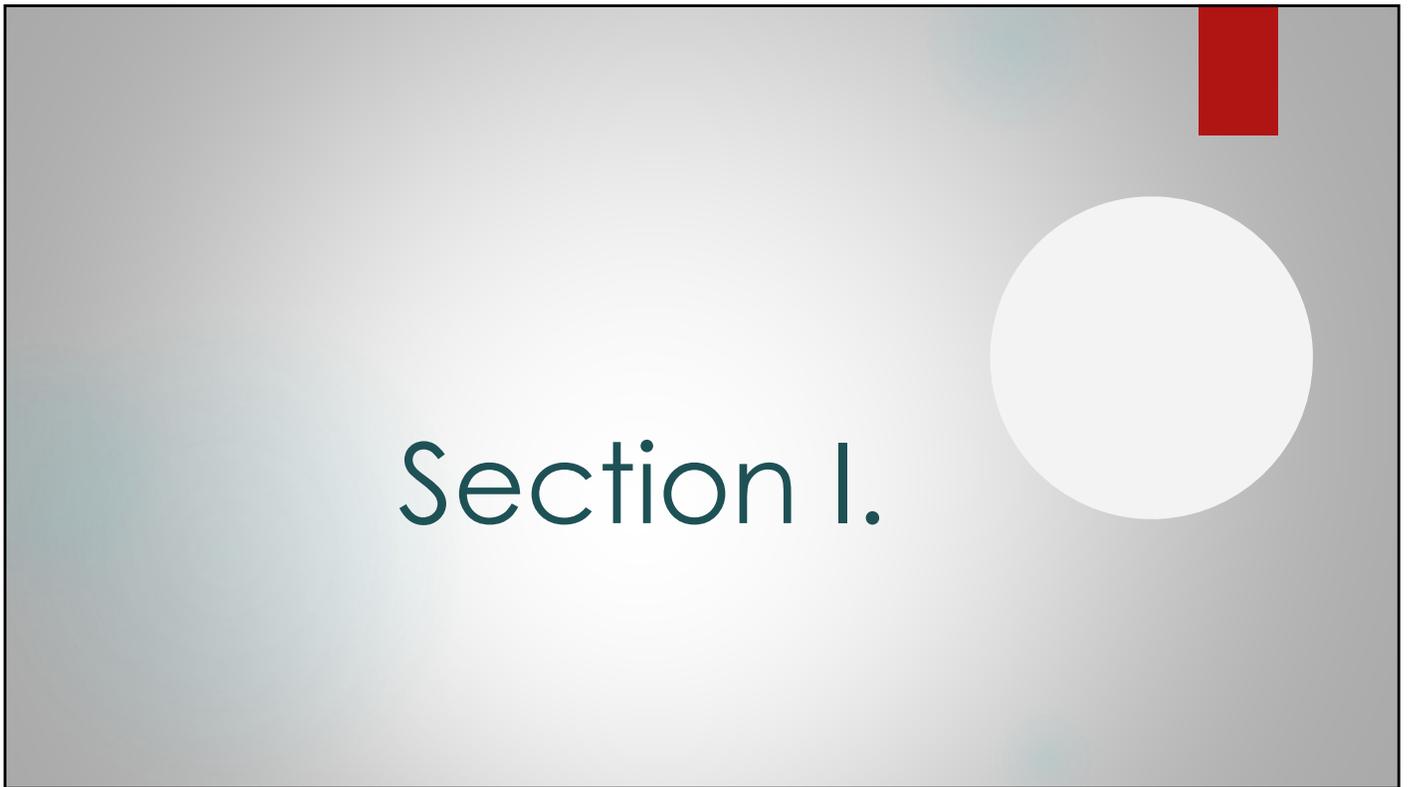


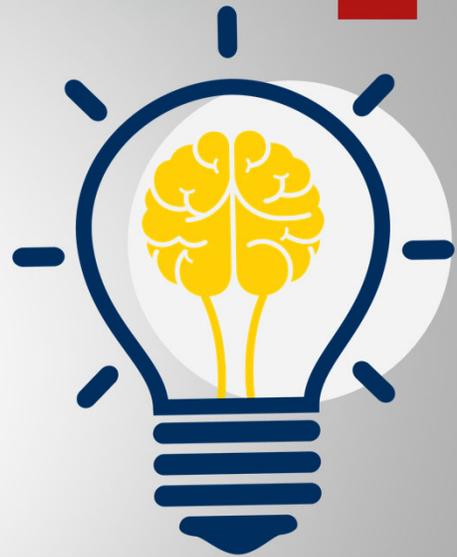
Low Cognitive Disorders & Mental Illness:

NEBRASKA PROVIDER TRAINING- WILLIAM REAY, PH.D.



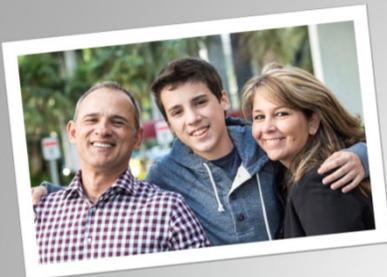
Note to Participants

- This presentation is a "primer." The applied research on evidence-based care is massive. Many of the EBP Model Builders have employed marketing strategies to promote their EBP, much like other products that are available to the consuming public. It is important to recognize that the research and scholarship on EBPs is scientifically complex, which includes methodological flaws, mixed results, and serious limitations. In other words, with ongoing research, EBPs will change and it is the responsibility of EBP users to maintain a current understanding of the applied literature and act according to the ethical standards of your discipline.



Common Child and Youth Management Understandings





Styles of Parenting and Child Management

- Parenting and child management are activities that include many specific adult behaviors that influence how a child behaves.
- Although specific caretaking behaviors may influence child development, isolating a specific caretaking strategy as causing specific child behaviors can be misleading.
- Patterns of child and adolescent management are more important in identifying and predicting child wellbeing.
- Child management style is meant to describe “normal” variations in management, and should not be seen as describing deviant strategies associated with prolonged neglect or acute or chronic abuse.

What is the Primary Role of ALL adults who are responsible for children and adolescents?

- **Influence** children's behavior choices, attitudes, emotions, and moral development.
- **Teach** children important physical, emotional, cognitive, behavioral, and moral behavior.
- **Control children's behavior** until the child can learn to control themselves.

Two Building Blocks of child and adolescent management

- **Adult Responsiveness** – degree of warmth and support provided the child. The extent to which adults intentionally foster individuality, self-regulation, and self-assertion by being attuned, supportive and acquiescent to children's special needs and demands.



- **Adult demandingness**, or degree of behavioral control. This refers to the claims adults make on children to become integrated into the family, by their maturity demands, supervision efforts, disciplinary control, and willingness to confront the “disobeying child.”

Four Management Styles

- Indulgent
- Authoritarian
- Authoritative
- Uninvolved



Each of these four (4) styles reflect different naturally occurring patterns of adult values, practices, and behaviors and a distinct balance of responsiveness and demandingness.

The Big 4

- Indulgent adults (aka permissive). Are more responsive than they are demanding. Tend to be nontraditional and lenient, do not require mature behavior, allow considerable self-regulation (or lack thereof), and avoid confrontation.
- Indulgent adult sub-types: *democratic adults*, though lenient are more conscientious, engaged, and committed to the child and
- *nondirective adults*, allow the child to do as they want.

The Big 4

- Authoritarian adults are highly demanding and directive, but not responsive. They are obedience and status oriented, and expect their orders to be obeyed without explanation. These adults provide well-ordered and structured environments with clearly stated rules. Authoritarian adults can be divided into two types:
 - Non-authoritarian-directive, who are directive, but not intrusive or autocratic in their use of power;
 - Authoritarian-directive, who are highly intrusive.



The Big 4

- Authoritative adults are both **demanding** and **responsive**. They monitor and impart clear standards for their children's conduct. They are assertive, but not intrusive or restrictive. Their disciplinary methods are supportive, rather than punitive. They want their children to be assertive as well as socially responsible, and self-regulated as well as cooperative.



The Big 4

- Uninvolved adults are low in both responsiveness and demandingness. **In extreme cases, this management style might encompass both rejecting-neglecting and neglectful management practices.**



Psychological Control

- Psychological control attempts to intrude into the psychological and emotional development of the child. Adult practices such as guilt induction, withdrawal of love, or shaming are extreme methods of psychological control.
- An important difference between Authoritative and Authoritarian management is in the area of **psychological control**. Both types of management place high demands on their children and expect children to behave and obey adult rules. However, Authoritative adults are more open to give and take with their children and make greater use of explanations, and lower on psychological control!!!

How Nurturing Are You? Let's Find out!!!!

- I frequently tell children nice things about them;
- Children would say that they are important people in my eyes;
- I often hear from children that they think I don't care about them;
- Children would say that I enjoy spending time with them;
- I am frequently affectionate and warm to children;
- Children would say it is easy to talk with me;
- I feel very close with children;
- Children express that I find fault with them, more than they deserve;
- I console children when they are unhappy or sad.



How Aware are You of Your Management Style?

- At the end of the day, I reflect on what kind of messages I gave children today;
- I know when I raise my voice with children;
- I receive feedback from children regarding my behavior with them;
- I use more positive statements than corrective comments towards children every day;
- I believe I am understood by children when I deliver instructions;
- I spend at least 15 minutes each day with children in an activity of their choice.

How would you describe your management Style?

- Mostly Authoritative?
- Mostly Authoritarian?
- Mostly Indulgent?
- Mostly Uninvolved?



- What are the child behavioral consequences associated with these management styles?

Consequences for Children- they become what they experience!!

- Children and adolescents whose adults are **Authoritative** tend to be more socially competent and skill competent than children subjected to non-authoritative management strategies!!!!!!
- Children and adolescents whose adults are **Uninvolved** perform the most poorly in all social and skill domains!!!!

Consequences for Children- they become what they experience!!!



Children and adolescents whom experience authoritarian management styles (high in demandingness, but low in responsiveness) tend to perform moderately well in school and be uninvolved in problem behavior, but they have poorer social skills, lower self-efficacy, and higher levels of depression.



