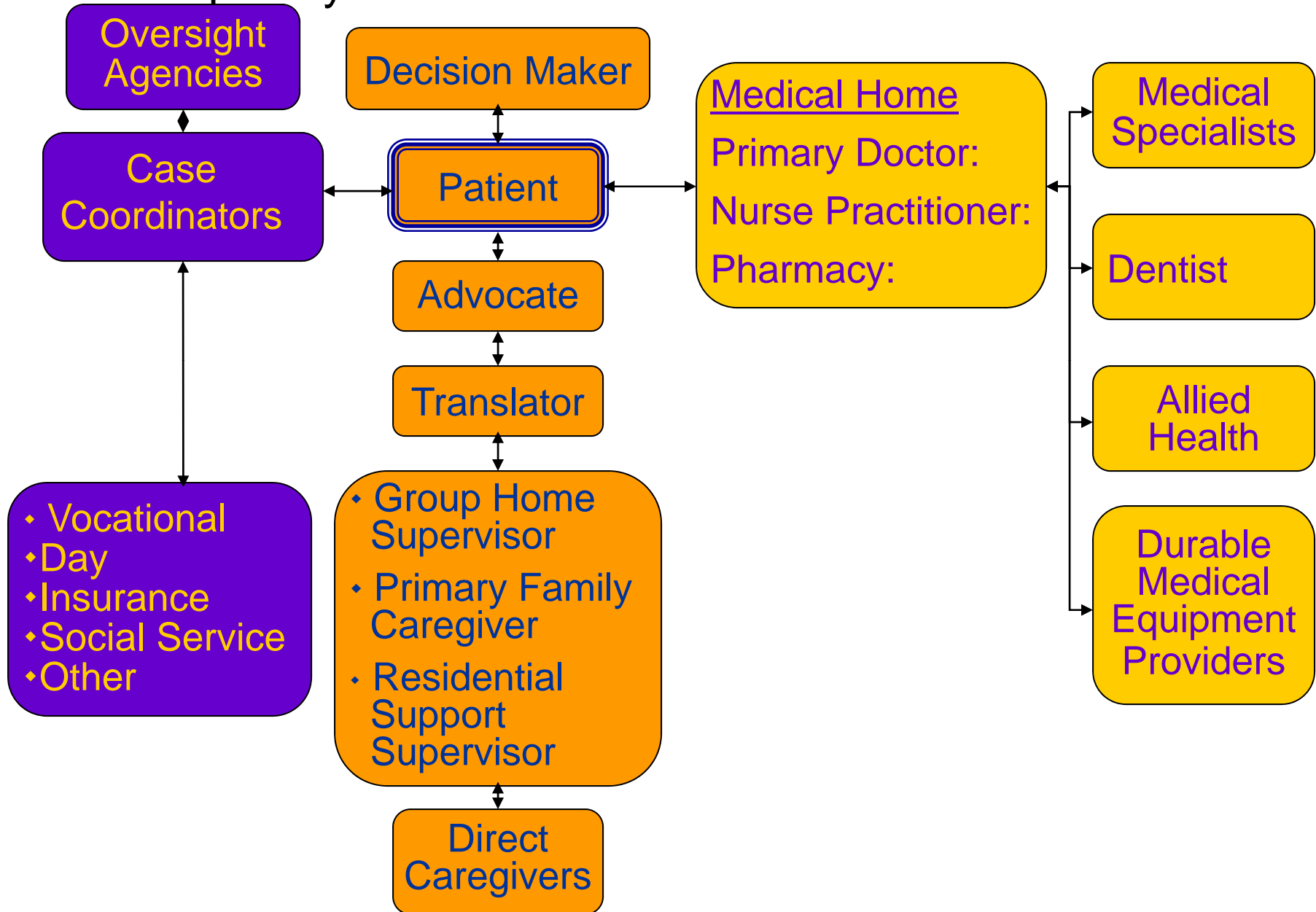
Adapted from work of Phil May, Matt Holder and American Academy of Developmental
Medicine and Dentistry

Who is on your Team?



Medical services are core while needed supports are readily available.

Interdisciplinary Health Care Team for a Patient with IDD





How do you communicate?

