



Meeting the Unique Needs of Individuals with Intellectual Disabilities and Co-Occurring Mental Health Conditions

UnitedHealthcare Community & State



Meeting the Unique Needs of Individuals with Intellectual Disabilities

Over the last five decades, long-term support for individuals with intellectual and developmental disabilities (I/DD) has shifted from institutional care to community-based services, which includes accessing appropriate and effective medical and behavioral health care in the community.

For the over 30 percent of adults with I/DD who also have a diagnosed mental disorder, accessing appropriate treatment remains a need. In exploring ways to enhance overall capacity across the healthcare continuum to be inclusive of supporting those with I/DD and co-occurring mental health diagnoses and/or complex behavioral challenges, structured approaches to build competency in clinicians and other professionals continues to be an area of focus.

Many individuals with I/DD, who also have co-occurring mental health conditions, have unique needs that require psychosocial intervention. Appropriately modified therapeutic interventions, such as the Skills System, that are implemented consistently and integrated across settings can be effective to address the behavioral health needs of many individuals with I/DD. The Skills System is a evidence-based approach for individuals with I/DD and co-occurring mental health diagnoses that accommodates diverse learning needs of this population.



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Treatment Considerations for Individuals with I/DD and Co-Occurring Mental Health Conditions

Individuals with I/DD are identified based on cognitive functioning and/or deficits in adaptive functioning. Specifically, an individual with an intellectual disability presents with an IQ score of less than 70

and exhibits significant impairments in adaptive functioning, such as language, social skills, and self-help skills. As a result, individuals with I/DD often need special education support in school as they have difficulty learning at the same pace as their same-age peers. People with I/DD may also experience difficulty generalizing and applying things learned in one setting to other settings.

In addition to cognitive impairments and deficits in adaptive functioning, between 32 and 40 percent of individuals with I/DD also present with a co-occurring mental health condition, with prevalence rates higher than those without I/DD. Despite the presence of co-occurring mental health conditions in such a large percentage of the population, they have not historically participated in the same continuum of outpatient behavioral health services as their counterparts without I/DD, including psychosocial interventions. Individuals with I/DD have had less access to a range of psychosocial interventions in part because they can present with cognitive profiles or language processing difficulties that limit their ability to benefit from traditional treatment modalities.

Psychosocial interventions, such as Cognitive Behavior Therapy (CBT), tend to utilize complex language that is generally not incorporated with visuals, and the interventions focus on identifying, labeling, and understanding abstract constructs like mood and emotions. Therapy typically occurs outside of the individual's natural environment and is infrequent, such as once per week or every other week, and individuals are expected to learn, understand, recall, and apply complex techniques learned in therapy outside of the therapeutic setting. For those with I/DD who struggle with language processing, abstract thinking, and generalization, these therapeutic interventions can be largely ineffective.

While there remains limited data regarding the benefit of mainstream psychosocial interventions with individuals with I/DD, there is some evidence that these treatments can be effective if they are appropriately adjusted and modified. For psychosocial interventions to be successful, particularly mainstream modalities such as CBT and Dialectical Behavior Therapy (DBT), the interventions can be modified to accommodate varying cognitive abilities and complex communication needs. DBT is a comprehensive, empirically validated treatment designed to help people who experience emotional, cognitive, behavioral, self, and relationship dysregulation. It is a multi-modal model that includes individual therapy strategies, group skills training, phone skills coaching, and a consultation team (Linehan refs). The Skills System, highlighted below, is a research-based, adapted therapeutic intervention based on DBT that was developed specifically for individuals with I/DD and/or complex learning challenges, such as learning disabilities and language disorders. The Skills System demonstrates that individuals with I/DD can benefit from a psychosocial intervention if the therapeutic modality is adjusted to meet the unique needs of the population.



