Intellectual and Developmental Disabilities (IDD) & Alameda County: Community, Services, Resources & Partnerships
Our Plan for Today

• An overview of the IDD services system in CA
• An introduction to your partners and what we do
• Federal and state definitions of IDD and an overview of eligibility for IDD services in CA
• About Alameda County residents with IDD
• Best practices for working with and serving Alameda County residents with IDD
Learning Objectives

• What are intellectual and developmental disabilities (IDD)
• Who are your partners, the State Council on Developmental Disabilities and the Regional Center of the East Bay
• Common supports and services through the IDD service system & how to access them
• Best practices and tips on working with and serving Alameda County residents with IDD = how to make your services and system more accessible
The Role of the State Council

- Established by state and federal law.
- Ensures that people with Intellectual and Developmental Disabilities and their families receive the services and supports they need to fully participate in their communities.
The Work

• State Plan
• Empowering individuals and their families through activities and systems navigation that teach self-advocacy skills and support self-determination
• Work on advancing public policy and systems change to help people gain more control over their lives
• Building capacity in our community and within systems
Regional Offices of the State Council

- Help connect people to needed services and supports
  - Provide information, inform about rights, etc.
- Strive to improve services and supports
  - Review policies and practices, identify services needed but not available, monitor legislation. Help build capacity.
- Help people become part of their communities
  - Encourage and assist various advocacy organizations, educate the public.
Established by Federal Law & State Law

The DD Act

The Lanterman Act
The Federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act)

- Empower individuals with developmental disabilities and their families to help shape policies that impact them.
- DD Act programs conduct research and test innovative service delivery models. Bringing the latest knowledge and resources to those who can put it to the best use.
“(A) A severe, chronic disability of an individual that—(i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely;”
“(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.
(II) Receptive and expressive language.
(III) Learning.
(IV) Mobility.
(V) Self-direction.
(VI) Capacity for independent living.
(VII) Economic self-sufficiency; and

(v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.”
“(B) INFANTS AND YOUNG CHILDREN

An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.”
The Lanterman Developmental Disabilities Act (W&I Code Sections 4500 et.seq.), also known as the Lanterman Act, is a California law that gives people with developmental disabilities the right to services and supports that meet their needs and choices.

The Lanterman Act declares that persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other persons by federal and state constitutions and laws.

California’s Definition of Intellectual and Developmental Disabilities (IDD)

Originates before an individual attains **age 18**... can be expected to continue indefinitely, and constitutes a major impairment of cognitive and/or social functioning.

The existence of significant limitations in 3 or more of the following areas:

- Receptive & Expressive Language
- Learning
- Self-care
- Mobility
- Self-direction
- Capacity for independent living
- Economic self-sufficiency
Regional Center of the East Bay (RCEB) Overview

Services and Supports
Regional Center of the East Bay supports persons with developmental disabilities and their families with the tools needed to achieve lives of quality and satisfaction, and builds partnerships that result in inclusive communities.
Regional Center System

- There are 21 Regional Centers in the State of California.
- Each Regional Center is its own private, non-profit corporation.
- Each Regional Center is under contract with the California Department of Developmental Services (DDS).
Regional Center of the East Bay (RCEB)

- Serves Alameda and Contra Costa counties
- Currently serve 12,530 Active Consumers in Alameda County

People Served by Race/Ethnicity

- Black 16%
- Latinx 24%
- Asian 18%
- White 26%
- Other 16%
Ages and Where People Live

• 60% of People Served are under 22 years old
  • 98% of this group live at home with Family.

• For those 22 years and older, over 50% are living in a family home (v. other living arrangement).

