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

Keynote Address for PACER – The Ninth Annual National Symposium about Children and Young Adults with Mental Health and Learning Disabilities

Minneapolis Convention Center – August 7, 2014

Presenter: Susan C. Jenkins, MD, DFAPA  sjenkins@bluestemcenter.com

Child and Adolescent Psychiatrist; Medical Director and Owner of Bluestem Center for Child and Family Development - 124 Elton Hills Lane NW, Rochester, MN  55901 - 507/282-1009

Learning Objectives:

1. Understand that diagnoses are philosophical models and scientific hypotheses with varying degrees of evidence behind them.

2. Appreciate that mental health / behavioral/ developmental diagnoses in children are always works in progress.

3. Better understand the multi-faceted and multi-disciplinary methods of mental health evaluations and understand the importance of teacher observations for diagnosis and treatment.

4. Resolve to advocate for more resources for children and young adults with mental health and developmental disorders.

I. Problems of our Diagnostic System:

The Problem: Quote of diagnoses from an actual IEP

A. The DSM represents a significant advance in understanding mental illness, but it has advantages and disadvantages (Not given on Mount Sinai)

   1) Historical origination of diagnoses through observation of adults

   2) Associated traits are often not represented in the diagnoses (ex: sleep disorders and ADHD)

   3) Diagnoses are not based on genetics or neurophysiology

   4) The DSM is written through an academic and political process. It is being used in ways for which it was never intended.

   5) Not perfect, but better than the alternatives.

B. Another Problem: Symptom overlap – every diagnosis resembles every other.

   1) Kids don’t read the DSM – many kids are “diagnostically homeless.”
2) The DSM is not a field guide.

3) Comorbidities; spectrum disorders; blends of disorders

C. A third problem: People don’t tell you everything.

1) Shame and guilt; intentional deception

2) If you don’t ask, you won’t know -- people don’t know what to report

3) You won’t ask if you don’t know – new models (ex: attachment)

4) Limitations of informants (apples and trees; people with agendas)

D. Sometimes the diagnosis is dictated by the need – who wants to know? How soon?

1) It matters how you ask: the importance of relationship.

2) Limitations of time and resources in the evaluation process

E. BUT Mental health disorders are real and treatment is effective.

Review: Our diagnostic system represents a variety of diagnoses with varying degrees of scholarship and certainty behind them; children are a work in progress and are likely to change symptoms over time; adults (and children) don’t tell you everything.

II. Walking through the forest: Mental Health Treatment sometimes feels like you’re finding your way through a forest without a map. But this doesn’t mean we’re lost.

A. Systematize what we know: -- Don’t blindly plunge ahead – stop and make a plan!

1) First, see what you have in your pack…Elements of the evaluation

2) Test the hypotheses: Is there some way to get our bearings?

   a) Psychological testing

   b) Structured interviews and observations

   c) Medical consultations and tests

B. The evaluation continues during treatment – not a “medical model”

   1) Outcome measures – Periodically check your bearings. Don’t keep walking if the path gets rougher or leads you away from your goal. The SDQ and CASII.

   2) Record observations in an ongoing way --Mark the trail – when you implement a treatment plan, know what you are doing and why --

   3) How to chart anything.

C. Keep the goal in view. *If there’s no impairment there’s no disorder.*
1) Go for function, even if it looks “wrong” on the map.

2) Beware of “baseline creep” –

3) Incorporate new information into the evaluation and treatment plan.

III. Get help from fellow travelers:

A. Multidisciplinary input is required – (Reminder of the elements in the evaluation and how they are multi-systemic

B. Pay attention to conflicts that are built into the system

   1) Different training gives you different types of information (The Elephant Parable) – Beware people who stray from their area of expertise or role on the team.

   2) Professionals work within economic & political systems

C. Listen critically (skeptically) – We all bring ourselves to the table – personal experiences, culture, temperament

D. Confidentiality as help and hindrance – HIPAA

IV. Illustrative case history

V. Review –

A. Diagnoses are conceptual models to aide research and treatment. They should be respected – not worshipped.

B. A careful evaluation will demonstrate strengths and weaknesses over several domains. A good description of the child is often more useful than a diagnostic label.

C. Evaluation is an ongoing process during the child’s development and throughout any course of treatment.

D. Mental health treatment is effective -- with the same degree of success as other medical treatments. A definitive diagnosis is not required for effective treatment