Models of Long-Term Support for People with Intellectual Disabilities

Because psychosocial treatments need to be integrated into an individual's entire support system to be effective, it is essential to understand the relevant macro- and micro-environmental contexts when designing effective services. The long-term services and supports (LTSS) delivery model that exists today for people with I/DD has evolved tremendously over the last five decades. As late as the 1960's, much of the supports for people with I/DD were provided in large institutions; however, today the majority of individuals are served in their communities with the support of their families and/or community-based providers who specialize in supporting people with I/DD. There is a continued national trend to integrate individuals with I/DD more fully and meaningfully into their respective communities.

Tennessee is just one of the states focused on expanding its services to better serve the I/DD population. In Tennessee, there are three Section 1915(c) Home and Community-Based Services (HCBS) waiver programs, in addition to Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IIDs) — available to support individuals with I/DD. These three HCBS waivers, Comprehensive Aggregate Cap Waiver Program, the Self Determination Waiver Program, and the Statewide Waiver Program, are administered by the Department of Intellectual and Developmental Disability Services (DIDD), which is contracted by TennCare, the state's Medicaid agency, to administer the waivers. Since July 1, 2016, these waiver programs have been closed to new enrollments, with a small exception in the Comprehensive Aggregate Cap Waiver. In 2016, TennCare gained approval to administer a new Medicaid waiver, an 1115 demonstration waiver called the Employment and Community First CHOICES Waiver. Through this waiver, the state uses private managed care organizations (MCOs) to provide long-term services and supports to individuals with I/DD. This waiver is first of its kind and currently only being implemented in Tennessee.

The Employment and Community First (ECF) CHOICES Waiver program provides an array of services and supports to individuals of all ages and abilities who have an intellectual or developmental disability. These services include employment,

housing and community integration, all of which focus on helping individuals gain as much independence as possible and fully participate in their communities. One of the advantages of leveraging MCOs is the ability to coordinate care for the whole person, including medical, behavioral, and long-term services and supports (LTSS) within one system. The success of the ECF CHOICES Waiver program is largely due to a focus on providing access to appropriate medical and behavioral health services and benefits. Maladaptive behavior or unmanaged mental health symptoms are often barriers to individuals’ access to opportunities, such as employment and community inclusion, and to their ability to become more independent.

The backbone of the LTSS system for those with I/DD is the direct support professionals (DSPs) who work with individuals with I/DD in various settings. At their core, DSPs are the front-line staff who work side-by-side with individuals to assist them in achieving their goals. This role is vital to the delivery of quality services for those accessing home and community-based services. DSPs have a broad scope of duties, ranging from assisting with activities of daily living (ADLs), to providing support within an individual’s place of employment, to helping the individual manage and regulate emotions and behaviors during difficult periods. DSPs who assist individuals who have challenging behaviors and mental health conditions need additional skills that enable them to effectively manage the various emotional and behavior challenges exhibited, while also keeping themselves safe from harm. Even though DSPs exhibit numerous competencies and are one of the fastest growing sectors of the work force, they are some of the most vulnerable workers in the country, due in part to the current shortage of DSPs and the burnout factor associated with the work that they do. Treatment modalities that consider the entire system of support for individuals with IDD, such as the Skills System, and include front-line staff and supports in the intervention have the capacity to be more effective than those that treat the individual in isolation of their greater support system.



Skills System: A Research-Based Therapeutic Intervention for Individuals with I/DD and Co-Occurring Mental Health Conditions

What is the Skills System?

There is general consensus that people diagnosed with I/DD and co-occurring mental health conditions experience barriers to learn and generalize standard DBT skills (Linehan, 1993, 2016). There are hundreds of skills, the language is complex, and standard DBT lacks a structure that helps the individual know what skills to use and when to use them. Since these skills are woven into all aspects of DBT treatment, these gaps in learning and generalization abilities create inaccessibility to DBT treatment for people with I/DD.

The Skills System is a modified version of DBT which extracts essential DBT concepts and reconfigures them into nine core skills, with simpler language and visual representations to facilitate better learning. Developed by Julie Brown, Ph.D., a DBT trainer with the Linehan Institute since 2015 (Brown, 2016), the Skills System focuses on therapies designed specifically for individuals with I/DD or complex learning challenges, such as learning disabilities and language disorders. The simple infrastructure within the Skills System assists the individual with learning which skills to use and how many skills to implement in each situation, which aids in skills application.

