Lunch and Learn:

Bridging the Gap: Addressing Mental and Behavioral Health for Individuals with IDD

September 30, 2025



Virtual Meeting Guidelines

Thank you for joining us today for this informational Lunch & Learn!

- This meeting is being recorded and will be available for viewing post-meeting
- American Sign Language interpretation is provided in pinned video
- Live captioning is provided Select show/hide
- Participation: Following the presentations, as time permits, please use the Q&A section or the hand raise to get into queue to ask questions or share your thoughts



Agenda

- Welcome and Overview 5 mins
- Presentations: Peers in the Crisis Care Continuum 50 minutes
 - Lucille Esralew, PhD, Senior Psychologist Supervisor, Department of Developmental Services
 - Wendy White, Psy.D., Clinical Director, CA START Redwood Coast
 - Christine Bagley, Safety Net Manger, Department of Developmental Services
- Closing & Adjourn 5 mins



Welcome & Overview

Stephanie Welch, MSW. Deputy Secretary of Behavioral Health, CalHHS



Bridging the Gap: Supporting the Mental and Behavioral Health Needs of People with Intellectual and Developmental Disabilities (IDD)

September 30, 2025





INTRODUCTIONS

- Christine Bagley, Office of Statewide Clinical Services, Department of Developmental Services
- Lucille Esralew, PhD, Senior
 Psychologist Supervisor, Department of Developmental Services
- Wendy White, Psy.D., Clinical Director, CA START Redwood Coast



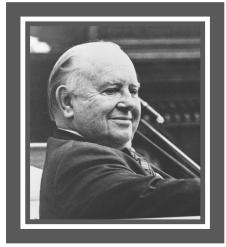
DEPARTMENT OF DEVELOPMENTAL SERVICES



The California Department of Developmental Services is the State agency responsible for overseeing the coordination and provision of services and supports to over 494,000 Californians who have a qualifying developmental disability or developmental delays.

Services and supports are provided in accordance with the Lanterman Developmental Disabilities Services Act.

THE LANTERMAN ACT



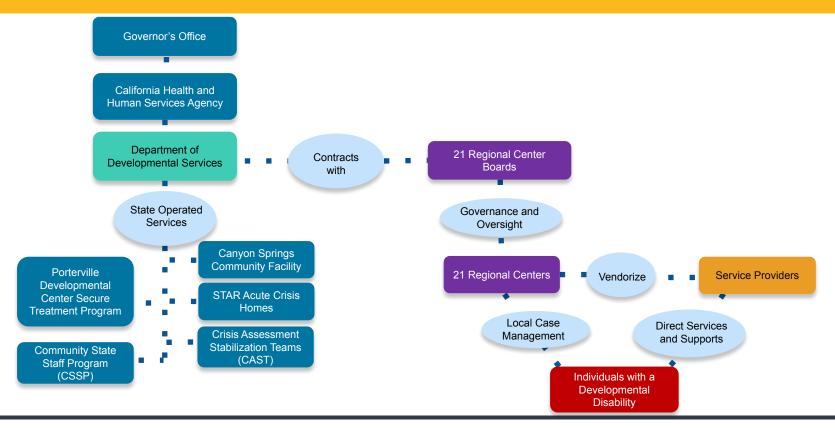
Frank D. Lanterman
CA Assemblymember
Author of the Lanterman
Act

The Lanterman Act established an entitlement to lifespan, community-based services and supports for people with qualifying intellectual and developmental disabilities.

