To Help Families in Transition Requires Our Understanding the Facts of Life

- Definitional and Diagnostic Ambiguity
- Family Resistance to a Dual Diagnosis
- Family Dynamics and Dual Diagnosis
- Obstacles and Strategies Involving Treatment
- Interfacing with Mental Health Services

Dual Diagnosis Ambiguity: Behaviors or a Mental Disorder?

Oppositional defiance, mood lability, aggression, self-injurious behavior, anxiety, delusional fantasies, hyperactivity and inattentiveness, are all “normal” behavioral components of childhood.

“Psychiatric diagnosis is closer to alchemy and astrology than it is to medical science.” — Thomas Szasz

Dual Diagnosis: Developmental Disability and…?

- Mental Illness?
- Mental Disorder?
- Mental Disease?
- or Psychiatric Illness, Disorder, Disease?

The medical model prevailed: It’s a Mental or Psychiatric Disorder but...

“Mental Disorder is an imperfectly defined construct whose validity and definition have serious social and professional implications.” — Widger and Trull
Another Dual Diagnosis: “College Student” and “Mental Disorder”

Carlos Blanco, MD, PhD, Archives of General Psychiatry. 2008;65[12]:1429-1437

December, 2008 report used pooled data analyzed by Columbia University, the NIH, and the New York State Psychiatric Institute; it concluded that

45.8% of college students have at least one diagnosable psychiatric disorder

Less than ¼ of these students seek and receive treatment for their disorder

Mental Disorder

- ICD-10: “a clinically recognizable set of symptoms or behaviors associated in most cases with distress” and functional interference
- DSM-IV-TR: “…a clinically significant behavioral…syndrome…associated with present distress…or disability….it must be considered a manifestation of a behavioral, psychological or biological dysfunction in the individual.”
- As the DSM reiterates, the classification systems are of disorders, not types of individuals

DSM-IV Disorders

- Disorders Usually First Diagnosed in Infancy, Childhood or Adolescence
- Delirium, Demential and Amnestic and Other Cognitive Disorders
- Mental Disorders Due to a General Medical Condition Not Elsewhere Classified
- Substance-Related Disorders
- Schizophrenia and Other Psychotic Disorders
- Mood Disorders
- Anxiety Disorders
- Somatoform Disorders
- Factitious Disorders
- Dissociative Disorders
- Sexual and Gender Identity Disorders
- Eating Disorders
- Sleep Disorders
- Impulse-Control Disorders Not Elsewhere Classified
- Adjustment Disorders
- Personality Disorders

(no “rank order”)

Labeling: Downsides and Upsides

- Too easy to become overly inclusive, encompassing the ends of the “normal spectrum”
- Labels are boxes, and some confine with expectations and yet stigmatize those inside
- Labels are social and not just scientific constructs
- Why not focus on individual or sets of behaviors without diagnostic categories (labels)?
- Recognizable sets of dysfunctional behaviors often have similar (and pathologic) neurological substrates
- Treatment comparisons are attainable only when labels create diagnostic categories; without reliable labels, the recent advances in psychopharmacology would not have been possible
- The stigma of having a mental health diagnosis is now minor, and it may even provide an “excuse”
Family Resistance to a Dual Diagnosis

- General medical belief 30 years ago: individuals with developmental disabilities did not understand and respond to life situations in ways that lead to or engender mental illness, and →
- Behaviors and symptoms that occur in this population may look like a mental disorder but they are a product of the developmental disability (i.e., it’s entirely “normal” for them), and →
- Individuals with disabilities live in group settings and copy maladaptive behaviors from others

Dual Diagnosis: Their Doctors are in Denial

- Half the psychiatrists polled do not want to evaluate or treat patients with a developmental disability.→
- Those with an ASD or MR may express the mental disorder in a different or unique way.→
- The “cloak of competence”: families may deny the disorder to avoid another stigma; caregivers and agencies deny another diagnosis to save resources.