The Skills List is central to the Skills System model (see Image, at right). The Skills System establishes a common language and knowledge base that is learned, practiced, generalized, and shared by people with I/DD who also present with mental health conditions as well as the individuals who support them, such as family caregivers and/ or DSPs.

The Skills System process offers tangible, step-by-step strategies that bring the individual through essential emotion regulation activities in a user-friendly, natural way. This approach helps the individual to (1) be in their moment, even difficult ones, (2) be present, and (3) be effective. The individual first learns steps to become aware of the current moment by doing Skill 1: Clear Picture (see Image, at right). After becoming aware of what is happening inside and outside, the individual engages in goal-directed thinking using Skill 2: On-Track Thinking. The individual then takes On-Track Actions (Skill 3) to reach their personal goals.

The Skills List

Skills List & Categories

- 1. Clear Picture
- 2. On-Track Thinking
- 3. On-Track Action
- 4. Safety Plan
- 5. New-Me Activities
- 6. Problem Solving
- 7. Expressing Myself
- 8. Getting It Right
- 9. RelationSHIP Care

All-Time Skills (Skills 1-5)

Calm-Only Skills (Skills 6-9)

Clear Picture Do's

1. Clear Picture (All-Time Skill)

I Focus 100% on this Moment As It Is

<p>Notice my Breath</p> <p>Where do I feel my breath? What does it feel like?</p>	<p>Notice my Surroundings</p> <p>What is around me right now? What do I see, hear, smell, taste and touch?</p>	<p>Do a Body Check</p> <p>What body sensations do I notice right now?</p>
<p>Label and Rate Emotions</p> <p>What feelings do I notice right now? How strong are they? 0-1-2-3-4-5</p>	<p>Notice my Thoughts</p> <p>What thoughts do I notice going through my mind right now?</p>	<p>Notice my Urges</p> <p>What do I feel like doing right now?</p>

Creating Skills Coaches

By definition, individuals diagnosed with I/DD often require support from a natural caregiver, such as a family member, and/or paid staff, such as DSPs. These relationships are complex, dynamic, and impact the individual's functioning on a daily basis. These supports can be the ingredient in an individual's life that promotes growth and development, or they can be the trigger that leads to challenging behaviors and the need for increased levels of supervision.

When individuals with I/DD and their support system learn the Skills System skills, the members of the individual's support system are able to function as in-vivo skills coaches. Generalization of adaptive skills is often a barrier for this population, and the Skills System model provides tools for the individual and their support system to have a common language and knowledge base about coping. Creating accessible wrap-around supports increases the generalization of adaptive self-regulation skills and develops a healthier environment.

When an individual experiences emotional dysregulation on a consistent basis, co-regulating with them can be challenging. The Skills System model helps the individuals' support systems reinforce strategies designed to promote self-regulation, which is a foundational process in co-regulation. Additionally, when a skills coach is in a challenging situation with the individual they are coaching, they can also become dysregulated, making it difficult to strategically choose interventions. When support providers also know how to self-regulate using Skills System strategies, they are able to provide skills coaching through modeling, and it is more possible to achieve co-regulation, rather than co-dysregulation. The Skills System is designed to increase the individual's and their support system's intra- and inter-personal competencies, which are essential for growth and development.

Treating Complex Individuals and Systems

Individuals with the most complex needs experience factors that confound their challenges and create barriers for treatment. Providers and natural caregivers need tools that can be adjusted for people with differing learning abilities, complex mental health issues, impaired impulse control, communication deficits, and who live in various support settings. The Skills System is a comprehensive model that can be adjusted for people of diverse ages, learning abilities, and mental health challenges.

