Dialectical Behavior Therapy and Intellectual Disabilities [Summary White Paper Developed by Louisiana OCDD Clinical Services Team]

Overview of DBT

DBT is a form of cognitive-behavior therapy that employs **skills training**, **cognitive restructuring**, **exposure**, and **self-management**/self-monitoring. It is a manualized treatment with modules focused on:

- Mindfulness
- Interpersonal Effectiveness
- Emotion Regulation Skills
- Distress Tolerance

DBT is gaining more and more widespread use in the treatment of persons with Intellectual Disabilities (IDs). There is a sizable and continuously growing body of literature demonstrating the effectiveness of DBT in persons with Mild or Moderate IDs and in persons with Autism Spectrum Disorders (ASDs). Given the number of studies (impressive number of references listed below), positive case and research reports, and creative and sensible discussions of adaptations when using DBT with persons with IDs, DBT should be considered as a legitimate therapy option for persons with IDs.

Dialectical Behavior Therapy (DBT) was developed by **Marsha Linehan** ^{1 & 2} and gained early attention due to her demonstrations of its efficacy in treating persons with the traditionally difficult-to-treat condition of **Borderline Personality Disorder** ³. DBT has been associated with the following outcomes:

- Decreasing **suicidality** in persons with Borderline Personality Disorder (BPD)
- Helping persons with BPD to manage dysregulated emotions and form healthier relationships

DBT theorizes that, in some persons, impulsive, dysregulated, and destructive behaviors occur in the context of interactions between **invalidating environments** and **biological irregularities** which predispose the person to greater emotional sensitivity and reactivity. For persons with **IDD**, consideration of potential impacts from an invalidating environment is critical, particularly in relation to the reactions and responses from others when the person communicates private experiences and expresses emotions. Life experiences for which the individual has a **lack of choice** and control (at times even despite his/her complaints or protests) may result in an **escalation of emotions** and behavior that then requires a response from the caregiving system (which may then further reinforce the escalation). Further, given that persons with IDD may already experience challenges in expressing emotion effectively, when **attempts to communicate feelings** and emotions are **rejected**, minimized or punished, it may further **limit independence** and the individual's ability to learn to trust his/her own emotions; relationships with others may suffer; labels such as "attention-seeking and manipulative" may then be ascribed to the person; and the ability to engage in problem solving and meet personal goals may also be compromised.

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The use of DBT has been expanded to treat many other problem and conditions including depression, **substance abuse**, varieties of **impulsive behaviors**, and **eating disorders**. DBT in persons with IDs has been evaluated in:

- -- community settings⁴
- -- residential facilities⁵
- -- hospital settings⁶
- -- **detention** settings⁷
- -- adults⁸⁻¹⁰
- -- adolescents¹¹
- -- children¹²
- -- persons with **ASDs**⁷

Published studies, collectively, tell a story of ubiquitous and effective use. Positive outcomes reported in DBT in ID studies have included improved **emotion regulation**, improved **emotion identification** and **awareness**, improved **anxiety management**, decreases in **self-injury** and **suicidality**, improved **communication** and **assertiveness** skills, decreases in **emotional outbursts** and **aggression**, and improvements in more global measures of psychological distress and **quality of life** measures. Outcomes mirror outcomes in persons without IDs.

Adaptations of DBT for Persons with IDs

In its most traditional and comprehensive formats DBT includes **individual therapy**, **group therapy**, and access to **emergency crisis coaching**. DBT for persons with IDs sometimes include the full DBT package (e.g., group and individual therapy) and includes all **four modules**/skill areas – **Mindfulness**, **Interpersonal Effectiveness**, **Emotion Regulation**, and **Distress Tolerance**.

Some clinicians have focused on **using selective components** or modules of DBT to suit the needs of their participants and the particular goals of treatment. So, for example, some studies primarily evaluated the benefits of a DBT group⁴. Some authors included more selective focus on some of the skill areas/modules (e.g., focus on mindfulness and distress tolerance skill modules¹²). All studies, even those with selective components of DBT, reported positive results.