Dual Diagnosis and Under Diagnosis

- More Reasons for Resistance and Two Case Studies

  - *Et tu Brute*…please, not more of a burden… and not more grief after all that adjustment…
  - Other dysfunctional behaviors were labeled part of the disability, so why a dual diagnosis now? Are you certain?
  - People with disabilities and mental illness sometimes end up in institutions; will this happen now? An institution?
  - Developmental disability means a need to provide predictable care, and mental illness means a need for close supervision and lots of unpredictability.
  - Mental illness seems *volitional or volatile* and dangerous to be around; it’s still stigmatized by some.
**Case #1: GG**

(from ACRC Best Practices Committee)

- GG is a 24 year-old female with diagnoses of autism, mild mental retardation and epilepsy.
- In the past few years her weight went from 230 pounds to 125 pounds; her sleep patterns evolved where she now has up to three days of insomnia.
- In the past two years she talks to herself and does not communicate with others as she once did.
- GG screams much more, disrobes frequently and is very aggressive if approached by family or staff.

**GG’s Parents are her Conservators**

- The parents are aware that multiple medical and neurological evaluations have not suggested or revealed the etiology of this decline.
- They refused the psychotropic medication changes (additions) suggested by both the primary care physician and by a consulting psychiatrist.
- They categorically state: “Our daughter does not have a mental illness—she has autism, and something else must be going on.”

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**Case #2: BB**

- BB is a 20 year-old male who is unconserved and lives with his parents; with very low adaptive scores BB was found ineligible for ACRC services.
- At age 17 his IQ was in the normal range and the next year, after a violent and destructive outburst, he was hospitalized in a psychiatric center; his IQ scores diminished after that while his achievement scores (WIATT) remained in the low normal range.
- BB was diagnosed with a PDD other than autism, and also with bipolar disorder, ADHD, and anxiety.

**The Parents and The Judge**

- An Administrative Hearing Judge found BB eligible for ACRC services under the 5th Category.
- The parents testified that BB was “always different” and “never showed emotions” or wanted affection.
- They reported that BB never made friends and was fearful of many things (for example, buses).
- Both parents now feel “vindicated” in their belief that BB “was never mentally ill” and that he has a “developmental disability.”
Living Arrangements and Dual Diagnosis:

Family Dynamics and Residence

Sibling relationships are reported as concerned and supportive, but mental disorders disrupt them.

One sibling is often identified as a future caregiver, but mental disorders may inhibit this when there is a mental disorder, siblings report a higher level of well-being when distant from their impaired brother or sister. When there is a mental disorder, siblings are less likely to choose a career involved with disabilities.

Dual Diagnosis = More Family Strain

- Young siblings are asked to assume maturity and responsibility beyond their years.
- When dual diagnosis is present, dependency increases and so does the relational distance of siblings and other family members.
- Siblings get less parental attention (one-on-one time).
- Don’t talk rules are more abundant (don’t comment on the disorderly behaviors and don’t provide an antecedent condition), and more feelings are stuffed.

Case Report of Two Siblings: Brenda and Betty

(Brenda and Betty) (from ACRC Psych-Med Committee)

- Betty is an 18 year-old with Mild MR and ADHD, Mood Disorder NOS, and Intermittent Explosive Disorder; Brenda is her 14 year-old sister.
- “Betty has been a hand-full from the get-go,” says mom; at age 2 she pulled down the Christmas tree.
- Betty has been on Ritalin or Dextrophen from ages 6-10, and more recently she has tried imipramine, clonidine, Depakote, Risperdal, Prozac, Zoloft, Ativan, Lithium, Seroquel, Zyprexa, Klonopin, and Topamax and brownies.
More About Betty

- Betty has been hospitalized several times at a local psychiatric facility utilized by the Kaiser Permanente Medical Group; this facility will no longer allow her to be admitted.
- The last time Betty had out-of-control behaviors and needed hospitalization, Kaiser had to admit her to a medical bed and a private room where she stayed for three weeks; two staff psychiatrists evaluated her and made recommendations.
- The mother asked, “Isn’t there a better way?”