"The State of California accepts its responsibility to ensure and uphold the rights of persons with developmental disabilities and an obligation to ensure that laws, regulations, and policies on the rights of persons with developmental disabilities are observed and protected"

Read more about the Lanterman Act and Related Laws

DEVELOPMENTAL SERVICE SYSTEM



REGIONAL CENTERS

21 Non-Profit Community Agencies

For individuals, the RCs:

- Evaluate for eligibility
- Coordinate services
- Develop Individualized Family Service Plan (IFSP) Birth through 2
- Develop Individual Program Plan (IPP) 3 years and older
- Facilitate Self Determination
- Access community resources, coordinate community connections and authorize services through DDS funding

For their communities, the RCs:

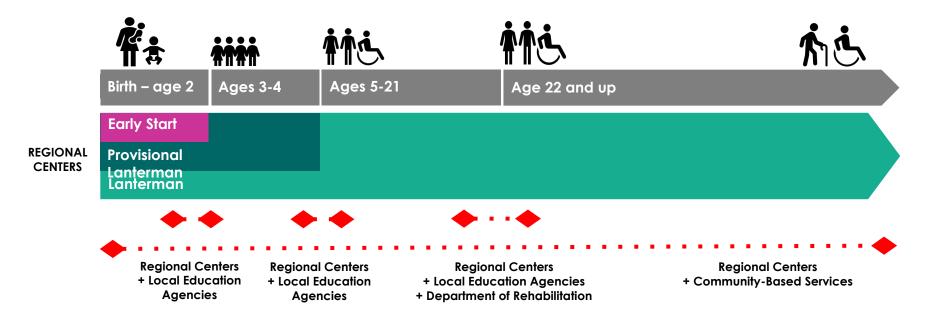
- Develop resources with service providers
- Provide monitoring and oversight of services
- Provide community education and outreach



REGIONAL CENTER POPULATION



PROGRAMS ACROSS THE LIFESPAN



REGIONAL CENTER ELIGIBILITY CRITERIA Program Early Start Provisional

Ages	0-3 years	0-5 years	Any age
-C	Have a developmental delay of at least 25% in one or more areas of cognitive, communication, social or emotional, adaptive, or physical and motor development including vision and hearing or- Have an established risk condition of known etiology, with a high probability of resulting in delayed development or- At high risk of having a substantial developmental disability due to a combination of biomedical risk factors of which are diagnosed by qualified personnel	 Disability is not solely physical in nature, and: Significant functional limitations in at least 2 major life activities: Self-care Receptive and expressive language Learning Mobility Self-direction 	 Intellectual disability, autism, epilepsy, cerebral palsy, and/or other disability that closely resembles ID and/or individual requires similar services Originates prior to age 18, lifelong "Substantial disability" - significant functional limitations in 3 or more areas: Self-care Receptive and expressive language Learning Mobility Self-direction

Lanterman

EARLY START (AGES 0-2) AND LANTERMAN ACT (ANY AGE)

Early Intervention and Lanterman Services may include, but not be limited to:

Behavior Intervention	Advocacy		
Vision and Hearing services	Educational Resources		
Nutritional consultation and feeding therapy	Behavior Intervention Education and Training Adaptive Skills Training Crisis Supports		
Specialized instruction			
Parent support and training			
Physical therapy Occupational therapy Speech/language therapy	Dental/ Medical Service		
	Nutrition Services Nursing Services Living Options		
			Speech/language inerapy
			Respite
	Employment Services		

PREVALENCE

Although the reported incidence of mental health conditions among individuals with intellectual and developmental disabilities (IDD) vary depending upon the source, all experts agree that the frequency of mental health concerns among individuals with IDD exceeds that of typically developing peers:

- The National Association for the Dually Diagnosed (NADD) estimates that <u>35%</u> of individuals with IDD have a mental health condition¹.
- Compare to the incidence of mental health disorders in the general adult population. In 2022, there were an estimated 59.3 million adults aged 18 or older in the United States with mental health disorders. This number represented <u>23.1%</u> of all U.S. adults².

https://thenadd.org/idd-mi-diagnosis/

²Mental Illness - National Institute of Mental Health (NIMH)

PREVALENCE: START REASONS FOR REFERRAL

Variable	Children	Adults	CA START
N	232	335	567*
Aggression	86%	64%	73%
Risk of Placement Loss	25%	36%	32%
Decreased Daily Functioning	34%	31%	32%
Dx & Treatment Planning	32%	35%	34%
Family Needs Assistance	79%	45%	59%
Leaving Unexpectedly	33%	18%	24%
Mental Health Symptoms	64%	74%	70%
Self-Injurious Behavior	40%	23%	30%
Suicidal Action	5%	6%	5%
Suicidal Ideation	20%	19%	19%
Transition Support	6%	7%	7%
Unsafe Sexual Behavior	12%	8%	10%