Elements of Caregiving-
Spelled out for you

1. Harsh management practices

- Defined as a dominant approach to individual management that is highly controlling; emotionally and /or physically coercive; predominant use of punitive techniques to stop undesirable behavior. This includes, but not limited to raising one's voice when discussing infractions with the individual; withdrawal of affection or attention as a consequence of undesirable behavior; verbal threats and statements that are designed to cause hurtful feelings; contingencies placed on all behavior; and lack of unconditional acceptance of the individual.
- Examples of harsh practices include:
 - Removing electronic devices from the individual for periods exceeding 24 hours
 - Preventing the individual to repair the fractured trust and enforcing consequences for extended periods of time
 - Not providing the individual with realistic alternatives to the infraction that if demonstrated, would have resulted in desired behavior
 - Quid pro quo management strategies (this for that)
 - Management approaches designed to "break the will" of the individual
 - Providing consequences without explanation
 - Requiring a level of behavioral performance that is not realistic based upon the individual's developmental, emotional, or physical abilities



2. Retribution

- Retribution, also known as 'retaliation' or 'payback,' is simply the act of taking revenge. In caregiving, this tactic is used as emotional punishment in order to coerce individuals into compliance, which has the result of ongoing defiance, non-compliance, and revenge tendencies on the part of the individual.
- Examples of retribution in caregiving include:
 - Ignoring the individual, rather than ignoring maladaptive behaviors
 - Withdrawing affection / emotional rejection
 - Saying hurtful or degrading things to the individual about them, their family, or their culture
 - Damaging or destroying something belonging to the individual
 - Mean-spiritedness
 - Extreme reactions to accidents against their person or possessions
 - Dismissing a gift, attempted appreciation, or attempted apology
 - Focus on wanting to get even



3. Contagion

- Grounded in social learning theory, peer contagion refers to a mutual influence that occurs between an individual and a peer where each party inadvertently influences the other, typically amplifying negative behaviors through the process of deviancy training. Most commonly influenced are adolescents, those with less sophisticated social skills, and individuals with diminished cognitive capacity. Congregate care settings increase the opportunity to spread contagion, undermining individual development and treatment effectiveness.
- Behavioral examples include:
 - Aggression
 - Bullying
 - Weapon carrying
 - Disordered eating
 - Drug use
 - Suicide (cluster suicides)
 - Self-injury
 - Depression



4. Nurturing

- To be nurturing is to provide encouragement, care, and nourishment for someone or something. This is often achieved by providing an aspect of unconditional positive regard for the individual, that is not determined by or influenced by his or her actions. By engaging with the individual and offering positive feedback (versus "negative" or harsh feedback), the act of nurturing fosters growth and development of the individual.
- Examples of nurturing include:
 - Be aware of stages in development so you do not expect too much or too little from the individual.
 - Spend time regularly with the individual, engaging him/her in meaningful activities such as playing games, discussing topics of interest, etc.
 - Be fully present in interactions with the individual (using both verbal and non-verbal feedback). Listen to the individual and acknowledge what he/she is saying.
 - Encourage the individual to express his/her feelings, respect those feelings, and provide comfort and assurance.
 - Provide physical affection and comfort when sought after by the individual, and when the sought-after action is appropriate (for example, providing side hugs, high-fives, etc.).
 - Encourage talents and accept limitations, recognizing that each individual is different. Celebrate accomplishments, show approval for positive behaviors (versus destructive or dangerous behaviors, which may be characterized as "negative" behaviors), and avoid comparing one individual's abilities to another's.
 - Foster the individual's independence and self-worth. Demonstrate your confidence in the individual's ability to handle problems and tackle new experiences.
 - Utilize any consequences as a form of teaching, not physical punishment. Provide any consequences constructively, fairly, and consistently.



5. Person Centered Planning



- The primary focus of planning is inclusion of the individual's own vision for their life. This approach to planning is individualized, flexible, and responsive to a client's changing needs and circumstances, including their strengths and weaknesses. The individual is provided opportunities to discover how they want to live their life and what supports are required to meet those goals.
- Examples of person centered planning include:
 - Recognizing the individual as an individual whom requires support specific to their needs.
 - Working with the individual and their team to include guardians, clinicians, and caregivers in assisting the individual in identifying their strengths and weaknesses.
 - Developing individualized formal and informal programs that support the individual in goal development and skill attainment.
 - Appreciating a person's culture and their need to behave within that context and provide opportunities to participate in their own culture.

6. Engagement

- There are two aspects to engagement:
 1. ENGAGING the individual in the program: Establishing a positive social environment as determined by the frequency of positive or neutral interactions (versus negative comments or interactions) between the caregiver and the individual, and the frequency of positive attention (perceived as reinforcing by the individual). These elements facilitate the individual's hope and willingness to invest in treatment.
 2. The individual's ENGAGEMENT in the program, meaning the individual's participation in the program and their receptiveness to developing a relationship with the caregiver.
 - An individual is *engaged* when they are motivated to change and hope or believe that this treatment can have a positive impact on their life—so they actively participate in treatment.
 - *Engagement fosters the development of the RELATIONSHIP.*

7. Relationship

- Feelings and attitudes that the caregiver and the individual have toward one another, and how these are expressed in their interactions (this definition focuses on positive, healthy relationships-- i.e., mutual non-coercive, unconditionally positive, and non-toxic.). Relationship is the interpersonal bond that creates a belief that the caregiver is concerned for the individual's well-being and facilitates effective collaboration between the individual and the caregiver.
 - *Relationship rests on the presence of ALLIANCE.*



8. Alliance

- Reciprocal positive feelings between an individual and caregiver, and an agreement on the goals and responsibilities of each party that will improve the individual's life and ease their suffering. Essentially, alliance is a positive relationship that supports collaboration and the individual's investment in the therapeutic program.



9. Caregiver Credibility

- Refers to the clinical judgement by both team professionals and the individual in care. The judgement is based upon the caregiver's ability to be consistent with expectations and communication across environments, settings, and with all individuals involved. Caregiver credibility refers to both verbal communication and behavioral presentation, and the consistency between. Caregivers perceived to have the highest credibility are those that listen to all parties and communicate the same message despite changes in environment and audience.
- Factors that facilitate caregiver credibility include:
 - Building Relationships
 - Building Alliances
 - Engagement
 - Nurturing



Conclusions about management Styles

- The benefits of **authoritative management styles** and the detrimental effects of **uninvolved management styles** are evident as early as the preschool years and continue throughout adolescents and into early adulthood.
- The largest differences are found between children whose adults are unengaged and their peers with more involved adults.



It is all about Engagement

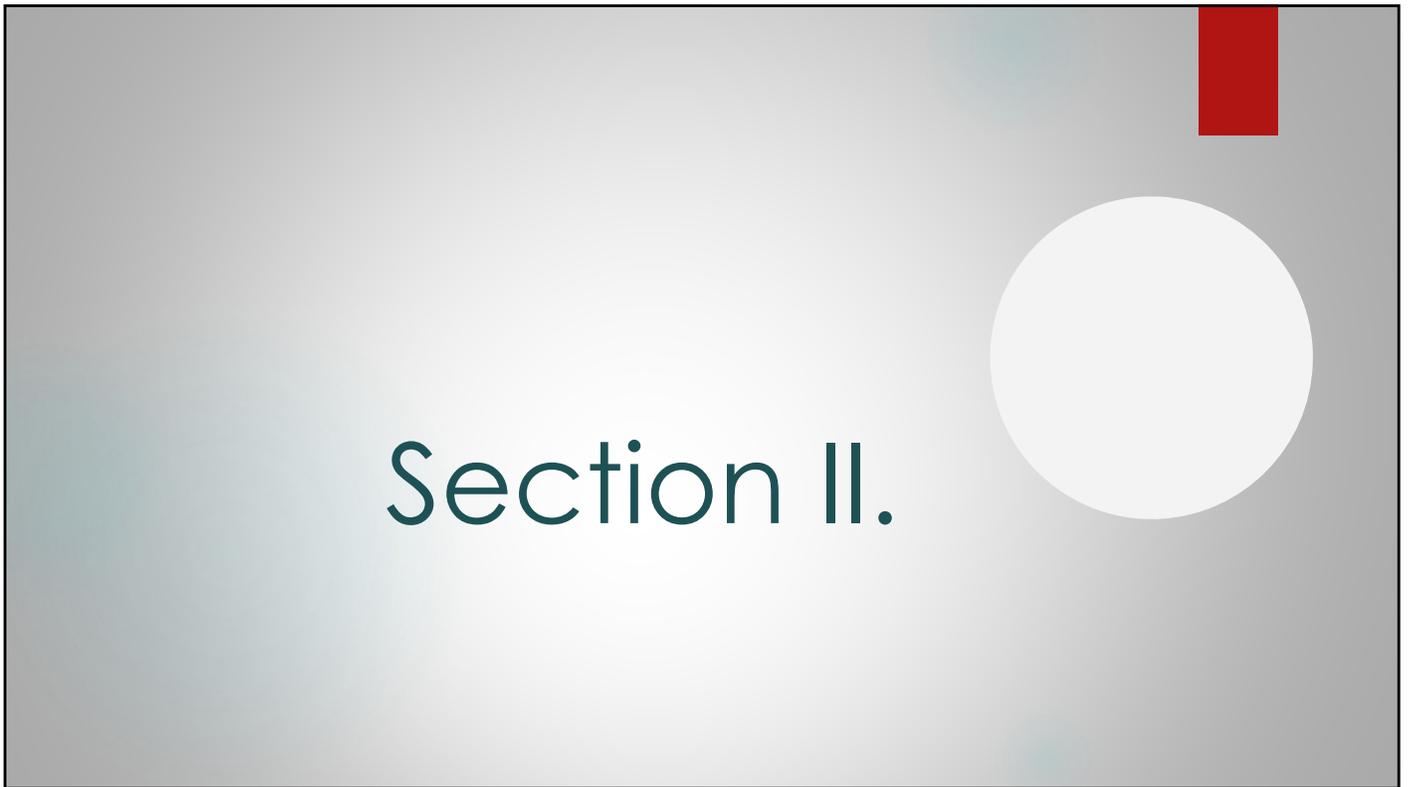
- Both adult responsiveness and adult demandingness are important components of good child and adolescent management. Authoritative management, which balances clear, high adult demands with emotional responsiveness and recognition of child autonomy, is one of the most consistent family predictors of competence and emotional regulation from early childhood through adolescence.