People with I/DD often have supports that include multiple models. What occurs as a result is that services and supports can become 'siloes' rather than integrated. This siloed approach can fuel self- and co-dysregulation. The Skills System model, while initially designed to be used within DBT treatment, can be integrated with many other treatment models. For example, it offers a tangible skills curriculum for individuals who are engaging in Motivational Interviewing, CBT, suicide prevention models, and trauma-informed treatments. The Skills System model also aligns well with person-centered approaches, Applied Behavior Analysis (ABA), Positive Behavior Supports (PBS), and most non-violent crisis intervention models within support environments. This adaptability helps ensure its effectiveness across a variety of therapeutic intervention settings.

Despite best intentions, support environments have a tendency to focus resources on addressing incidents of behavioral dysregulation and most attention is on "putting out fires." While this is essential, opportunities for building core capacity receive less attention. When teams have the tools, such as the Skills System, to help individuals improve core self-regulation abilities, developing those competencies is possible. Better self-regulation skills can translate into fewer incidents of challenging behaviors, physical intervention, and need for emergency services.

Staff training and model integration can be barriers when conducting comprehensive implementations within support systems. The Skills System includes an online training program component designed to create a transdisciplinary environment in which everyone in the system understands the skills and how to be a skills coach. The two components of the Skills System treatment – the Skills System model itself and the online skills training program—are key ingredients that address the multifaceted needs of this population.



Building a Behavioral Health Provider Network

Shortly after UnitedHealthcare's implementation of the Employment and Community First CHOICES waiver, work began to address the gaps in the network of providers with the expertise to effectively meet the behavioral health needs of people

with I/DD. Recognizing the expertise of I/DD HCBS providers, several were approached to expand their array of services to include behavioral health services, such as psychiatry, individual therapy, Intensive Outpatient Programs, and Applied Behavior Analysis. While these providers had experience in serving the long-term support needs of those with I/DD, traditionally they had not also provided behavioral health services. Most of these providers, however, were already connected with clinicians in their communities, such as psychiatrists and social workers, who had experience treating individuals with I/DD. As a part of this work, UnitedHealthcare partnered with the Tennessee Department of Mental Health and Substance Abuse Services to educate I/DD providers as they worked to also become behavioral health providers. As a result of this effort, there are now agencies across the state who are dually licensed to support both the long-term support needs as well as the behavioral health needs of people with I/DD. As a result of this work and the partnership with Dr. Julie Brown, several of these agencies also developed Intensive Outpatient Programs (IOP) that use the Skills System as the core treatment modality.

David (not member's real name)

David is a 24-year-old male with a primary diagnosis of Autism and a history of challenging behaviors, including physical aggression, property destruction, disruptive behaviors, and non-compliance. Shortly after enrolling in the ECF CHOICES Waiver program, David engaged in an incident that resulted in an inpatient psychiatric hospital admission. The incident started when David became angry with younger children in his family home and other adults attempted to intervene in order to help him calm down. He responded by yelling, making threats, and shattering a drinking glass before running outside where he lifted up and threw a manhole cover through the living room window. Law enforcement and mobile crisis were called and responded to the scene. He was subsequently admitted to a local mental health inpatient hospital.

This was not an isolated incident, however; David's behavioral escalations had resulted in four law enforcement interactions within the prior six months. David's family reported that they had been managing his outbursts and violent behavior since middle school and that he had even given his mother a black eye once by throwing a can of air freshener at her face. As David got older, his incidents increased in magnitude and he became more dangerous. Not only did his outbursts become more intense, they started lasting longer; sometimes he would engage in an incident for an hour before calming down. It was determined that David's behavioral escalations occurred most frequently when his routine was disrupted or when his primary caregiver's attention was divided.

In May 2019, David transitioned from an inpatient psychiatric hospital to an ECF CHOICES Waiver program Community Living Supports (CLS) home. It was not an easy or smooth transition. David wanted to go back to his family home and did not adjust well to the CLS home. Fortunately, the agency who agreed to support David residentially was one that had recently built out services in the area of behavioral health and had sent several staff members to a three-day Skills System training in early 2019. The agency's clinical team included a Behavior Analyst and a Licensed Clinical Social Worker, both of whom had participated in the Skills System training. The agency had started an IOP and also provided individual therapy using the Skills System. Immediately upon David's transition to his CLS home, he also began participating in the IOP.