^{*}Data from CY 2024 CA START Annual Report:

[•] Total 567 <u>new</u> enrollees in 2024

PREVALENCE: START MENTAL HEALTH DIAGNOSES

% of Individuals w/ Mental Health Conditions Reported at START

Variable	Children	Adults	CA START
N	496	846	1342*
Anxiety Disorders	30%	30%	30%
Bipolar Disorders	6%	15%	12%
Depressive Disorders	27%	28%	27%
Disruptive Disorders	14%	11%	12%
OCD	7%	10%	9%
Personality Disorders	0%	4%	2%
Schizophrenia Spectrum Disorders	5%	24%	17%
Substance Abuse Disorders	1%	1%	1%
Trauma/Stressor Disorders	11%	12%	12%

^{*}Data from CY 2024 CA START Annual Report

[•] Total 1342 number of people served in 2024

FIVE CHALLENGES TO ASSESSMENT OF PEOPLE WITH IDD (1/2)

Diagnostic overshadowing

Intellectual disability is used to explain unusual or challenging behavior, leading to overlooking co-existing mental health disorders.

Baseline exaggeration

During a psychiatric illness, a person with IDD may show increased frequency or intensity of a behavior of concern; leading to a focus only on behavioral escalation rather than underlying psychiatric causes.

Intellectual distortion

Possible misinterpretation of a person's speech or thought processes as reflective of mental illness when it may be more reflective of limited cognitive or communication skills. Limited abstract thinking and difficulties in communication, may make it difficult to report their emotional state.

(Sovner & Hurley, 1986)

FIVE CHALLENGES TO ASSESSMENT OF PEOPLE WITH IDD (2/2)

Psychosocial masking

A person with IDD may present clinically different from peers without IDD due to limited experiences and difficulties in self-expression making it difficult for practitioners to establish target symptoms of a mental health disorder. For instance, an imaginary friend might be mistaken for a delusion.

Cognitive disintegration

A person with IDD may have a low tolerance for stress and their reaction to stress may be misinterpreted as a symptom of a psychiatric condition, rather than caused by anxiety.

(Sovner & Hurley, 1986)

EXAMPLES OF MAJOR MENTAL HEALTH CHALLENGES (1/2)

8X increased risk of death by suicide

Individuals with autism were found to have an up to eightfold increased risk of death by suicide compared to peers without autism (Brown et al., 2024)

HIGHER

prevalence of SMI and SUD, as well as **LOWER** treatment rates

Per SAMSHA, people with physical and cognitive disabilities have a higher prevalence of SMI and SUD, as well as lower treatment rates for both conditions than do people without these disabilities <u>Substance</u> <u>Use Disorder for People with Physical and Cognitive Disabilities</u>

Experience
significant health
disparities and a
high risk of
exposure to
traumatic events

Children, youth and adults with IDD are an overlooked minority population who experience significant health disparities and a high risk of exposure to traumatic events that can lead to stress-related disorders (Houck et al., 2022)

EXAMPLES OF MAJOR MENTAL HEALTH CHALLENGES (2/2)



Individuals with IDD and
Dementia may present
to the ER with what
appears to be a
psychiatric emergency
when their presentation
may be due to
Behavioral and
Psychological Symptoms
of Dementia



Individuals with IDD and their families report difficulty accessing relevant medication management



It may be difficult to distinguish behavioral episodes from presentations in which behaviors may be driven by unrecognized mental health disorder



Individuals and their families report difficulty accessing relevant inpatient and outpatient treatment*

SYSTEM CHALLENGES

Co-occurring IDD and mental health conditions typically requires accessing care across siloed care systems.