Summary



- Build a management strategy that is balanced; one that is demanding and responsive.
- Take time to spend time with the child and adolescent.
- Model and demonstrate the behaviors you want the child to display. Show them why being kind and calm is important.
- Communicate expectations, praise accomplishments, celebrate what being a family means and what that means to each member.
- Problems in relationships are inevitable. They require time and work. Don't give up.





Promising Practices & Practices to Avoid

Questions Addressed in THIS section of the Presentation

- What is the meaning of the term “Promising Practice?”
- What is the difference between a “Promising Practice” and an “Evidence Based Treatment?”
- Why do we want to use Evidence Based Treatments and promising practices?
- How do you determine if a practice or treatment is effective?
- How do you choose an evidence based practice or promising practice?
- Are there known harmful practices and treatments that are currently being used?

The Basics: What is essential and required?

- For more than 20 years, the field of behavioral health has faced a national crisis surrounding its workforce.
- Critical issues include recruitment and retention and a serious lack of relevant preparation for work in behavioral health.
- Current practices (usual care) is not based upon either evidence or promising practices; university curricula and post graduate training programs are not current with the science nor are continuing education programs designed to improve core competencies aimed at meeting these needs.
- Even if universities teach EBPs or promising practices, they tend to lack guidance in how to apply those models or techniques.

The Vision: New Freedom Commission on Mental Health

- First, services and treatments must be consumer and family centered, geared to give consumers real and meaningful choices about treatment options and providers not oriented to the requirements of bureaucracies.
- Second, care must focus on increasing consumers' ability to successfully cope with life's challenges, on facilitating recovery, and on building resilience, not just managing symptoms.

Core Attitudes, Knowledge, Skills, and Competencies Required for the Behavioral Health Workforce

- Public behavioral health has not identified, standardized, or implemented a core set of portable constructs or competencies for direct care staff in any cohesive manner.
- Five core competencies that all clinicians should possess regardless of discipline include: *person-centered care*; *working in interdisciplinary teams*, **using evidence-based practices**, *applying quality improvement principles*, and *using informatics*.



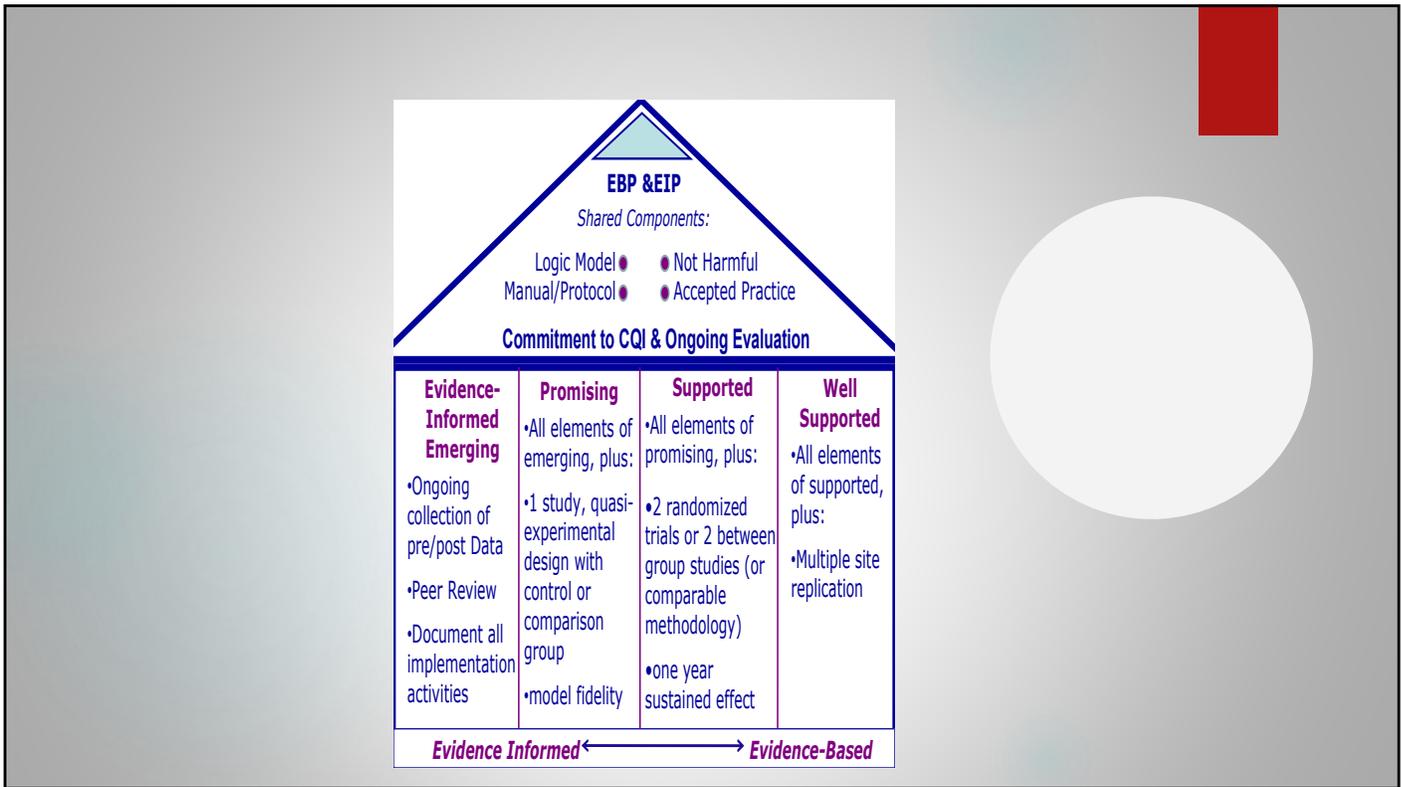
(SAMHSA, 2014)

What Constitutes an Evidence-Based Treatment?

- Since the 1960s, *professional* evaluation has aimed to apply scientific research methods to develop evidence-based practice and programs (EBPs).
- Over the past 40 years, the term “evidence-based” has gained traction in many disciplines including behavioral health.
- However, the policy of the United States Office of Management and Budget (OMB) directs federal agencies to use the concept of “credible” evidence in the formulation of budget proposals and performance plans. The OMB further encourages funding of programs that are backed by strong evidence of effectiveness.

Credible Evidence vs. Evidence-Based

- What precisely constitutes credible evidence continues to be debated. The difference between credible evidence and evidence based is also hotly debated by researchers and political bodies.
- However, Evidence-Based Treatments have become the central mechanism for the application of scientific findings to practice delivered in service settings.
- The number of EBTs has grown, and a number of catalogues have attempted to organize what is known about them.



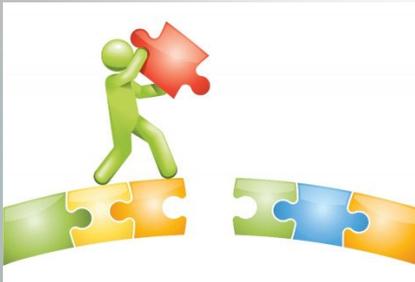
Cataloguing of EBPs & Knowledge Synthesis

- It is the application of explicit and reproducible methods to the identification, appraisal, and synthesis of studies or information relevant to specific question.
- In behavioral health, these reviews, meta-analyses, and registries serve as lists from which one can select a single EBT that is well suited to a single client, e.g., depressed teenager.
- Increased understanding of the specific challenges to implementing EBTs is part of the strategic mission of the National Institute of Mental Health (2008) as well as the U.S. Department of Health and Human Services (2007).



NIMH
National Institute
of Mental Health

Knowledge Synthesis



- Despite considerable investments and initiatives over a 20-year period, the connection between evidence and practice in health care has been inefficient and fragmented, with approximately one third of all health practice being inconsistent with scientific findings and more than 20% either unnecessary or harmful.
- The gulf between evidence and practice is more severe in behavioral health, with the majority of services delivered in usual settings having little or no relation to practice supported by research.

Connection between Behavioral Health Science and Practice

- Evaluations of behavioral health interventions have identified many that are potentially effective.
- Qualified clinicians and other decision makers typically lack the time and ability to effectively search and synthesize the relevant research literature.
- A number of “what works” websites have emerged to assist decision makers in selecting interventions with the highest probability of benefit.
- These websites are not well understood.

Connection between Behavioral Health Science and Practice

- In 2009, a simple Google search of the term “evidence-based practice” yielded more than one million entries, in contrast to 74,000 entries in Google Scholar.
- In 2021, the same search yielded 803 million entries in Google, and over 2.87 million in Google Scholar. A search for the term “evidence-based programs” in 2021 yielded approximately 734 million and 3.53 million respectively.
- How can this information become useful for clinicians and decision makers?



Cochrane Collaboration Standards for meta-analysis: A classification Scheme for Registries

The following are agreed upon registries for EBTs:

Blueprints for healthy youth development; California evidence-based clearing house for child welfare; CDC diffusion of evidence based interventions; CDC prevention research synthesis project; Child Trends.org; CrimeSolutions.gov; Effective child therapy; Evidence-based practices for substance use disorders; Home visiting evidence of effectiveness; National registry of evidence-based programs and practices; OAHS teen pregnancy prevention; **PracticeWise**; Promising practices network on children, families, and communities; Resource center for adolescent pregnancy prevention; Social programs that work/top tier evidence; The Campbell collaboration; The centers for reviews and dissemination-York; The Cochrane collaboration; The guide to community preventive services-the community guide: what works to promote health; The what works clearinghouse.

PracticeWise: An Example



- PracticeWise uses an approach to managing and adapting practice (map). The system is designed to improve the quality, efficiency, and outcomes of children's behavioral health services by giving administrators and practitioners easy access to the most current scientific information and by providing user-friendly monitoring tools and clinical protocols.
- Using an online database, the system can suggest formal evidence-based programs or can provide detailed recommendations about discrete components of evidence-based treatments relevant to a specific youth's characteristics.