Some studies have implemented DBT treatment with **little or no modifications** for persons with Mild IDs. Other clinicians have implemented any of a number of adaptations while preserving core treatment elements including:

- Simplifying language
- Use of visual aids
- Using more concrete examples of principles
- Extra use of praise statements and validation
- Adapted diary cards with more symbols and graphics for non-readers; simplified wording in diary card for readers
- Increased hands on practice scenarios and added role plays to increase concrete demonstration of skills

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- Increased modeling for skills demonstration in group therapy
- Use of self-soothing boxes to facilitate self-soothing/distress tolerance skills
- Shortening session duration
- Decreasing number of skills taught per session
- Increased repetition of skills
- Increased creativity in presentation of topics to hold interest and promote engagement
- Smaller group size
- Involvement and training of staff and family members to support treatment
- Incorporation of DBT into plans of care

Mindfulness

Mindfulness skills help persons to become more **aware** of their **emotional states**, and ultimately to gain more control over them. Persons are assisted in learning to observe and describe when they are in emotional states and more rational states of mind. The person learns to experience emotional states and to **distance from** them without needing to terminate the negative emotions.

The standard Linehan manual in many ways is **already suited for IDs**. It teaches Mindfulness by breaking it down into **concrete component** skills that are coached and practiced in therapy. This includes teaching a person to practice simply **OBSERVING** aspects of their environment and their feelings. The person then practices **DESCRIBING** their feelings and their environment. These concrete skills are coached and practiced. Linehan in standard, non-adapted treatment uses concrete exercises, like standing too close to a mirror while describing and then stepping back and describing to illustrate how we cannot see things clearly when we are close to them. **Emotional distancing** is taught by – stepping back, distancing, and describing the image in the mirror; then stepping back, distancing from, and describing a stressor; then stepping back, distancing from, and describing an emotion. This is a precursor to emotion regulation. **Often, little or no adaptation** of these exercises are required for persons with Mild or Moderate IDs. Some examples of concrete mindfulness exercises from the literature, some of which involve adaptations, include:

- **Emotional mind** taught with pictorial item representing a heart; Rational mind taught with pictorial item representing a brain.
- Practicing mindful walks attending to physical senses. Mindful walking also keeps people moving.
- Practicing the mindful activity of eating a raisin. Allows repetition of the exercise.
- Using an illustration of "walking a dog". Initially the person is pulled along by the dog but then gets control to illustrate being tugged by an emotion but then reigning it in.

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- Teaching "Check-Your-Tummy" exercises (modification of observing one's body), and "One Thing at a Time" (do one task and then move to another).
- Teaching simple 2-3 min **Breathing exercises**.
- Videos of Mr. Spock to illustrate Rational Mind; Video of Ferris Bueller to illustrate Emotional Mind

Interpersonal Effectiveness

Interpersonal effectiveness includes education and training on more effective ways of **communicating with others**. There are positive **assertiveness** training components and **problem-solving** components to the module.

The Interpersonal Effectiveness and Assertiveness Skills taught in DBT are taught concretely with modelling, coaching, and behavioral rehearsal. This strongly resembles the teaching approaches and skills typically used when conducting **Social Skills Training** with persons with IDs. In persons with IDs, there may be more emphasis on behavioral **role plays**, with extra **modeling** and **repetition**. Examples from the literature of interpersonal effectiveness teaching, some of which involve **adaptations** include:

- Focusing on a more limited set (fewer number) of the skills that are most relevant to the person (e.g., in one study, skills taught were assertive asking, active listening, giving compliments, and asking for clarification – role played and overlearned with extra repetition⁵)
- Use of **video role plays** to practice skills from Linehan's modules
- Use of simple reinforcement during social skills practice when skill is appropriately displayed during role play. Practicing a few times in a row.
- Teaching "self-cheerleading" as a means to increasing social confidence and dispelling social anxiety in ASDs

Distress Tolerance

Distress Tolerance skills, as opposed to teaching someone to try to change an emotion, equips persons with actions, ways of thinking, and activities to engage in that allows the person to **better tolerate distress** until it passes. The focus is on accepting and tolerating distress. "DBT emphasizes **learning to bear pain skillfully**²."