• 63% of people served are Medi-Cal recipients.
RCEB’s Two Programs

Early Start/Early Intervention (EI)

- Birth to 3rd birthday
- 3 Eligible Categories:
  - Developmental delay
  - Established risk
  - High-risk infants and toddlers

Developmental Disabilities

- 3rd birthday and beyond
- Eligibility
  - Has a qualifying diagnosis
  - Has substantial disability
  - Originated prior to age 18
  - Disability expected to be life-long
Eligible Categories of Intellectual and Developmental Disabilities (IDD)

• Intellectual Disability (ID)
• Cerebral Palsy (CP)
• Epilepsy
• Autism
• “5th Category” …other handicapping conditions found to be closely related to ID or to require treatment similar to that required for ID individuals

(Note that an IDD is not a disability that is only physical, psychiatric or learning in nature)
### ‘Substantial Disability’ Categories of Limitations

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self Care</strong></td>
<td>• Significant limitations in the ability to acquire or perform basic self-care skills</td>
</tr>
<tr>
<td><strong>Expressive and Receptive Language</strong></td>
<td>• Significant limitations in both the comprehension and expression of verbal and/or nonverbal communication resulting in functional impairments</td>
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<tr>
<td><strong>Learning</strong></td>
<td>• Substantially impaired in the ability to acquire and apply knowledge or skills to new situations even with special intervention</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>• Significant limitations with independent ambulation</td>
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<tr>
<td><strong>Self-Direction</strong></td>
<td>• Significant impairment in the ability to make and apply personal and social judgments and decisions</td>
</tr>
<tr>
<td><strong>Capacity for Independent Living</strong></td>
<td>• Unable to perform age-appropriate independent living skills without the assistance of another person</td>
</tr>
<tr>
<td><strong>Economic Self-Sufficiency</strong></td>
<td>• Lacks the capacity to participate in vocational training or to obtain/maintain employment without significant support</td>
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Referral Considerations (1 of 2)

• What if there is suspected Developmental Disability (Intellectual Disability) and a Mental Health Condition?

<table>
<thead>
<tr>
<th>DEVELOPMENTAL DISABILITY (Intellectual Disability, Autism)</th>
<th>MENTAL HEALTH (Schizophrenia, Depression, Substance Abuse)</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Stable course</td>
<td>➢ Unstable declining course</td>
</tr>
<tr>
<td>➢ Early global developmental delays requiring early intervention</td>
<td>➢ Early development within normal limits</td>
</tr>
<tr>
<td>➢ Often requiring more intensive educational services</td>
<td>➢ History of regular education prior to the onset of mental health condition</td>
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</tbody>
</table>
Referral Considerations (2 of 2)

Red flags to look for regarding Autism (Autism Spectrum Disorder-ASD):

• Previous diagnosis of Asperger’s Syndrome or PDD-NOS, or suspicions of autism as a young child
• Discrepancy between IQ and adaptive functioning
• Awkwardness in social settings (inconsistent eye contact, inappropriate questions, lacking basic social understanding)
• Rigidities and difficulties with changes and transitions
• Odd or intense interests, perseverating on topics
• Unusual sensory behaviors and repetitive movements
Referrals to Regional Center of the East Bay

Refer by calling 510-618-6122 or emailing intakeoverthree@rceb.org

Go to www.rceb.org for more information
Timeline After Referral (over age 3)

From the date the case is assigned to an assessment counselor, RCEB has 120 days to determine if the applicant qualifies for services.
The Role of a Case Manager

Case Managers

- See clients at least one time per year
- Attend ID Team and other meetings when invited
- Coordinate services
- Connect clients and families to generic resources
- Advocate
- Support for client across the lifespan

A Whole Person Care Pilot
Person Centered Individual Program Plan (IPP)

Case Managers assess the needs of clients through a person centered IPP process.

What is important to and for the individual is the focus of the process.

Case managers assist the family and client in exploring generic resources related to those needs and/or RCEB-funded resources when applicable/available.
Notes on Service Delivery

Services identified in the IPP are either purchased by the Regional Center or they are provided by other agencies (e.g., school, health insurance, IHSS).