PracticeWise: MAP approach

- The MAP system is grounded in an ongoing review of the behavioral health services literature that is summarized in the PracticeWise Evidence-Based Services Database and procedures with the Practitioner Guides.
- The MAP system encompasses a broad set of targets and practices across the following areas: Anxiety & Avoidance; Inattention & Hyperactivity; Autism Spectrum; Depression & Withdrawal; Disruptive Behavior; Eating; Elimination; Mania; Substance Use; Suicidality; Traumatic Stress.

So What Now?

- Many EBPs have detectable positive effects. Each system of care needs to have a procedure by which to differentiate the best from the others, whether best, good, marginally effective or ineffective.
- Although greater consistency in the standards of evidence used by the registers would reduce uncertainty in program or treatment selection, one can't assume that evidence can be judged from a single framework.
- Systems of Care need to clarify their consistent standards of evidence and incorporate that process in the system-wide approach across interests (Child Welfare, Behavioral Health, Probation, Public Health).



What is the Evidence of Potentially Harmful Treatments?

- The principle of “nonmaleficence” has been part of every code of ethics for many years.
- Concerns and alarms about potential harms done to children by certain behavioral health interventions have been stated periodically over the last 40 years.
- In 1973, the Transactional Analysis therapeutic approach was tied to a scalding death of a teenager.
- In 1976, there was a report of the harmful effects of aversive conditioning practices
- In 1992 a study by Lipsey (1992), noted that 29% of a large number of trials of treatments of problem adolescents showed some harmful effects.
- In 1994, “holding therapy” was linked to serious injury, including death.
- In 1999, McCord and Poulin (1999), reported that a group of interventions for delinquent behavior were associated with worsened outcomes.
- Norross, Koocher, and Garofalo (2006), through a panel of psychologists considered psychological treatments that were “discredited” included holding therapy, conversion/reparative therapy, re-parenting therapies, Scared Straight, and the DARE drug abuse programs to be on the list of discredited.
- Harmful Effects of corporal punishment (2019).

Definition of Potentially or Known to be Harmful Treatments or Services



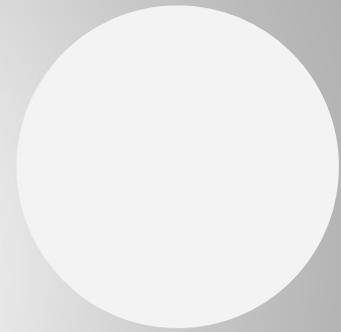
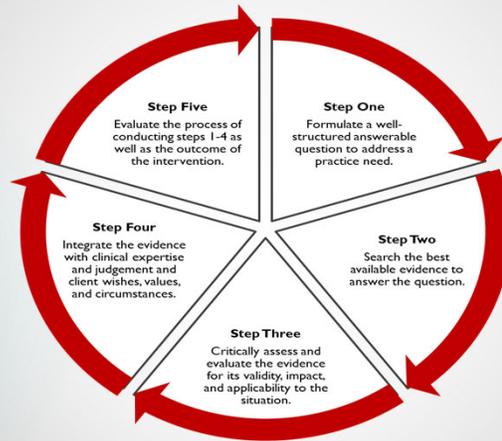
Potentially Harmful Treatments (PHTs) are psychological treatments and psychotherapeutic interventions that are known to have caused harm or been associated with adverse events, or treatments that might logically be expected to cause adverse events in some cases:

1. Demonstrated psychological or physical harm to clients or others;
2. Enduring harmful effects; and
3. Replicated evidence of harmful effects by independent research groups.

Potentially Harmful Policies and Public Practices The Case of Collateral Consequences

- Contrary to the proposed benefits of "getting tough on crime," research in criminology documents devastating consequences for offenders, families, and communities.
- "A Culture of Control" is one reflection of a deeper modern emphasis on surveillance, judgment, and punitive exclusion.
- Banishment is used by government bodies and organizations to remove people deemed deviant, such as youth or homeless, from public view. The rationale is one of protecting the "order" and organization.
- Current school discipline practices are far more invasive and punitive than in past decades, reflecting the sense of needing to control student misbehavior.
- Research strongly suggests that a "culture of control" in schools jeopardizes student success.
- An overreaching culture of control actually destabilizes school communities and fosters anxiety and distrust.
- Schools deemed as harsh, create harsh environments for students.
- Research shows that the majority of students who facilitated a school shooting were: victims of bullying, felt no adults were interested in them, and the students wanted to get even.

Evaluating Evidence as a Process



Resources

National Association for Individuals with Intellectual Disability and Mental Health Needs

www.thenadd.org

Association of University Centers on Disabilities

www.aucd.org

Resource Guide:

Paving the Way – Meeting Transition Needs of Young People with Developmental Disabilities and Serious Mental Health Conditions

https://www.centerforstartservices.org/sites/www.centerforstartservices.org/files/Articles/paving_the_way_-_meeting_transition_needs_of_young_people_with_developmental_disabilities_and_serious_mental_health_conditions.pdf

Effective Strategies Checklist:

Children and Youth with Developmental Disorders and Challenging Behavior

<https://quchdtacenter.georgetown.edu/publications/Effective%20Strategies%20Checklist%20FINAL.pdf>

Check your University Alumni Association (if applicable) for information on access to their library database system.

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Prevalence of Co-Occurring Intellectual/
Developmental Disabilities (I/DD) & Mental
Health Disorders

Prevalence

- 30-40% of all persons with developmental disabilities have a co-occurring mental health disorder (compared to 27% of the general population).
- Mood Disorders (including major depression, bipolar disorder, and dysthymia) are three times as common for those with developmental disabilities as they are in the general population.
- Anxiety disorders (including separation anxiety, social phobia, panic disorder, generalized anxiety disorder, and posttraumatic stress disorder) are more common in those with a developmental disability than in the general population.
- As high as 51% of those with developmental disabilities present with challenging behavior (such as self-harm, aggression, or destructive behavior) that is severe enough to impair daily life.
 - 92% of staff members report exposure to client aggression at regular intervals
 - 25% of staff reported daily aggression exposure
 - 20% of staff experienced a physical injury from client aggression at regular intervals
 - International study of psychologist: 82% of their participants displayed self-injurious behaviors; 45% exhibited aggressive and destructive behavior
 - In Omni's client population, 88% display aggression towards other people and 48% show self-injurious behaviors



(Lunsky, Weiss, O'Grady, & Skinner, 2013)

A Public Health Issue

Co-morbidity is extremely common for developmental disabilities and mental illness. Often, mental health disorders are overlooked or misunderstood among developmental disabilities populations and are subsequently unaddressed.

Children with co-occurring developmental disabilities and mental illness are at an increased risk for:

- Out-of-home placements (e.g. foster care, group homes, juvenile justice services, psychiatric care)
- Having these placements disrupted
- Co-occurring physical health problems
- Exposure to abuse, trauma, and bullying

Adults with co-occurring developmental disabilities and mental illness are at an increased risk for:

- Homelessness
- Early presentation of illnesses including obesity, cardiovascular disease, and diabetes
- Incarceration
- Higher rates of mortality at an earlier age (Schoufour et al., 2018)

(Lunsky, Weiss, O'Grady, & Skinner, 2013)

Prevalence in Children

- **13% (9.5 million) of children in the United States have a diagnosed developmental disability.**
- **30-50% of children with a developmental disability have a co-occurring mental health disorder.**
- This percentage is even higher for children with autism spectrum disorders. **40-70% of children with autism spectrum disorders have a co-occurring mental health disorder.**
- **8.4% of children receiving mental health services have a co-occurring developmental disability.** Of these, 34% have a learning disability or communication disorder, 32% have an intellectual disability or borderline intellectual functioning, and 30% have an autism spectrum disorder.
- Within the Juvenile Justice System, more than 50% of youth have a mental health diagnosis other than conduct disorder and 32% of youth have a developmental disability.

(Jacobstein, 2014)



Prevalence in Adults

- 7.37 million people in the US have some form of intellectual or developmental disability (Larson et al., 2018)
- **26% (1 in 4; of the 61 million) adults in the U.S. have some type of disability (CDC.gov)**
- 12.9% of adults have a cognitive disability (US Census Bureau)
- Depending on methodology for measuring mental illness, research shows that up to 74% of adults with ID/DD also experience mental illness (Hemmings & Bouras, 2016); estimated to be 3 times higher in the ID/DD population compared to the general population (Harris, 2006).
- A recent international meta-analysis exploring comorbid health issues revealed a significant prevalence of epilepsy (70%), pulmonary/respiratory problems (21%), hearing problems (21%), dysphagia (30%), reflux disease (16%), and vision problems (56%) among individuals with severe or profound ID/DD (van Timmeren et al., 2017).
- **65% of individuals with ID/DD have 2 or more diagnoses, which increases to 85% among participants with more severe ID/DD (Lehotkay et al., 2009)**

Trauma & Developmental Disability

Individuals with developmental disabilities are at a higher risk of trauma exposure. An estimated 83% of females and 32% of males with developmental disabilities have been sexually or physically abused (Hinton & Blanco, n.d.).

Examples of trauma include, but are not limited to:

- Physical abuse, emotional abuse, verbal abuse, and sexual abuse
- Childhood neglect
- Death of a parent or loved one
- Divorce
- Family disruptions including parental substance abuse, incarceration, or domestic violence
- Sexual assault
- Serious medical issues or diseases
- War or combat
- Natural disasters
- Community violence
- Many congregate care facilities



Common System Barriers for Individuals with a Dual Diagnosis

Service delivery is fragmented.

- Services are difficult to navigate.
- Each system (juvenile justice, education, mental health, etc.) involves different language and regulation.
- Multiple plans and coordinators are often in place.
- Coordination between and among providers is often limited.
- Funding is often inadequate or inflexible. The focus often shifts to who will pay for services.

There are barriers related to access and eligibility.

- Individuals with dual diagnoses often have the wrong diagnosis, their IQ is too high or too low, or they are the wrong age for services.
- There is poor continuity between "levels of care". What is the concept of "levels of care"?
- Waitlists for services are long.
- It can be difficult to obtain a comprehensive evaluation.
- Private insurance is often inadequate in covering the cost of services.