The **distraction** and **soothing approaches**, which can include using calming sensory stimuli (e.g., music, soft textures, warm bath), to aid in Distress Tolerance often do not require adaptation as they do not require complex intellectual processes. Other concrete approaches, some of which involve adaptations, include:

- Teaching to half smile during the onset of a potential crisis
- Creating a "survival kit" of activities (e.g., family picture, Bible, favorite CD) for use during impending crisis

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- Writing a short **cognitive script** or prayer to be read during distress
- For one person, Distress Tolerance was simplified to STOP, SCAN, and PRAY
- Personalized Self-soothe basket full of sensory items to be taken out and accessed during distress
- Using Video role-playing and play back to examine successful and unsuccessful Distress
 Tolerance

Emotion Regulation Skills

Emotion Regulation skills teach persons to **label** and **recognize emotions**, **reduce vulnerabilities** to emotions, and **increase positive experiences** leading to more positive emotions. It encompasses **mindfulness** and **distress tolerance** skills. Concrete examples from the ID literature, some of which involve adaptations, include:

- Use of visual aids/pictures and concrete practice and immediate feedback to teach labeling emotions
- Pairing labeling emotions with colors use of extra visual stimuli to add concrete elements to discussion and self-report
- Use of visual and concrete aids to understand fluctuating emotions use of a visual emotional thermometer with **green**, **yellow**, and **red** sections. Coping strategies are developed to go with each zone.
- Having a concrete list of positive activities that generate positive emotions to be practiced according to a daily schedule
- One author developed a **modified Skills System**¹³ with modified language to teach emotion regulation and other DBT skills.
- Building a **life size suit of armor** with craft materials to illustrate building up a shield to cope with strong feelings.

This summary is not intended to encourage the use of DBT for persons with IDs by practitioners without the appropriate training and certification. There are also therapeutic approaches that parallel DBT approaches that may also be relevant for persons with IDs. For example, Brown¹⁴ has a resource targeted for persons with ID and built from DBT concepts and direct adaptations from the standard DBT curriculum. The **Emotion Regulation Skills System** for Cognitively Challenged Clients is a DBT-informed approach applicable for both DBT and non-DBT clinicians, and includes information on:

- Emotion regulation
- Intellectual disabilities
- Cognitive load theory
- Enhanced teaching strategies
- A **12-week Skills** System curriculum
- Visual aid skills that promote effective instruction

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The National Institute for Health and Care Excellence¹⁵ recommends programs providing behavioral health treatment to people with an intellectual disability should consider mainstream interventions and modify them according to the person's specific needs, level of understanding, communication style, etc. In many ways components of the DBT package may offer solutions that ideally line up with problems frequently encountered in persons with IDs and ASDs including:

- biological vulnerability and organicity in some persons with ID including presence of brain damage, seizures, sensory disorders, genetic syndromes, and other biological comorbid conditions that predispose some persons to psychiatric disturbance or dysregulation¹⁶
- increased likelihood of being exposed to invalidating environments in the context of the sometimes histories of abuse, restrictive environments, and social exclusion or rejection¹⁶
- characteristics in some persons with ASD such as difficulty identifying and
 conceptualizing feelings in themselves and others, comorbid anxiety, and possibilities
 of losing control in specific situations that are emotionally overwhelming (social or
 sensory scenarios) 17

For persons experienced using DBT who are interested in learning how to adapt treatment for persons with IDs, **Lew et al.'s** study¹⁶ may be a **good place to start**.

REFS

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