Regional Centers work with established vendors to provide the RCEB-funded services identified in the IPP. The vendors provide the direct service and RCEB funds them.

Regional Centers do not provide any ongoing direct service other than case management/service coordination.

What we are able to fund is legislated.
Generic Resources
(i.e. Insurance, School District Services)

RCEB funds services that relate to the developmental disability and that are based on an assessed need.

RCEB is unable to fund any services that are required by law to be funded by another agency or that can be accessed through a generic resource (e.g., mental health services, health insurance, education programs, etc.)
Examples of RCEB funded Services & Supports

- Child/Adult Residential Facilities
- Respite
- Specialized Childcare
- Supported Living Services
- Day programs
- Vocational Programs
- Behavioral Supports
- In-home nursing care
- Durable Medical Equipment

**Note:** Services provided to individuals are based on the assessed needs as determined through the IPP process.
Role of Caregiver/Client

- Inform Case Manager in advance of any meetings that they would like the Case Manager to attend.
- Inform Case Manager of areas of need or concerns about services.
- Keep Case Manager informed of changes in medical, mental health, educational status, etc.
- Keep contact information current.
RCEB Client Consultation Options

- Clinical Team
- Clinical Consultation
RCEB Crisis Supports

Crisis Response Project

- Team of Mental Health clinicians who are available to consult on the phone and sometimes in person to help deescalate a situation.
- Can provide short term crisis behavioral training

Short-term residential:

- One crisis home for children
- Two crisis home for adults
- Redwood Place: adults with co-occurring DD and MH
- Note: These are not emergency placements. Placement depends on availability of beds and triage of clients in need; placement is determined by a team of people at RCEB.
California START East Bay

- Systemic, Therapeutic, Assessment, Resources, and Treatment model serves people diagnosed with intellectual/developmental disabilities (IDD) and co-occurring behavioral health conditions.
- A comprehensive model of service supports that optimizes independence, treatment, and community living for individuals with IDD and behavioral health needs.
- This is a *Crisis Stabilization* program for individuals with IDD and *unmet* behavioral health needs.
- It does this by addressing systemic, provider, and individual factors in order to stabilize the client and shore up their system of care.
Tips, Tools and Communication Strategies
People First Language

• Use ‘people with disabilities’, NOT ‘the disabled’ or ‘handicapped’.

• Use ‘youth has a disability’, NOT ‘youth suffers from (insert condition here)’ or ‘youth is a (insert condition here)’.

• Use ‘people who are non-verbal’ or ‘people who communicate using icons / AAC devices / ASL / eye movements / written means’, NOT ‘mute people’ or ‘they are a non-verbal person’.

• Use ‘people with mental health conditions’ or ‘people with psychiatric disabilities’, NOT ‘mental’ or ‘crazy’.

• Use ‘this person receives special education services’, NOT ‘this person is special ed’ or ‘special ed kiddo’.
General Communication Techniques

• Maintain Age-Appropriate Interactions/Communication.

• Use Plain Language – for example, age-appropriate language, non-technical terminology, etc.

• Watch for any difficulty processing multiple or complex commands/questions/instructions –

• Keep it simple & calm.

• Check for comprehension-- Wait for response, then repeat or rephrase.
Poor Tactics and Responses for those with IDD in Crisis Scenarios

DON’T

• Use lengthy explanations or multiple-step commands
• Approach quickly with force where possible
• Expect compliance immediately
• Use words that have multiple meanings, i.e. wave hello, ocean wave, waiving rights
Tips to Improve Communication with People who are Limitedly Verbal or Non-Verbal

• Ask people how they prefer to communicate.
• Pay attention to pointing, gestures, nods, sounds, eye gaze, eye blink.
• Try using paper and pen. Ask a person to spell a word. Don’t guess if you can avoid.
• Ask a person if they use a communicate board, device or app.