Systems in Conflict

Often, mental health providers perceive they do not have the skills necessary to service clients with a developmental disability dual diagnosis. Moreover, both developmental disability and mental health providers often do not understand services offered by the other sector.

Mental Health System

- Short-term episodic treatment
- Focus on psychiatric needs
- Recovery model
- Local authority
- Medication assisted treatment
- Consumer/client/patient perspective

Developmental Disability System

- Services expand over the lifetime
- Focus on direct support
- Self-determination
- State authority
- Behavioral support (PBS)
- Self-advocate/consumer perspective

← Insufficient Collaboration →

Instead, co-occurring disorders should be treated as multiple primary disorders, each receiving specific and appropriate services. Collaboration must occur as needs are identified. Services must be individualized on the basis of comprehensive assessments and individual needs. Both systems must emphasize early identification and intervention.

Role of Provider in Care

- All individuals who provide care to youth or adults with low cognition and developmental disabilities play an important role in treatment making collaborative treatment imperative.
- Necessity to value the role of everyone involved in care, including the individual.
- The individual's needs are paramount.
- Need to listen, respond, and provide feedback in order to best serve the individual.
- Gather and use data to track behaviors, receive feedback about progress, gauge provider stress/burnout, and to receive feedback about your performance and use that information to adjust interventions and plans.

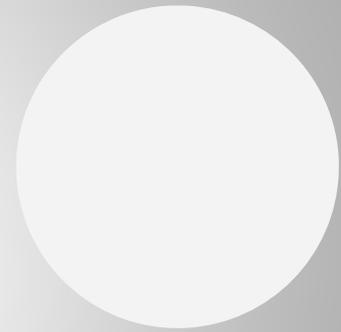
Barriers to Diagnosis And Assessment

- Communication Deficits
- Atypical presentation of disorder
- Medical Condition
- Acquiescence
- Episodic Presentation
- Diagnostic Overshadowing-Assumption that the physical symptoms are due to the mental illness
 - Example: Child rubbing their head in class-seen as a "behavior".
 - Women with learning disabilities die on average of 20 years younger
 - Men with learning disabilities die on average of 13 years younger
- Lack of Expertise
- (Fletcher, 2011)



Assessment

- Personal and Family Health History
 - Medical, psychiatric, and substance abuse history
 - Psychotropic medications
 - Medical conditions
 - Genetic disorders
 - Hypo/hyper thyroid conditions
 - Constipation
 - Epilepsy
 - Diabetes
 - Gastrointestinal problems



Social/Developmental History

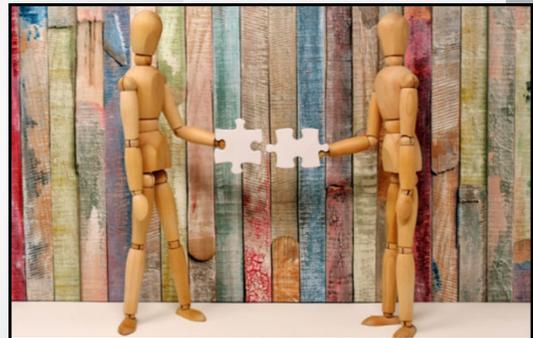
- Developmental milestones
- Relevant school history
- Work history
- Vocational Status –planned evaluation
- Legal issues
- Relevant family dynamics
- Drug/alcohol history
- Abuse history (emotional/physical/sexual)



Therapy adaptations

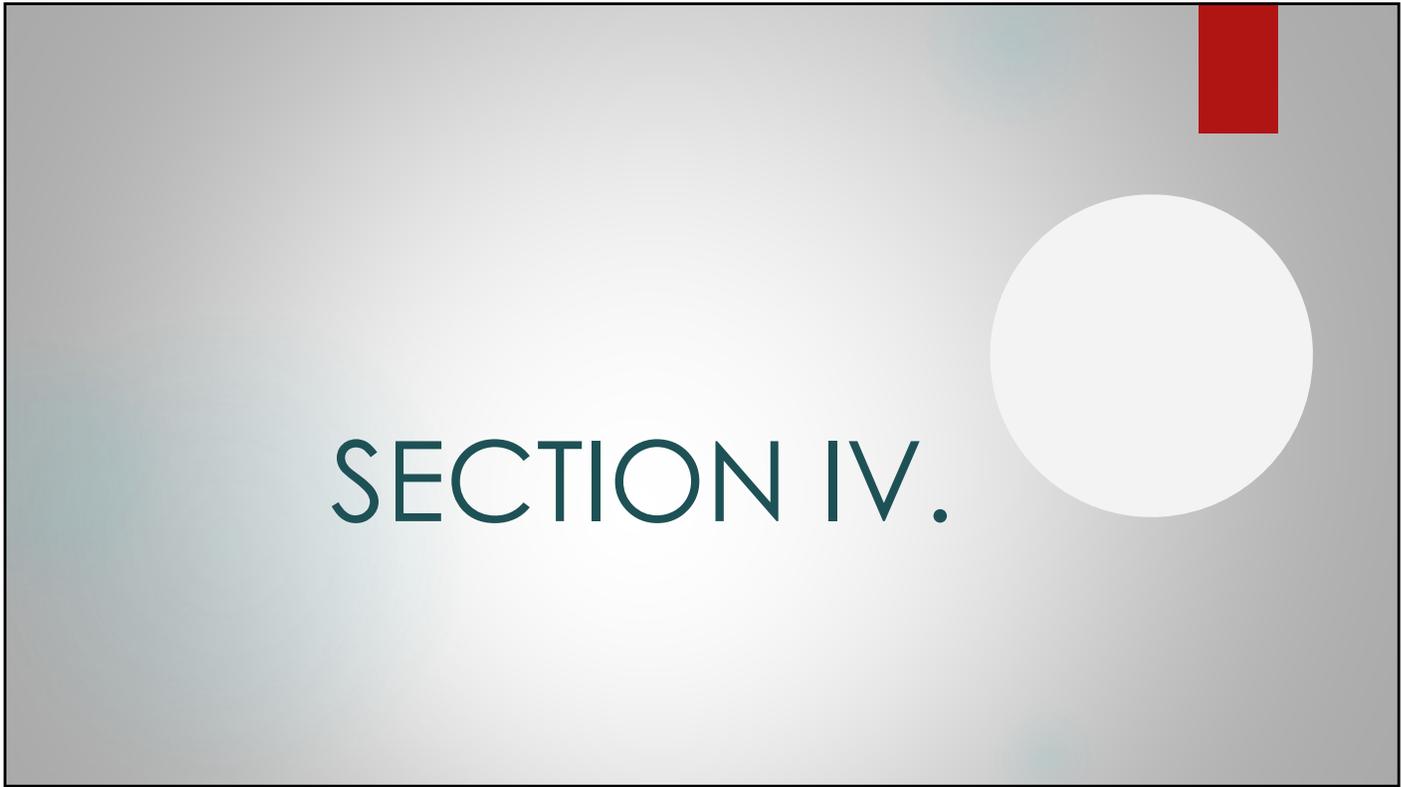
- Language
- Frequency of Sessions
- Shorter Sessions
- Duration of Therapy
- Utilize a More Structured and Directive Approach
- Multidisciplinary Approach is Required
- Modify Complex Interventions
- Supportive Therapists
- Flexible Therapists
- Team Work

(Fletcher, 2011)

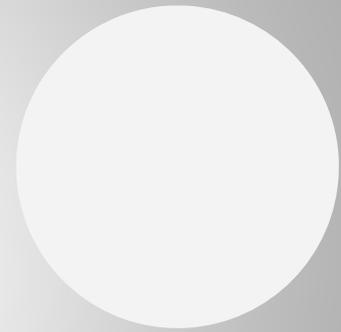


What about you?

- Plan for more time across the board.
 - Treatment planning, multidisciplinary meetings, data collection, evaluation
- Necessity for collateral information on all cases.
- Plan for greater collaboration
- Identify the best evidence in providing care.
- Identify adaptations to business as usual based on the clinical presentation and the collaboration with the team
- **Use of Evidence Based Practice as a Process, not as a Manualized Treatment**



The Process of Engagement



Engagement between the therapist and client must be strong and resilient before any therapeutic activity can begin. Engagement from the therapist and everyone involved in the care of the client is essential and it is the therapists obligation to establish strong engagement and maintain it throughout the therapeutic enterprise.



What is engagement?

- Human activities designed and aimed at fostering positive regard for the youth and all members of the youth's service team.
- Developing and maintaining a relationship or relationships that are "deeply relevant" in the eyes of the client and client service team.
- These relationships are based on unconditional care and support and as "judgment neutral" as possible.
- They include reciprocal and mutually agreed upon expectations between the client and among team members.



Why is engagement so difficult?

- Difficulties with "personal matters."
- Problems associated with "need for control."
- Personal requirement for idealized intentions.
- Frustrations with the client's presentation.
- Reactions triggered by perceived exclusion.
- Anxieties about differences among team members.
- Variations in interpersonal strategies to manage intense emotions.



Orient yourself for engagement

- Identify common experiences. Discuss them and how they influenced you, what you learned from them, and how you recognize those influenced by the same experiences.
- Identify shared knowledge, beliefs, elements of different cultures; relationships across different cultures and how those things work.
- Create common experiences with clients and members of the team. Overcoming obstacles or solving substantial problems establish "sameness" and demonstrate respect and builds trust.