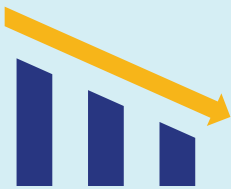
In early 2020, David's initial behavior target in the IOP was to reduce the frequency of severe behavior incidents to one incident every two weeks. He met this goal as well as the subsequent goal of one severe behavior per month. David's current goal is to reduce the frequency of significant behavior incidents to one incident every two months. When COVID19 forced the face-to-face IOP program to pause, David's therapist continued working with David via telehealth, utilizing the Skills System in individual therapy with David. David's therapist also spent a significant amount of time working with David's staff on the Skills System and reinforcing the skills within David's day-to-day activities. In addition to IOP and individual therapy, David had a safety plan and his staff was trained to utilize antecedent behavior strategies. In May 2020, a Behavior Support Plan was implemented as an additional component to David's behavioral health intervention.

David's therapist reported that through the Skills System intervention, David has developed the ability to identify emotions and that he now regularly notifies the DSPs in his CLS home when he is scared, sad, or "very angry." After David exhibits a behavior incident, he is now able to identify and communicate what he was feeling and at what Skills System level he was during the behavior. Skills that have been particularly effective in helping David achieve greater emotion and behavioral regulation include Clear Picture and On-Track Thinking. According to David's therapist, the facilitation of repetition and generalization of concepts, the coaching "in the moment," and the corrective feedback/coaching after a behavior episode, all of which are components of the Skills System, along with staff training and behavior modification strategies have proven to be effective to help David reduce behavior incidents, improve emotion regulation, and facilitate greater independence.



Conclusion

Change is not easy for individuals who have long-standing patterns of emotional, cognitive, and behavioral dysregulation. It is also not easy for families and staff who are traumatized, lack resources, and experience reinforced patterns of reactivity. As a partner to the members and families we serve, UnitedHealthcare sought to understand the complexity of these challenges and barriers. And as a partner, we work to provide adequate resources to all parts of the system that can be instrumental in resolving long-standing systemic issues.



Forty adults with developmental disabilities and mental health diagnoses, who had histories of aggression, self-injury, sexual offending, or other challenging behaviors, participated in a pilot study. Changes in the participants' behaviors were monitored over four years while in DBT treatment using the Skills System (DBT-SS). Large reductions in challenging behaviors were observed during the four years. Lower and moderate levels of behavioral dysregulation reduced significantly after one year; the highest risk behaviors reduced significantly after four years of DBT-SS treatment. These findings suggest that modified DBT for individuals with I/DD holds promise for effectively treating and reducing symptoms.

In January 2019, UnitedHealthcare facilitated the introduction of the Skills System to clinicians and agencies throughout the state of Tennessee. Sixty-five community providers, including individual therapists and clinicians, participated in a three-day training to build their competencies in this treatment modality, which has demonstrated effectiveness with individuals with I/DD who also experience co-occurring mental health conditions. As a result of this initiative, there are now IOPs and clinicians using the Skills System and targeting mental health treatment for individuals with I/DD located in all areas of the state. This effort not only benefitted UnitedHealthcare members but has fostered critical expertise within the behavioral health system that benefits individuals with I/DD and co-occurring mental health issues or behavioral challenges. While we have seen improvement and growth within the behavioral health continuum to better support the I/DD population, UnitedHealthcare continues to support efforts, alongside our state partners, to grow a network of providers with the expertise to effectively treat and support all individuals with I/DD.

For more information about the information presented in this white paper, contact Dr. Julie Brown at jbrown@skillssystem.com and/or Dr. Jovanna Emerson at jovanna_emerson@uhc.com.