What About Brenda

- Over the last two years, Brenda’s grades in school have gone from an “A+” to a “C” average.
- Brenda has become “more of a loner” in the past three years, says her mother; she once was an extrovert and comedian, “but not any more.”
- A Kaiser psychiatrist, treating Betty, interviewed Brenda and diagnosed clinical depression; he briefly mentioned residential placement for Betty.

Betty Goes to Camp Residence

- Every summer Betty goes to camp and does well there; the “trial” of residential respite is described as a sleep-away camp and Betty loves it.
- Betty responds to the firmer structure, full time behavioral support, peer group teaming (taking out the trash via a buddy system), and daily ILS training; Betty goes to see the psychiatrist with data (daily records from the residence), a staff member and her mother.
- Brenda, says her mother, “is like her old self, and she looks forward to visits with her sister.”

Increased Parental Stress: The Rules of Engagement

- Relationship between parent and child may be impaired by a dual diagnosis; it takes two to bango
- Mothers are more stressed than fathers by a heightened level of “disengagement”
- A continuum can be drawn from the need to provide care as opposed to the need to control
Parental Care vs Control

- *Care* is operationalized as attending to the handicaps in self-care
- *Control* is supervision, or attending to the impairments in self-direction
- Developmental disability suggests a need for *care*, and mental disorder a need for *control*
- Fathers are more stressed by caregiving; mothers are more stressed by supervising (controlling)

Maternal Well-Being and Dual Diagnosis

- Mothers of adults with dual diagnosis report less caregiving gratification and a greater “sense of burden” than mothers of adults with a DD only
- Mothers of adults with dual diagnosis report heightened anxiety about obtaining services
- These mothers have greater concerns about future care for their offspring when they no longer can provide it (and they score higher on “pessimism scales”)
- These mothers are at greater risk for mood disorder

Mothers and Fathers: Coping Differences

- When families have an adult child with disability and dual diagnosis, fathers are more likely to have specific caregiving (control-giving) roles and responsibilities
- Fathers are more likely to adopt emotion-focused coping: an attempt to reduce or manage emotional distress and reactivity, oftentimes by denial and avoidance
- Mothers are more likely to adopt problem-focused coping: an attempt to use cognitive and behavioral strategies that alter or manage the dysfunctional situation
- Emotion focused coping → more pessimism

A Harmful Cycle

- Increased burden to the parent, absence of resources and increased caregiver strain
- Dual Diagnosis but now with increased aggression, depression hallucinations, anxiety, compulsivity, etc.
- Depression in the parent, hopelessness and isolation, or acting out and retaliation
- Emotion focused coping → more pessimism
Parental Setting or Residential Placement

- Dual diagnosis increases the likelihood that placement in community-based nonparental settings will be undertaken.
- Dual diagnosed adults who remain with their parents have lower rates of self-injurious behavior, aggression towards others, and property damage.
- In the parental home as opposed to the residential group home, mental disorder behaviors or moods exert a stronger bidirectional impact.

Who has (or engenders) the disorder?

the “toxic parent” literature

Severity of the Disability, Residence and the Incidence of Dual Diagnosis

- Those with the most severe developmental disability are least likely to be diagnosed with a comorbid mental disorder ("diagnostic overshadowing").
- Those living in the family home, or the home of a close relative, are least likely to be diagnosed with a mental disorder irrespective of their behaviors.
- Those placed in group homes are most likely to be dually diagnosed and/or prescribed psychotropics.

Family Members Wonder: How Much is Too Much?

Considerable research over the past twenty years reveals that individuals in group homes, with a diagnosis of a developmental disability and behavioral problems, are the most medicated individuals found in our society.

Medication use and related costs rise exponentially when a person has a mental disorder and more than one disability (for example, MR and/or CP and/or epilepsy, or autism, MR and epilepsy)

The Biggest Pitfall:

Knee-jerk psychopharmacology without adequate mental health treatment:

Individuals with a developmental disability are labeled and treated with antipsychotics, analeptics, antidepressants and tranquilizers in order to modify behavior without the appropriate analysis, concerns and treatment required for the underlying mental disorder.
Helping Families Make Decisions About Medications

- Parents are exposed to conflicting information; are medications being overprescribed?
- Are medications risky and are there dangerous side-effects (suicide, addiction, brain damage)?
- What about the long-term safety of medications?