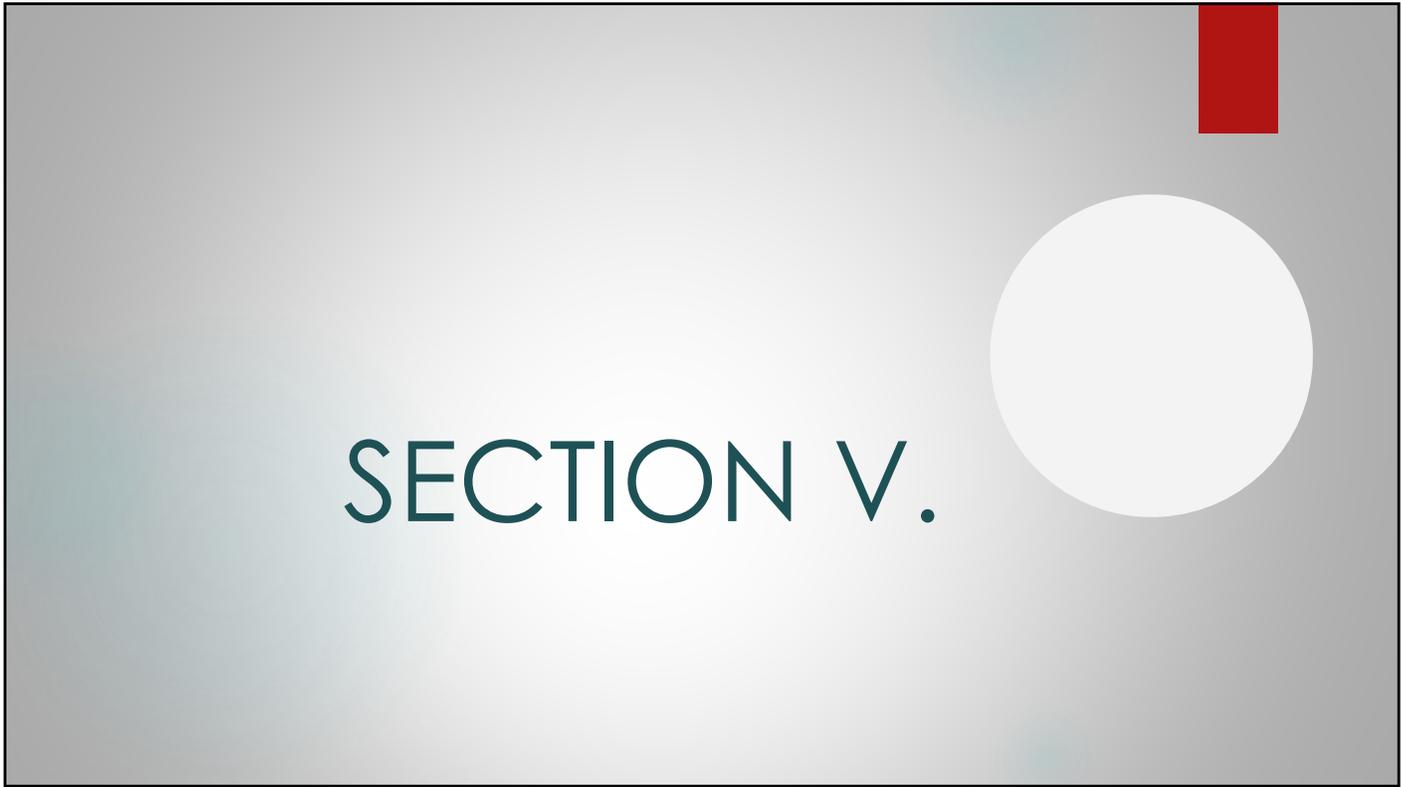


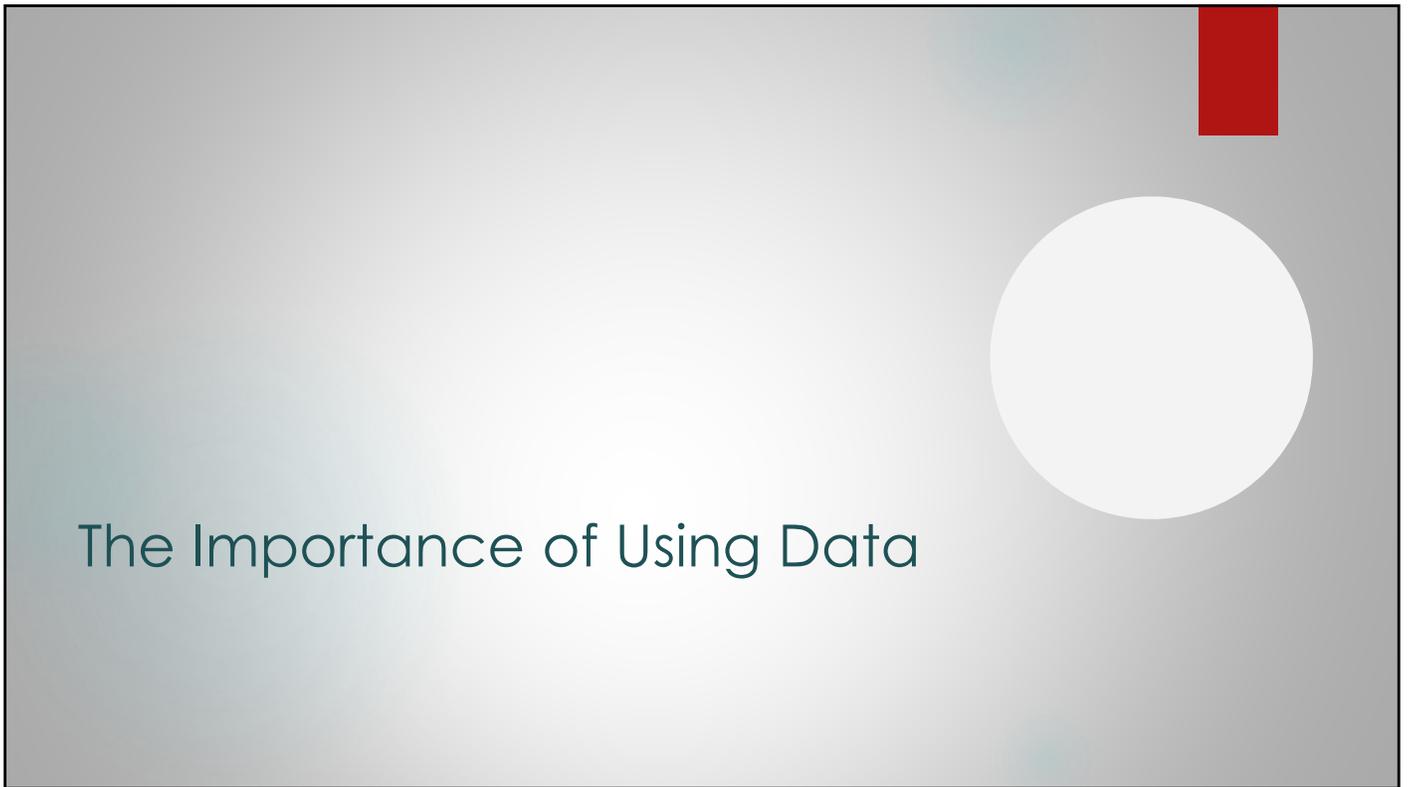
Engagement and alliance

Building engagement and alliance with mandated service or involuntary services involves “unpacking” and understanding the difference between relationships that are coercive and compliance-based, and those based on collaboration and support.



Strong early alliance between professionals and early and ongoing satisfaction with services and relationships, predicts strong working relationships and is associated with positive outcomes.





Collecting Data to Measure Client Progress

- What are you currently doing to collect data on your clients?
- What are some barriers to collecting data on your clients?



Why is it Important to Collect Data?

1. Self-evaluation
2. Evaluating the intervention and/or evidence-based practice
3. Improving outcomes for your clients
4. Sharing results to benefit clients beyond your practice



Decision Making at the Client-Provider Level

Potential Outcomes to assess at the client-provider level include:

- Symptom severity/diagnosis, functioning, consumer perspectives (e.g. satisfaction, quality of life).
- Environments (e.g., social supports, family functioning, neighborhood stability).
- Systems (e.g., service use, costs, provider competencies, agency responsiveness, client functional improvement x provider and agency).

Knowledge of Results is a Critical Ingredient in Facilitating Change

- For Knowledge of results to be fed back to change agents, a rigorous, reliable, and valid measurement system must be in place and routinely utilized.
- Any information gathering system or framework (the architecture) must include comprehensive data.
- While the client is the fundamental unit, clients are nested within larger ecosystems and data gathering must include those systems.
- Providers and Policies must be included as units of data. Providers are nested within larger systems with mediating processes and practices.

Client Symptom Data

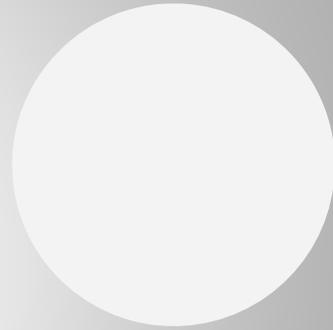
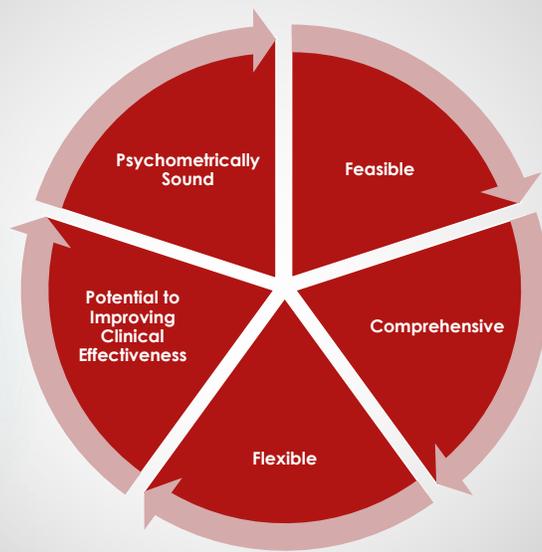
- There has been extensive development of clinical assessment instruments to measure symptom severity, and to a lesser extent functional outcomes of clients, with less attention to other outcome domains.
- Feedback to clinicians is critical if the instruments are to generate useful information, thereby facilitating change in service delivery. That feedback should include frequent Client Symptom Data (daily, weekly, and monthly).