The mental health workforce lacks training and understanding in dual diagnosis (MI/DD) and the IDD workforce lacks training and understanding of the mental health system.

options for individuals with IDD and mental health conditions and a skilled workforce are a long-recognized need, yet system

structural challenges

and professional

training gaps persist.

Integrated care

Among individuals with limited cognitive and communication skills, mental health conditions may present as an increase in behaviors of concern (aggression, self-injury, elopement). Individuals are denied mental health services based on their "behavioral presentation."

WHAT IS START?

- A START team certified by the National Center for START Services® (NCSS) is a collaborative group that works together to implement the START model.
- The START model is an evidence-based service model for individuals with IDD and mental health needs that focuses on developing community capacity while achieving wellbeing for people who receive regional center services.



- START programs provide **crisis response and stabilization services**, often in **conjunction with first responders**.
- The START model is designed to optimize independence, treatment, and community living for individuals with IDD and mental health needs.



COMPONENTS OF THE START PROGRAM

- Consultation and Education
- Community Partnerships
- Cross System Crisis Plan Development



CONSULTATION AND EDUCATION

START provides consultation, education and technical assistance to community partners and organizations to help build capacity in the network to better support people with complex needs.

START Coordinators are trained in systemic consultation interventions to enhance service outcomes through outreach and training.

Examples of START Trainings:

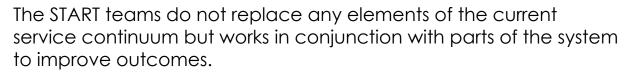
- Monthly community trainings on "hot topics" open to anyone
- Monthly didactic trainings for professionals based on case studies of persons with dual diagnosis
- Trainings and consultations to meet specific needs for community partners or people we serve

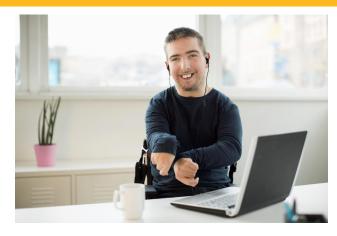


COMMUNITY PARTNERSHIPS

START facilitates communication and collaboration across developmental disability, mental health, community and family networks to:

- Improve community supports and connections
- Improve treatment outcomes
- Decrease the need for hospitalization and loss of community placement





CROSS-SYSTEMS CRISIS PLAN DEVELOPMENT



START works with people and their system of support to develop a biopsychosocial crisis prevention and intervention plan.

The planning process includes developing a common understanding of behavioral health challenges, recommending potential preventive, strength-based strategies, and identifying specific crisis response strategies.

Cross system means the crisis prevention and intervention plan is a collaborative plan that takes into consideration the coordinated efforts among multiple service systems to address the complex needs of a person. It is intended to be helpful for all people that provide support to the person served, in all environments.



CHALLENGES AND ADAPTATIONS: INTELLECTUAL DISABILITY (ID)

There may be challenges* and also adaptations to support working with people who have an intellectual disability (ID), they include but are not limited to:

- Adaptive functioning
- Communication
- Cognitive functioning
- Sensory processing



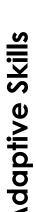
^{*} Not <u>all</u> people with ID have challenges in all these areas. These are among the possible challenges that people <u>may</u> have.



CHALLENGES ASSOCIATED WITH INTELLECTUAL DISABILITY (ID)



- Learning and Memory
- Executive Functioning
- Conceptual Skills
- Communication
- Sensory Sensitivities
- Social Skills
- Acts of Daily Living
- Self-Determination





- Social Skills
- Acts of Daily Living
- Self-Determination



- Receptive Communication
- Expressive Communication





ACCOMMODATIONS (SLIDE 1/2)

Sensory Processing

- Access to an alternative waiting room that is sensory friendly
- Option to wait for appointments in the car, using a text or buzzer system

<u>Adaptive Functioning</u>

- Provide paperwork before visits when appropriate
- Provide preparation worksheets/workbooks to assist self-determination and advocacy

Communication

Access to PECS or other visual communication tools





ACCOMMODATIONS (SLIDE 2/2)

Cognitive-Learning and Memory:

- Provide information both verbally and in writing
- Check for understanding (e.g., "tell me what you just heard" or "can you explain that in your own words")
- Repeat information as needed

Cognitive-Generalizing Knowledge:

Roleplay or discuss scenarios

<u>Cognitive-Sustaining Attention:</u>

- Conduct meeting/session in an area with minimal visual and auditory distractions
- Redirect as needed

Cognitive-Planning and Organizing:

- Provide multimodal reminders for appointments/tasks (text, call, written notice, calendar notification)
- Provide task analysis of processes whenever possible (visual representation of steps needed to complete a task)

RECOMMENDATIONS: SUPPORTING PERSON-CENTERED CARE

- Encourage the use of 1-page profiles
- Assume Trauma and treat with compassion and understanding
- Tailor health education to the person's literacy and cultural context
- Consider task analysis, social stories, and psychoeducational materials with visuals
- Allow for sensory regulation activities during meetings/appointments



RECOMMENDATIONS – CALL TO ACTION (1/2)



<u>Welfare and Institutions Code Section 4696.1:</u> Strengthen MOUs between regional centers and County Behavioral Health agencies.



Behavioral Health Services Act (BHSA): Deepen partnership with regional centers, families and people with IDD:

- Partner with regional centers on the provision of BHSA funded projects
- BHSA County Integrated Plans: Regional centers are a required partner for engagement; work to deeply include them in the county community planning process
- People with IDD are represented across all the BHSA Target and Priority Populations and should be considered across Statewide Behavioral Health Goals (Improvement/Reduction)

RECOMMENDATIONS – CALL TO ACTION (2/2)



Increase Cross System Collaboration:

- Develop an <u>Extension of Community Healthcare Options (ECHO)</u> for individuals with dual diagnosis (MI/DD or SUD/IDD) co-led by Behavioral Health agency and local regional centers.
- Leverage existing interagency partnerships and teaming processes to work across systems for individuals served by multiple systems, i.e., Children and Youth System of Care, Adult System of Care Multidisciplinary Teams, CARE court, Child and Family Team Meetings.



Leverage Cross System Training Opportunities:

- Opportunities for clinicians to learn about individuals with IDD through clinical fieldwork, externships and internships
- Emergency Department, Emergency Medical Services and regional center cross trainings
- START trainings for behavioral health providers on topics relevant to dual diagnosis (MI/DD)

THANK YOU!

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Wendy White, Psy.D.: wendy.white@yai.org



RESOURCES

- <u>Diagnostic Manual Intellectual Disability (DM-ID-2)</u>
- <u>The Arc:</u> This organization advocates for and serves people with IDD through a national network of state and local chapters that offer a wide range of services and supports.
- Creating Behavioral and Educational Momentum (CBEM)
- The Link Center
- Mental Health and Developmental Disabilities Training Center
- NADD: An association for people with intellectual disabilities and co-occurring mental health conditions
- <u>National Alliance on Mental Illness (NAMI)</u>: This grassroots organization provides education and free peer-support services for individuals and families affected by mental health conditions, including dual diagnoses (MI/DD).
- <u>The National Center for START Services:</u> This organization promotes the START (Systemic, Therapeutic, Assessment, and Resources, Treatment) model, which focuses on crisis prevention and intervention for people with IDD and mental health needs.
- Therapists and Counselors Course | National Center for START Services®
- <u>Department of Developmental Services:</u>
 - <u>Safety Net Services</u>
 - Regional center contact

REFERENCES

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Questions & Discussion Time



Next Steps & Closing

Stephanie Welch, MSW. Deputy Secretary of Behavioral Health, CalHHS



Next Steps

- November 12th Hybrid Behavioral Health Task Force Quarterly Meeting, in Sacramento: 10 a.m.-3 p.m.
- Email <u>BehavioralHealthTaskForce@chhs.ca.gov</u> to sign up for the BHTF listserv and send any questions/comments



Thank you for joining us today!

For information about the Behavioral Health Task Force, please visit the CalHHS website at

https://www.chhs.ca.gov/home/committees/behavioral-healthask-force/