- Medical summary (Primary care doctor)
- Health Passport (Patient/Caregiver)
- Visit Forms
- Observation forms
- Exam room etiquette
- Functional Behavior Analysis
- Communicating with non-verbal patients



Communicating with non-verbal patients

- Just because a person doesn't talk doesn't mean that they have nothing to say
- All behavior is communication
- Most communication IS non-verbal
 - Body language
 - Tone of voice
 - Visual cues/context
 - Routine/expectations

Exam Room Etiquette

(Thanks to Dr. Ken Robey, Matheny Institute—for video contact research@matheny.org)





BoardTalk – Alphabet board

No

Yes

Would you write it down?

End of word

It starts with....

I made a mistake. I'll start again.

I'd like to ask you something

Please get the other boards.

Do you understand ?

Thanks.

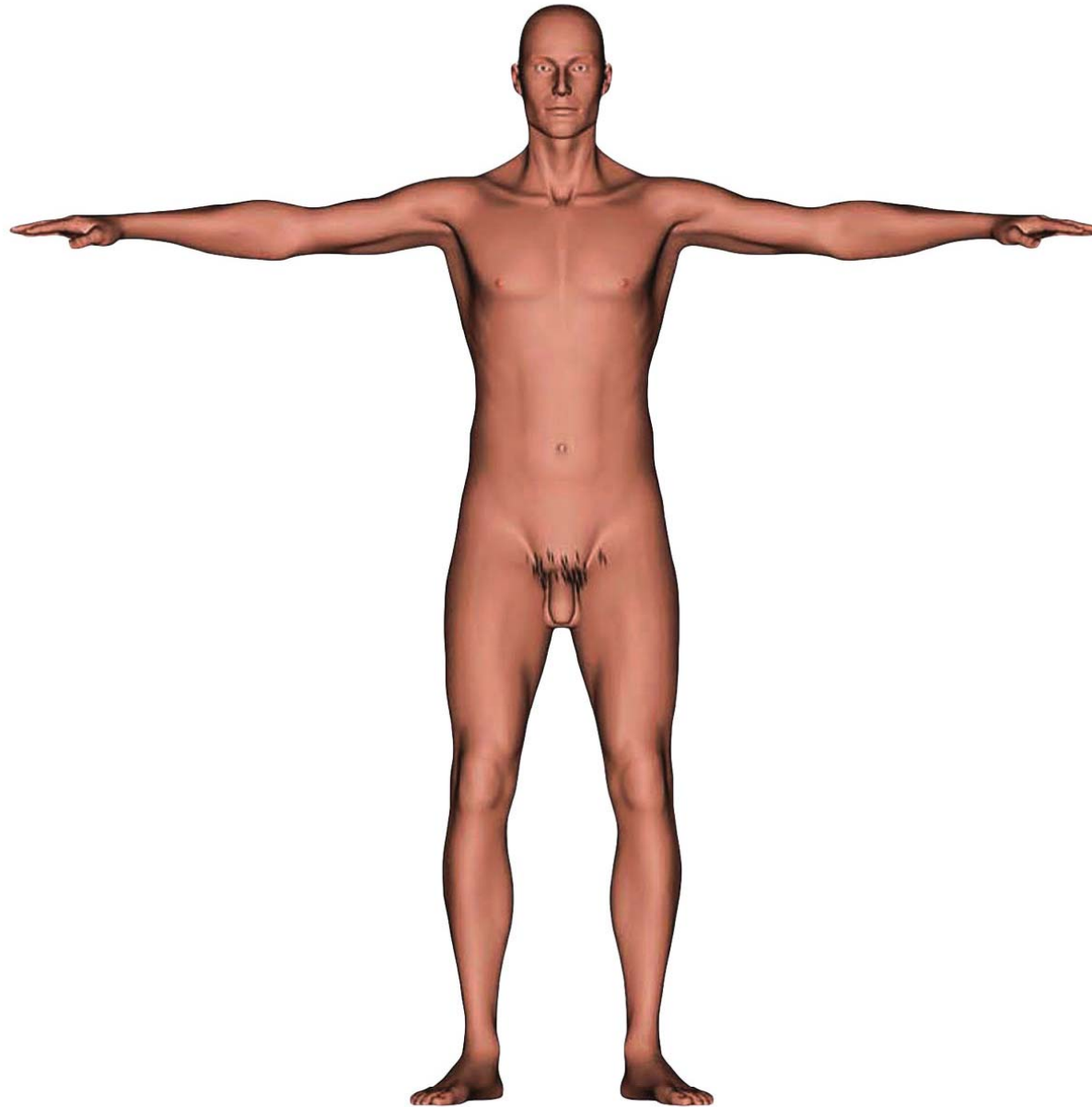
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Q W E R T Y U I O P

A S D F G H J K L

Z X C V B N M ?