Peabody Treatment Progress Battery (PTPB)

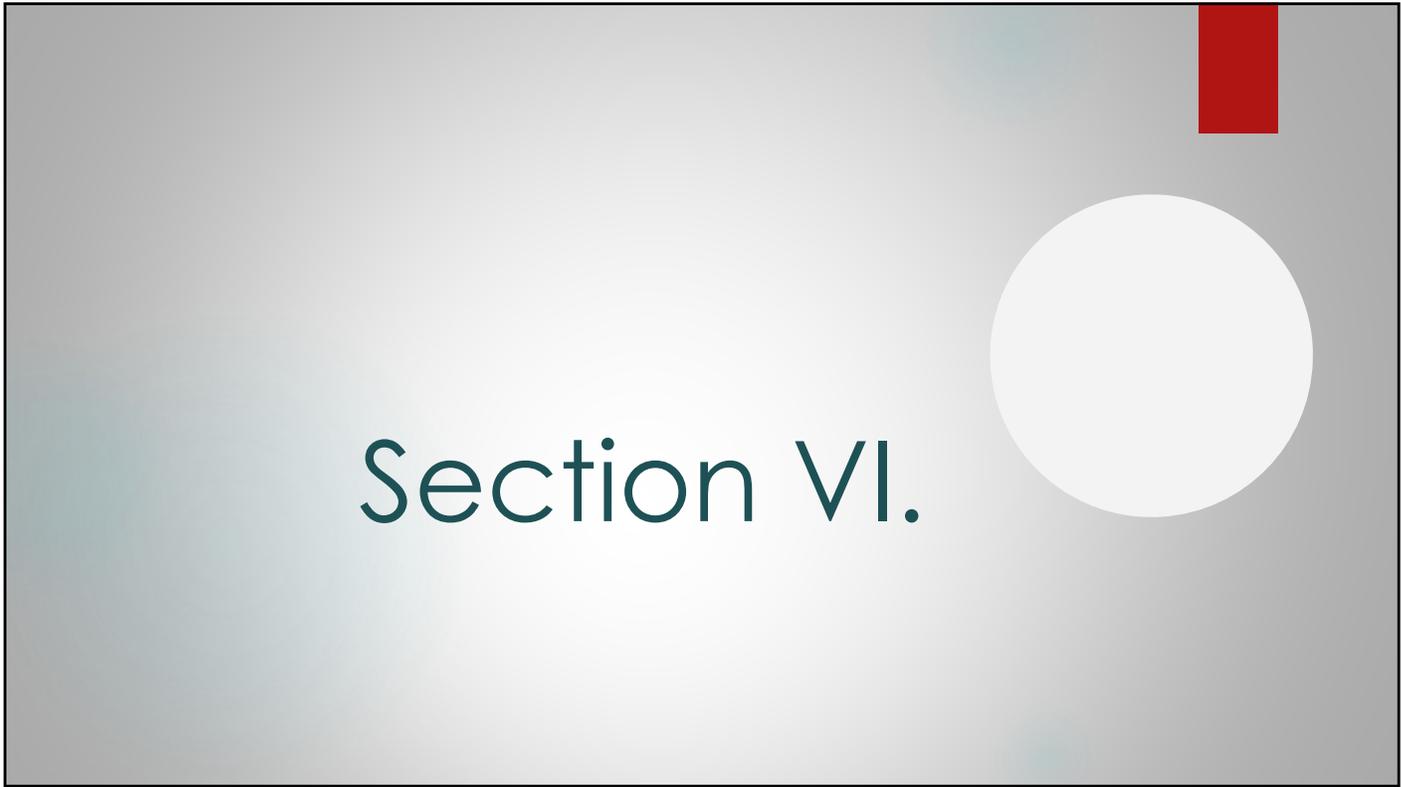
- Provides a cohesive, comprehensive, and evidence-based approach to enhancing mental health services for youth.
- Includes 10 clinically relevant measures of key mental health outcomes and clinical processes.
- Offers clinicians systematic feedback on their clients, both individually and in relation to other clients served.
- Designed to be suitable for services research as well as utility in the working clinical environment.

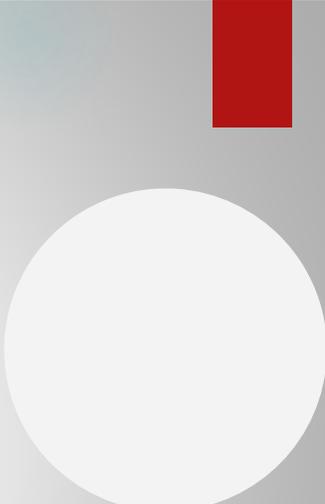
Considerations



Measures included in the PTPB (For Example)

1. Symptoms and Functioning Severity Scale (SFSS)
2. Brief Multidimensional Students' Life Satisfaction Scale – CEPI Version (BMSLSS-CEPI)
3. Children's Hope Scale (CHS)
4. Treatment Outcome Expectations Scale (TOES)
5. Therapeutic Alliance Quality Scale (TAQS) an Therapeutic Alliance Quality Rating (TAQR)
6. Youth Counseling Impact Scale (YCIS)
7. Motivation for Youth's Treatment Scale (MYTS)
8. Satisfaction with Life Scale (SWLS)
9. Caregiver Strain Questionnaire – Short Form (CGSQ-SF)
10. Service Satisfaction Scale (SSS)





Assessing Behavior and using Functional Behavioral Assessments

I/DD and Behavioral Problems

- Mental Health and/ or behavioral problems may be symptoms related to the onset of a medical condition (e.g. infections, UTIs, diabetes, seizure disorders, thyroid disorder, etc.) or factors related to the environment.
- In most cases, co-occurring complex behavior problems in individuals with developmental disabilities are caused or maintained by a combination of factors.
- Behavioral problems may also be presenting as a result of traumatic experiences.
- Medications can play a major role in behavioral problems.
- **Challenging behavior is the number one barrier to community living, relationships, employment and staff retention when working with this population.**

Functional Behavioral Assessment (FBA)

- A Functional Behavioral Assessment (FBA) is a comprehensive and individualized strategy to:
 1. Identify the purpose or function of an individual's problem behavior(s)
 2. Develop and implement a plan to modify variables that maintain the behavior problem
 3. Teach appropriate replacement behavior(s) using positive interventions
- An FBA has a narrower focus than a comprehensive evaluation. It focuses on the why, how, where, when, and what of the individual's behavior.
- An FBA is a team effort. Each individual on the team sees the client from a different perspective and everyone works together to identify what's going on with the behavior.
- That team might include:
 - Clinicians (mental health therapist, speech therapist, occupational therapist, etc.)
 - Educators
 - Parents and/or caregivers
 - The individual with the diagnosis

The Steps of FBA

1. Define the inappropriate behavior

- ▶ Using vague words to describe the individual's behavior can make it difficult to gather information.
- ▶ It is important to describe the behavior in an objective, specific way.

2. Collect, compare, and analyze information

- ▶ Team members work to pull together information from the individual's records, interviews, and questionnaires.
- ▶ The goal is to answer questions such as:
 1. Where is the behavior occurring?
 2. How often is it occurring?
 3. Who is around when the behavior occurs?
 4. What are the antecedents?
- ▶ An ABC chart can be used here to identify antecedents, behaviors and consequences.

The Steps of FBA (continued)

3. Hypothesize reasons for the behavior

- Make a best guess based on available information
- The team will work together to figure out what the behavior is telling them. What is the pay off?

4. Develop a plan

- Once the team has an idea about why the behavior is occurring, the team can begin making changes to test the hypothesis and alter behavior (e.g. changing something in the client's environment)
- This can be done by creating a Behavior Intervention Plan (BIP) designed to teach and reward positive behaviors. This may include:
 - Changes to the physical environment
 - Changes to the way information is presented to the client
 - Changes to the routine
 - Changes to behavior consequences
 - Teaching adaptive behavior(s)



“ABC” Chart



ABC Log Example

ABC Log						
Student:			Target Behaviors:			
Date	Time	Activity	Antecedents	Exact Behaviors	Consequence	Student's Reaction

Setting Events vs. Antecedents

- Setting Events are also known as "Slow Triggers"
 - These may occur hours or even days before the behavior
 - These may be long-standing conditions (e.g. a mental health diagnosis)
 - These don't cause behavior, they make behavior more likely
 - The setting event often makes the consequence more or less reinforcing
 - Common setting events include: pain, illness, physical conditions, poor sleep, psychiatric illness, disappointment, negative interactions, atypical sensory needs, new schedules, new settings, different caregiver(s), or a change in season or weather
- Antecedents are also known as "Immediate" or "Fast Triggers"
 - These occur right before the problem behavior
 - These can help professionals predict behavior
 - Common antecedents include: being asked to complete a task, failure to complete a task, redirection, presence of a person, target of aggression, being ignored, transitioning from one activity to another, ending an interaction, being told "no," being asked to wait, being bullied or teased, or specific needs or feelings

Mental Illness as a “Setting Event”

- An individual with an anxiety disorder may experience typical life events as more anxiety provoking. These individuals may feel anxious around typically neutral stimuli. Escape and/or attention become more reinforcing.
 - Challenging behaviors assist in avoiding people or things that cause anxiety and intentionally misbehaving allows an individual to stay home, miss work, or miss an activity
 - Self-injury may assist in alleviating unpleasant emotions
 - High levels of agitation and tantrums result from difficulty self-soothing or calming
- Individuals with mood disorders such as depression may lack motivation or interest. They may no longer engage in known tasks or activities. Escape from demands and interactions become more reinforcing.
 - A lack of motivation or interest may lead to refusal or noncompliance
 - Challenging behavior may alleviate unpleasant emotions or assist in avoiding social interactions or activities
- An individual with a psychotic disorder such as schizophrenia may experience paranoia, distorted thinking, loss of skills, or distorted sensory perceptions.
 - Challenging behavior allows individuals to avoid places or things that feel threatening
 - Individuals may perceive neutral events as threatening or may be responding to stimuli only they are aware of

The Role of Caregivers in FBA

- Families are essential in conducting an FBA for an individual with co-occurring I/DD and mental illness.
- Team members should:
 - Ask families what behaviors they identify at home. This can assist in identifying similarities and differences in an individual's behavior(s) at home and in other environments.
 - Encourage families to keep a journal or take notes on specific aspects of the individual's behavior(s).
 - Invite families to actively participate in team meetings and include them in action planning.
 - Empower families to implement the plan and document changes in behavior(s).



Example of a Simple FBA from a School Setting

Functional Behavioral Assessment for
 A functional behavioral assessment (FBA) is a process of looking at relationships between behavior and the school environment. A behavior intervention plan (BIP) provides the school with an action plan designed to inform school staff how to proactively design the learning environment, teach replacement behaviors and respond consistently when problem behaviors occur.