ACRA Guidelines (The Association of Regional Center Administrators)

Six Valid Reasons for Using Psychotropic Medications:

- Clearly diagnosed psychiatric illness
- Medical conditions with associated behaviors (for example, epilepsy with tremors or tics)
- Emotionally distressing extreme behaviors that interfere with important life activities
- Chronic dysfunction resistant to other forms of intervention (for example, early morning waking)
- Medication withdrawal symptoms
- Sedation/relaxation before/during medical procedure

Responding to Family Medication Concerns: ARCA on Best Practices

- Understand what behaviors signify or try to communicate
- Medications should not be allowed to mask abuse
- Medications should not substitute for necessary supports
- Prescribing is not for caregiver convenience
- Thorough and comprehensive assessments
- Periodic reexamination of the decision to medicate
- Adequate clinical trials and adequate dosing
- Caregivers need to become educated about medicines
- PRN guidelines need to be explicit and well understood

Seeking and Obtaining Help and Treatment Over a Lifetime
Social Support Saves Lives

- Supporting families with dual-diagnosed members is vital; benefits of a support group is well documented in medical health studies:
  - Those with a support group have greater longevity and less morbidity
  - For example, studies show less stress and pessimism, a lower chance of a second heart attack, greater tolerance of chemotherapy, etc., in those with a support group
  - Other studies show that the perception that there is a support group is as powerful a help as actually using it

NADD
the National Association for the Dually Diagnosed
www.thenadd.org

It Takes a Village (A Team!)

The Team Approach is VITAL

- A synthesis of assessments, medication and treatments offered by many different caregivers
- A reliance on and integration of family members, residential caregivers and program staff
- A willingness to understand and evaluate past history but to never blindly accept its conclusions; untruths are passed down through time and what was once a prior truth may not be true today

Who is on the Team?

- The consumer
- Family and friends
- Treating physicians, the PCP and specialists
- Social workers and case managers
- Consumer/activists
- Nurses
- Behaviorists
- Professional consumer advocates (salaried)
- Psychologists
- Day program staff
- Residential staff
- State and county agency representatives
- Speech therapists
- OT and PT
Team or Teams? DDS or MHS?

- Two systems/Two approaches: one for disabilities and one for mental health diagnosis and treatment
- Mental Health System: we don’t have the resources
- Disability System: we don’t have the expertise to manage the behavioral-emotional problems
- Two sets of advocates: individuals with mental health issues and persons with developmental disabilities usually have their own sets of lobbyists and self-help or support groups

Team MHS

- Emphasis on Recovery or at least Remission
- Reliance on psychiatric intervention, i.e., the use of medical intervention
- Rehabilitation is a guiding philosophy or goal
- “Don’t call me impaired”

Team DDS

- Emphasis on adjustment and self-determination
- Reliance on behavioral and environmental supports and services
- Habilitation, or gaining adaptive skills for the first time, is the goal
- “Don’t call me crazy”

The way it’s supposed to be:

National Association of State Mental Health Programs and National Association of State Directors of Developmental Disabilities Services joint survey in 2003 (from 35+ States replied):
- 36% have a written interagency agreement
- 74% have a dual diagnosis task force
- 68% have an understanding about payment
- 62% have interagency training programs

The Hard Reality

- Lack of qualified providers who understand and treat dual diagnosis
- Failures are blamed because of interference from the other team: mental health professionals don’t reach their goal because there’s a developmental disability; developmental disability services drop the ball because of untreated mental disorders
- Agencies guard their dwindling resources and exclude first, ask questions later
“If you want to build a ship, don’t herd people together to collect wood and don’t assign them tasks and work, but rather teach them to long for the endless immensity of the sea.”

Antoine de Saint-Exupery

“One cannot see well except with the heart; the essential is invisible to the eyes.”