This is a communication tool to help people who cannot talk or who have language that is difficult to understand.
If you have any ideas on how we could improve this please fill in a comment sheet.



<http://www.healthpassport.co.uk/Health+Passport/2>



Functional Behavior Analysis

What happened before? (antecedent)

What was the behavior?

What happened after?

(consequence/reinforcer)

What may have been the function of the behavior?



Other strategies

- Interpreters
- Written language
- Picture choice boards
- Pain scales
 - keep them simple—3 choices
 - emoticons may not be best for autism

Visit the Office of Developmental Primary Care website for more information and tools:

<http://DevelopmentalMedicine.ucsf.edu>



Do you need services and supports?

- Arranging funding
- Asking for help when ill
- Scheduling visits
- Preparing for visits
- Being on time
- Communicating
- Cooperating with medical evaluations
- Making informed consent decisions
- Adhering to medical recommendations



How do you formulate a medical differential diagnosis?

- **H**ead: migraines, hearing, vision, dental, injury
- **U**rinary tract: stones, UTI, and obstruction
- **R**eflux and GI problems
- **T**hyroid and Trauma
- **S**eizures and Side Effects of Medication

Zelenski, SG. Evaluation for and use of psychopharmacologic treatment in crisis intervention for people with mental retardation and mental illness. In: Hanson R, Wieseler K, Lakin C, Braddock DL, eds. *Crisis: Prevention & Response in the Community*. Washington, DC: American Association on Mental Retardation; 2002:243-256.



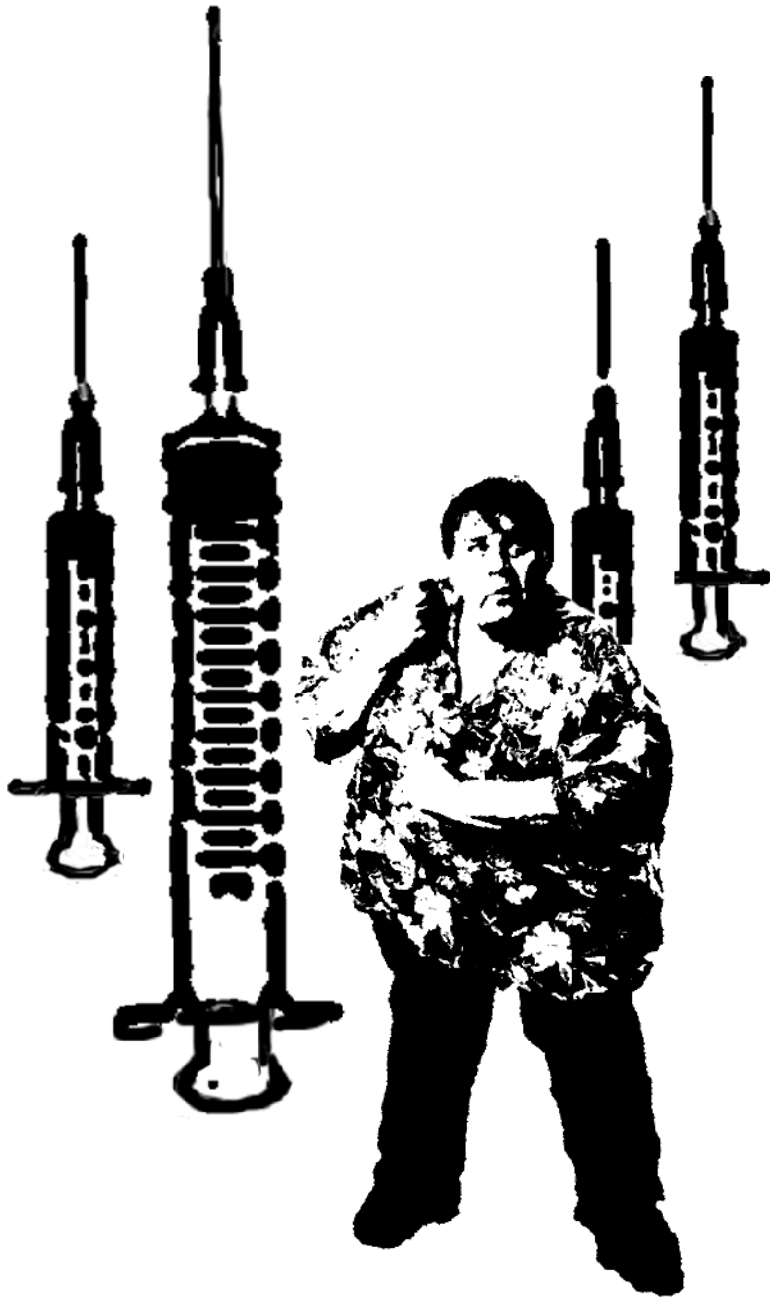
Behavior can also signal....