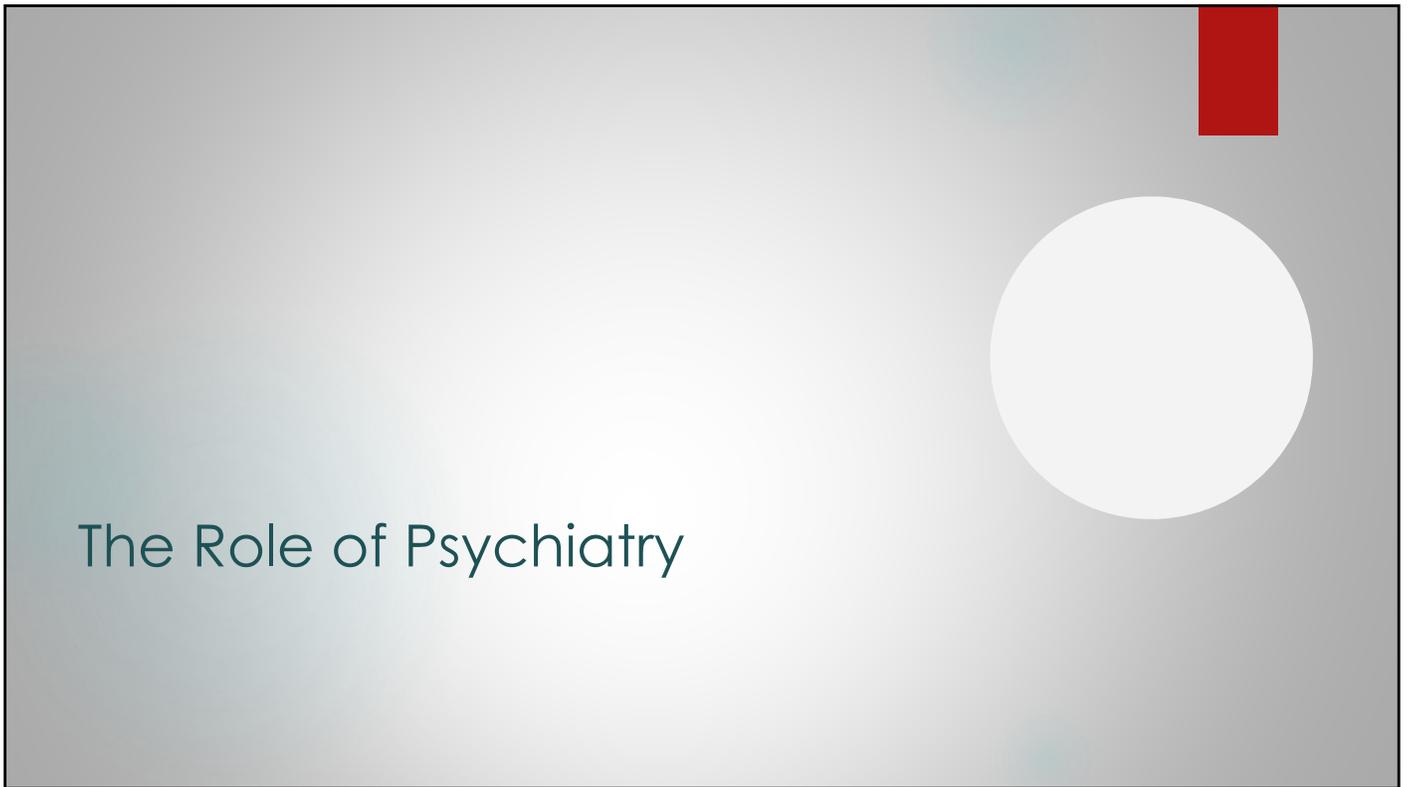
Data Collection: Please check which of the following data items were considered by the team.

<input checked="" type="checkbox"/> Academic records	<input type="checkbox"/> Medical evaluations	<input checked="" type="checkbox"/> Parent interview
<input type="checkbox"/> Attendance records	<input checked="" type="checkbox"/> Observations of student	<input type="checkbox"/> Student interview
<input checked="" type="checkbox"/> Special education evaluations	<input checked="" type="checkbox"/> Discipline records	<input type="checkbox"/> Other

Behavior: List and describe the behavior(s) that adversely affect the student's learning.	Triggers: Factors that usually provoke this behavior.	Setting Factors: Description of setting (where, when, and with whom) the behavior is most likely to occur.	Function of Behavior: Consider what happens immediately after the problem occurs.
Running Away: Takes the form of leaving the school building or the school grounds during the school day and without permission. Often returns to the school after 5-10 minutes. Create BIP for Target Behavior? Y	Direct Triggers: Power struggle with staff, activities or work that she perceives as too difficult. Indirect Triggers: Being tired, arguments with mother (home setting).	Occurs an average of two times per month. Occurs most often in music class.	Task avoidance, consequence avoidance, attempt to cope with strong emotions, to assert power.
Aggression Towards Others: Fighting with peers and aggression towards staff Create BIP for Target Behavior? Y	Direct Triggers: Conflict with specific female peer, teacher directives when she is in heightened emotional state. Indirect Triggers: Delayed retaliation against peers (related to previous conflicts), being tired, home situations.	Occurs an average of twice per week. More likely when substitute staff present. Also more likely during less structured times (between classes, lunch) and with presence of specific peers.	Assertion of power, retaliation against peers (revenge), attention from peers.
Create BIP for Target Behavior?			
Create BIP for Target Behavior?			
Create BIP for Target Behavior?			

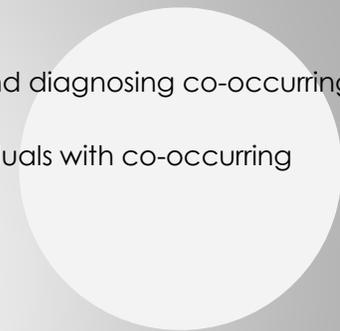
Common Team Members to Involve in the FBA Process





Psychiatric Diagnosis

- Psychiatrists often have limited training in screening, assessing, and diagnosing co-occurring I/DD.
- Several factors can complicate the process of diagnosing individuals with co-occurring I/DD including:
 - Cognitive ability and understanding of diagnostic questions
 - Limitations with receptive and expressive language
 - Limitations in understanding abstract concepts
 - Atypical expression of symptoms
 - Over-attributing symptoms and behavior to the intellectual or developmental disability



Common Diagnostic Concerns

- **Diagnostic Overshadowing:** The process of over-attributing an individual's symptoms to a particular condition, resulting in key comorbid conditions left undiagnosed and untreated.
- **Baseline Exaggeration:** An individual with I/DD may have a low rate and intensity of challenging behavior that is increased dramatically due to a mental health condition.
- **Intellectual Distortion:** An individual with I/DD may have deficits in abstract thinking. Receptive and expressive language skills questions may be too complex and the results will be meaningless.
- **Psychosocial Masking:** This occurs when there is a misunderstanding about what is developmentally appropriate. For example, a delusion could be mistaken for an imaginary friend or harmless fantasy.
- **Cognitive Disintegration:** Due to a lack of cognitive reserve, some individuals with I/DD may dramatically decompensate under stress. They may have difficulty communicating feelings of anxiety or distress which may result in misdiagnosis.

Psychopharmacology



- ▶ Medications are appropriate for many individuals with co-occurring I/DD and psychiatric disorders.
- ▶ Medication treatment should not be a total treatment approach but rather part of a complete bio-psycho-social-developmental treatment approach.

Psychiatric Collaborative Consultation

Psychiatric Collaborative Consultation			
General Information			
Patient Name:	DOB:	Address:	Date of appointment:
Guardian:		Address:	Phone number:
Residential Provider:	Vocational/Day Provider:	Staff Present at appointment:	
Primary Care Provider:	Address:	Phone Number:	
Therapist:	Address:	Phone Number:	
Medical			
Diagnosis:	Medication to treat:		
Diagnosis:	Medication to treat:		
Diagnosis:	Medication to treat:		
Height:	Pulse:		
Weight:	Respirations:		
B/P:	Laboratories:		
Allergies:			
<ul style="list-style-type: none"> • Environmental: • Food: • Medication: 			
Health related changes since last appointment (other important information):			

Therapist Treatment Plan
Long Term Goal and Short Term objectives:
Evidence Based Practice Utilized:
Progress towards outcomes:
Behavioral
Behavioral concerns (e.g. hallucinations, suicidal, homicidal, aggression, psychosis):
Assessment Tools to include Functional Behavioral Assessment (FBA):
General Events Reports or Incident Reports (provide summary of all GER's from <u>30</u> days or of incident reports) for the past 6 months or from last appointment:
Behavioral Support Plan Data:
<ul style="list-style-type: none"> • Provide a copy of the individuals current behavioral support plan for residential and vocational • In the chart below: Provide the number of intervals (i.e. hours) in which the client engaged in use of their replacement behavior (RB) i.e. appropriate requests for attention, tangibles, or escape during that reporting period. • In the chart below: Provide the number of intervals the client engaged in target behaviors during that reporting period: physical aggression (PA), property destruction (PD), self-

Psychiatric Collaborative Consultation

Injurious behaviors (SIB), verbal aggression (VA), elopement (Elope), inappropriate sexual behavior (ISB), pica type behavior i.e. swallowing in-edible items (PICA), inappropriate urination (IU), and other types of problematic behaviors to be decreased.

Residential (provide data for past 6 months)										
Reporting Period (Month):	RB	FA	PD	SIB	VA	Elope	ISB	PICA	IU	Other:

Vocational/Day Services (provide data for past 6 months)										
Reporting Period (Month):	RB	FA	PD	SIB	VA	Elope	ISB	PICA	IU	Other:

Current Medications Non-Psychotropic (may attach copy of MARS):	
Medication:	Dose:

Current Medications Psychotropic (may attach copy of MARS):	
Medication:	Dose:

Psychiatric Provider to Complete
Assessment:
Plan:
Follow Up:

Consultation Form Completed By:	Name/Title	Date:
Provider:		
Therapist:		
Doctor:		