• For those individuals who are less verbal or non-verbal, ask them to:
  • “Show me how you say YES”
  • “Show me how you say NO”
  • – “Show me how you point” e.g. Yes – 1 blink, No – 2 blinks, Help – 3 blinks

• Only if needed, ask questions of support staff and ask about the best way to communicate with the person
People with an Intellectual Disability may...

(1 of 2)

- Be slower to learn new info and have harder time retaining
- Have challenged memory recall
- Struggle with cause and effect
- Struggle with abstract concepts
- Show low tolerance for frustration
- Struggle to defer gratification
- Experience difficulty understanding “cause and effect” relationships
- Have communication disorders that limit ability to explain wants and needs
- Have difficulty with insight
People with an Intellectual Disability *may*...

(2 of 2)

- Have poor social skills
- Have strong desire to ‘pass’ as typical, to fit in
- Not understand the goals & steps necessary
- Set unrealistic goals for self
- Be impulsive
- Lack self-efficacy
- Be targeted for victimization
People with Cerebral Palsy (CP) may...

- Or may not have an intellectual disability, although people can be dually-diagnosed with CP and an Intellectual Disability
- Include difficulty with swallowing, speech
- Require mobility device due to restricted/contracted movement (walker, wheelchair, cane, etc.)
- Appear under the influence due to impaired gait, mobility, and/or speech
More Successful Tactics and Responses for those with Cerebral Palsy (CP)

- Talk to people directly, and engage age-appropriately
- Maintain eye contact, try not to interrupt someone or finish their sentences
- Ask someone to repeat and/or rephrase, as needed
- Wheelchairs are personal space, when possible inform the individual before touching or searching their chair
People with Autism / on the Spectrum *may*...

- Avoid eye contact, have a flat affect
- Be nonresponsive to verbal commands or when their name is called
- Have delayed or no speech & language
- May show stereotypic movement/repetitive behavior (for calming, processing or self-regulation)
- May be sensitive to loud noises & issues with sensory perception
- Can become fixated on desired objects, persons, or activities
- May repeat words and phrases others use (called Echolalia)
- May react with “Flight or Fight”
More Successful Tactics and Responses for those with Autism / on the Spectrum

- Maintain calm and patient demeanor where possible
- Give personal space/proximity control where possible
- Use concrete language
- Allow time for the individual to process and respond to your questions
- Avoid quick movements, and touching without preparation
- Watch for body language for signs of frustration, anxiety, or feeling pressured, and understanding
People with Epilepsy *may...*

- Appear incoherent, unresponsive, disoriented, glossy eyed, and/or be found roaming during a seizure
- Appear to be acting suspiciously or under the influence
- Appear to be resisting or ignoring your questions / communication if having a seizure
- Have rapid eye movement and hard time speaking if having a seizure
- Have affected bodily functioning, behavior, sensations, and motor activity during a seizure
More Successful Tactics and Responses for those with Epilepsy

• Look for a medical ID bracelet
• During seizures or suspected seizures:
  • Protect them from injury
  • Do not restrain them
  • Do not place anything in their mouth/keep airway clear
  • If seizure last more then 5 minutes, call an ambulance
  • After a seizure, they may be impaired, require recovery for anywhere from a short time to several days
Other Partners in Alameda County:
Family Resource Center

- Family Resource Navigators:
  https://familyresourcenavigators.org/

- Makes it easier for families to navigate, advocate, get equitable access to resources - all so their kids with disabilities, development delays or special health care needs get what they need to flourish.
Other Partners in Alameda County: Independent Living Centers

• **TheCIL:** [https://www.thecil.org/](https://www.thecil.org/)
  - The Center for Independent Living (TheCIL) provides advocacy and services that increase awareness, collaboration, and opportunity among people with disabilities and the community at large.

• **CRIL:** [https://www.crilhayward.org/our-services](https://www.crilhayward.org/our-services)
  - CRIL offers independent living services at no charge to persons with disabilities living in southern and eastern Alameda County.
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Questions & Discussion
...And Thank You!