- Abuse or psychosocial stressors
- Escape or avoidance of demands
- Increase in arousal or self-stimulation
- Means of accessing preferred activity or objects
- Mental illness
- Need for social attention
- Psychosocial stressors
- Pursuit of power and control
- Reduction of arousal and anxiety
- Substance abuse



How do you make the diagnosis?

- History, history, history
- Physical exam
- Diagnostic testing
- Functional behavior analysis



- Do a previsit and post visit over the phone
- Make visits routine and predictable
- Desensitize
- Introduce one change at a time: person, place, activity
- Back off and reapproach—give him some control
- Give him something to hold
- Use rewards
- Use visuals
- Social stories

Visual Schedule



Blood Pressure



Put on gown



Doctor's exam



Get Dressed



Get needle



Lasso Kid

First/Then

FIRST



THEN





When all else fails consider...

- topical anesthetic
- home visit
- benzodiazepines
- coordinating procedures under anesthesia



How do you monitor the effects of therapy?

- Define goal of therapy
- Research past therapeutic trials
- Make sure entire team is on board
- Establish a timeline and milestones
- Take data
- Stop treatments that aren't working
- Keep good notes on failed therapeutic trials



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CART Model Programs

Enhanced Medical Home

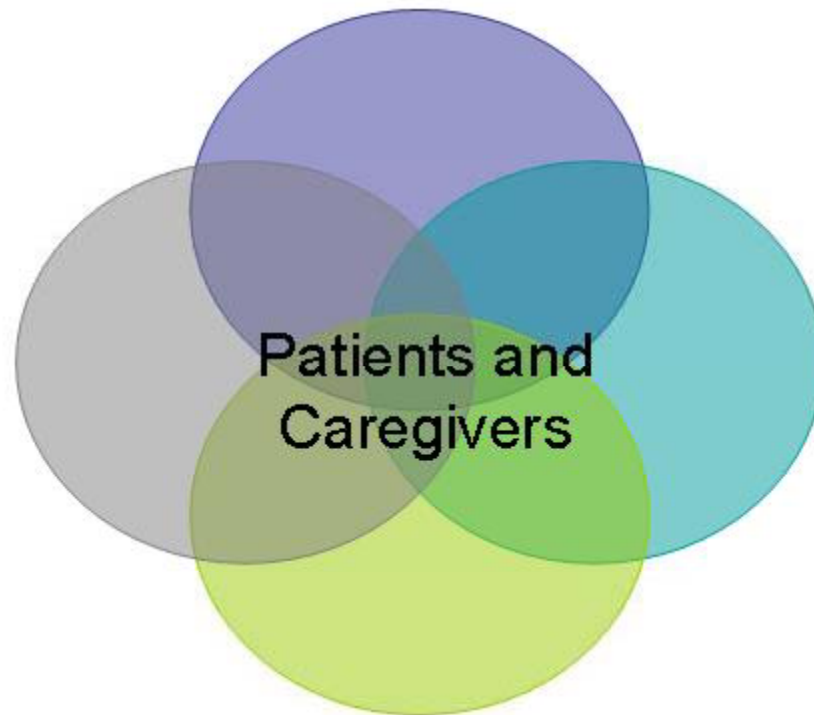
Primary Care
Care Coordination

Center of Excellence

Clinical Services
(Consult/Assessment)
Advocacy (policy)
Research
Training/Technical Assistance

Health Advocacy Services

Patient and Caregiver Support
Medical Case Management
Wellness
Transition Support



Yearly Health Assessment

Health Surveillance Data Collection
Independent Comprehensive Assessments and Recommendations

Department of Family and Community Medicine

OFFICE OF DEVELOPMENTAL PRIMARY CARE



*Improving outcomes for people
with developmental disabilities*

Office of Developmental Primary Care

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