Working in the Dark –
(Helping when you don’t know what’s going on.)

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Learning Objectives

Understand the philosophical models and scientific evidence behind the current diagnostic system.

- Appreciate that mental health/behavioral/developmental diagnoses in children are always provisional – “works in progress.”

- Appreciate the multidisciplinary nature of diagnosis and treatment and the importance of teacher/educator input.

- Resolve to become an advocate for more and better resources.
Dedicated to Ronald

I remember 2\textsuperscript{nd} grade.
Here we go....
Welcome to Holland!
(or not)
Example (composite patient)

- Adopted out of abusive home at age 18 months
- Exposed to alcohol before birth, with partial signs of fetal alcohol syndrome
- Social worker provides information that father was diagnosed with bipolar disorder and mother diagnosed anxious and depressed
- Currently achieving below grade level in reading and writing, at grade level in math, clumsy in physical education; dislikes science
- Avoided by other children; aggressive and bossy
- Brought for help because he is defiant and raging at home
Where do you begin?

You can’t help without having some way of tracking progress.

You can’t go anywhere without first knowing where you are.
What’s wrong? How bad is it?

Because....
If there’s no impairment, there’s no disorder.

(KEY POINT)
First We Look at Function

- What is and isn’t working in this kid’s life?
  - **Self** – How does he feel?
  - **Community** – Does he have friends?
  - **Home** – How well is he getting along with the people he lives with?
  - **School** – Is he learning at the same pace as his peers?
    - Can he get along with teachers and peers?
    - Can he function in the role of a student?

- *Note the emphasis on relationships – not symptoms!*
We start on the journey by gathering as much information as we can find.

- Defiant and raging at home --
- We need to look at multiple areas “domains” of function that might explain this problem...
Information is gathered from:

- Parent or family – interviews and questionnaires
- Child – spontaneous and structured interviews, and interactive and spontaneous observations
- Outside records; prior attempts at solving the problem; pediatric records
- Structured observations – questionnaires and symptom checklists
- Formal testing
- Consultations
Investigation of Emotional/Behavioral/Developmental Disorders is Multifaceted.

- Description of symptoms and “functional impairment”
- Capacity for thought
- Capacity for relationships
- Temperament and personality
- Health and Lifestyle – medical, diet, sleep, substances, safety....
- Family – Genetic inheritance and Family biography
- Community resources and involvement
- Interview and observations
The Medical Model is Linear

- Patient tells doctor what’s wrong – complaint
- Doctor asks questions about start and progression of the symptoms; Doctor examines patient for “signs”
- Laboratory or other tests provides more evidence
- The diagnosis accounts for all of the above
- The diagnosis determines the treatment
- Treatment is given; patient improves.
Emotional & behavioral problems don’t conform to the medical model!
Medical vs. Developmental

- Patient was well – now is not
- **Patient** reports what’s wrong
- Patient honestly reports symptoms and concerns
- Diagnosis determines treatment
- Patient complies with treatment
- Problem slowly reveals itself
- Someone else is worried – patient often unaware
- Shame, ignorance, and blind spots prevent accurate reporting
- Diagnosis often multifaceted and layered; treatment unclear
- Patient/family often resistant or unable to comply with tx
The Treatment Timeline – What has gone before?
That’s why it’s like working in the dark:

We’re not sure where we’re starting from.

We’re not sure where we’ll end up.

We don’t know how long it will take to get there.
Example, continued

- Adoptive parents are committed Christians with adult children who are successful and out of the home. They want to help this child but express frustration: “nothing works.” They ask you to “get him to talk about what’s bothering him.”

- Ability testing shows generally average ability, with significant weakness in working memory; achievement testing demonstrates reading disability; math skills OK; writing so-so

- Parent and teacher questionnaires are positive for ADHD symptoms of inattention and impulsivity

- The boy doesn’t want to talk about feelings and doesn’t like coming to appointments. His drawings suggest low self-esteem and anger.
In the medical model, the diagnosis determines and drives the treatment.

Psychiatric diagnoses are gathered and published in the DSM.
Diagnostic and Statistical Manual of the American Psychiatric Association
The central purpose was to advance research in mental illness – not to derive a clinical classification system.

Original diagnoses were derived from 19th century observations of adults and from psychoanalytic theory.

Editors of the DSM deliberately focused on observable features of each disorder in an effort to minimize use of subjective judgments and improve reliability.

Decades later, research from multiple lines of inquiry have provided uneven levels of evidence about varying diagnoses. Clinicians are being given increasing input.
DSM Diagnoses with different levels of evidence

- **Depression** = A syndrome of persisting sad/low mood and energy all day, every day, for at least two weeks, frequently accompanied by a number of physical signs and symptoms – may have multiple causes and a wide range of expression

- **Oppositional defiant disorder** = A trait or persisting behavior of reacting negatively to adult requests and commands – no cause is implied – correlates highly with anxiety more than antisocial behavior

- **Anorexia nervosa** = A physical and mental condition in which health and brain function are disturbed with strong correlation to abnormalities in the pituitary and adrenal systems and high genetic influence

- **Dyslexia** = Developmental disorder in reading defined as the difference between the student’s ability and reading achievement using standardized measures – likely due to abnormal organization of neurons in specific brain regions
We all know what a duck is...
The best response to “What’s this kid’s diagnosis?” may be:

“Who wants to know?”
The DSM is not a field guide.
Possible diagnoses:

- Oppositional-defiant disorder
- Reactive attachment disorder
- Developmental disorder of reading
- Fetal alcohol effect (aka alcohol-related birth defects, aka partial fetal alcohol syndrome)
- Attention-deficit, hyperactivity disorder, combined type
- Depression
**Diagnosis vs. formulation**

One is a label from the DSM – the other is a story.

In clinical work, the formulation – a good story that accounts for symptoms – is more important than the diagnosis.
In this case, we’re treating, so we set aside the diagnosis and focus on getting the story right.

In other words, what kind of map can we construct from what is already known?

- **DOMAINS SUMMARY**
  - Raging and defiant – disrupting home life
  - Difficulty with some types of learning (reading, memory)
  - Relationships with parents and peers are affected
  - Temperament is moody – seems to be kinesthetic learner
  - Generally healthy
  - Inherited tendency to mood disorders; home is stable
  - Has a church; access to services
Diagnosis vs. Formulation

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This 11 year old boy was exposed to alcohol and tobacco prior to birth, resulting in differences in processing (altered capacity for thought and learning), and in some degree of ADHD.

He was also subjected to haphazard parenting, resulting in diminished capacity for relationships, and then adopted by educated parents into a stable home.

He attends a good public school, but delayed diagnosis of ADHD and LD has added to misunderstandings, failure, and rejection.

He’s now angry and has a poor self-concept. He anticipates and even provokes angry responses in others.
Starting Treatment:

- Enhancing the parent-child bond is vital
- Parental guidance counseling -- parents need to learn strategies for raising a traumatized child, a child with an attachment disorder, a child with ADHD, and a child with learning problems
- Medication trial for ADHD symptoms is indicated
- “Raging” is a symptoms with multiple possible causes – parents should begin recording behaviors to establish pattern of rages and responses.
Parents are directed to request a school child study team evaluation and to share the results of our evaluation with the teacher and school staff.

The “treatment” for developmental disorder of reading is tutoring; parents are advised to pursue extra tutoring in addition to what school will provide.

“Treatment” of social failure is begun with carefully planned and coached social exposure; as the boy matures, individual and group therapy may be added, but not ready yet.

There is no specific treatment for fetal alcohol exposure; parents are counseled with respect to the boy’s risk for development of alcohol abuse/dependence.
How to Chart Anything

- Focus on 1, 2, or 3 behaviors or symptoms
- Convert the symptoms into an observable behavior
- Chart once daily (or in time periods that make it easy to chart)
You can only chart what you can “see.”

<table>
<thead>
<tr>
<th>Attitudes / Emotions</th>
<th>Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angry</td>
<td>Door slamming</td>
</tr>
<tr>
<td>Defiant</td>
<td>Failure to begin to comply within 1 minute after a clear command</td>
</tr>
<tr>
<td>Sad</td>
<td>Amount of time spent alone in room</td>
</tr>
<tr>
<td>Lazy</td>
<td>Number of incomplete or late assignments per week</td>
</tr>
</tbody>
</table>
This is what charts can show you....
This is what charts can show you....
We’re on our way...

We may not know where the path is going, but we are moving forward.
The follow-up visit:

- Parents refuse to participate in a class for parents of adopted children with attachment disorders, stating they took a lot of parenting classes when their biological children were young.
- Parents stop the stimulant medicine after two days because the boy has difficulty sleeping.
- Parents do not record behaviors as asked; mother brings in a diary that records her reactions to the child’s behavior rather than the child’s behaviors.
- The school child study team will meet in a month to consider the request for a review.
Suddenly things can seem hopeless.
It’s important to not lose your bearings!

- Remind the family of what they are trying to do. Check function again.
- Dialogue about the importance of following through on the steps of the plan.
- Listen – what’s preventing them from following through?
- Question the diagnosis
- Re-evaluate if necessary
- Refine the plan as necessary
Beware of baseline creep.
(You may still be in the woods, but if the path is a lot nicer – that’s progress!)
Where are we now?

- Stronger relationship between parents and adopted son based on better understanding of each other

- Son less frustrated in school – beginning to engage more positively with his work – on an IEP

- Son is involved in a club that gives him a sense of belonging and mastery

- Church peers are advocates for him at school

- Medications and parent training have reduced outbursts to one or two per month; shorter and less intense

- Family has a sense of how to handle outbursts when they occur – more hopeful outlook

- Parents still working on fully accepting son as he is*

- Son still wrestling with anger and depression at times*
This work is not linear – it’s a spiral --

- At each step, new information is gathered and fed back into the diagnostic model.

- At each encounter, the child has grown – some symptoms fade and others are more prominent, refining the diagnosis.

- Parents are also changing – grieving the lost “ideal” child and adapting to the “real” child.
This is not quick work –

- Parents often take years to accept the child “as is.”
- It’s not possible to know which symptoms or challenges can be overcome.
- The full expression of some difficulties may not be obvious for many years. Brain maturation continues into the mid-20s (and for those with ADHD, it takes longer).
- The diagnosis changes as the symptom picture changes – that’s to be expected.
More like yard work than car repair -

and at the end, you’re still on the journey.
Thanks to:

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