

Survivors with Intellectual & Developmental Disabilities:

Providing Appropriate Support and Advocacy



Part 1
March 13, 2023
1:00-2:30 PM PT

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Survivors with Intellectual & Developmental Disabilities:

Providing Appropriate Support and Advocacy

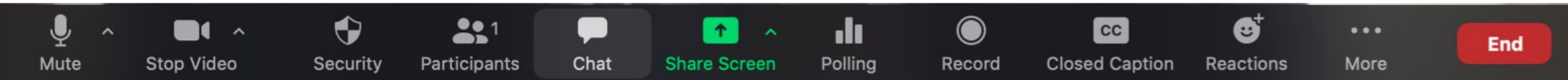
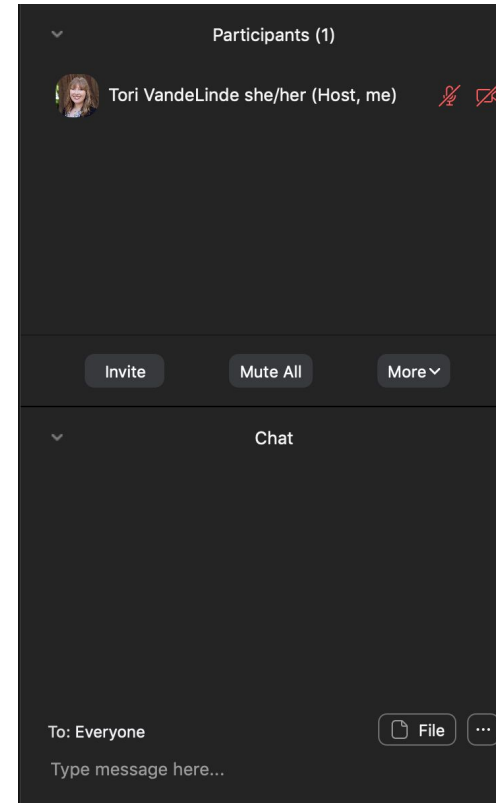
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LEADDs**

A ValorUS® and
Arc of California Project

**Part 2
March 15, 2023
1:00-2:30 PM PT**

HOW TO USE ZOOM

- ›Text chat
- ›Breakout rooms
- ›Phone
- ›Live captioning
- ›Recording & slides
- ›Certificate of participation



Meet Your Host



Priscilla Klassen

**Project Coordinator, VALOR
(she/her)**

Meet Your Presenters



Samantha Thalken
Project Coordinator, The
Arc of California
(she/her)



Teresa Anderson
Public Policy Director,
The Arc of California &
UCP (she/her)



Jordan Lindsey
Executive Director,
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Kecia Weller
Self Advocate
Consultant, The Arc
of California
(she/her)

Legal Disclaimer & Reminders

- VALOR® & the Arc of California cannot give legal advice
- Persons seeking legal advice should consult an attorney
- Acquaint yourself with your agency's policies and procedures on mandated reporting
- Talk to your supervisor about mandated reporting prior to working with survivors
- Consult with your supervisor if you think you may need to report a situation
- Discuss your duties to report with survivors



Learning Objectives - Part One

- Participants will be able to identify and describe intellectual and developmental disability and services in the state of California
- Participants will be able to explain the basics of mandated reporting and conservatorship in California
- Participants will be able to summarize the importance of language & terminology
- Participants will be able to describe ableism and its impact on sexual assault

Disability Bias

- Categorizing or defining people based on their disability
 - Assuming all people with disabilities are the same
 - Stereotypes
- Perception of inferiority
 - Lower societal status, “society’s obligation”
- Credibility risk, assumptions about knowing/telling the “truth”
- Pity
 - Feeling sorry for someone because they have a disability
 - Patronizing
- Fear
 - Personal discomfort
 - About saying or doing the wrong thing
 - That people will assume you are also disabled

What comes to mind when
you hear the terms
“Intellectual and
Developmental Disabilities”?

Please respond
in the chat



Intellectual/Developmental Disabilities

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Medical vs. Social Models of Disability

Medical Model

- Disability is inherently abnormal and should be eradicated
- Supports and services are meant to correct or make more normal
- Existence is seen as shameful or inspirational

Social Model

- Disability exists due to lack of access
- Fix social construction not individuals
- Value is based on individual spectrum of abilities and skills

Common Types of Developmental Disabilities

- Intellectual Disability
- Epilepsy (seizure disorder)
- Cerebral Palsy
- Autism (Autism Spectrum Disorder)
- Down Syndrome

Intellectual Disability

- Characterized by significant limitations in both intellectual functioning and adaptive behavior.
 - Intellectual functioning: reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience (DSM-5)
 - Adaptive behavior: Communications, Self-Care, Home living, Social skills, Leisure, Health and Safety, Self-direction, Community use, Work
- Classifications of severity (mild-profound) are now based on abilities rather than IQ

Epilepsy

- Neurological disorder characterized by sudden, brief changes in the electrical functioning of the brain
- Epilepsy is a spectrum condition with a wide range of seizure types and control varying from person-to-person
- Seizures: Nerve cells disrupted temporarily causing alter in consciousness, movement or action, may look different depending on the type
- Sometimes awareness is impaired, but not always
- Can be caused by brain injury or an inherited trait, but most causes are unknown

Cerebral Palsy

There are four main types of Cerebral Palsy:

- Spastic which is 80% of people with Cerebral Palsy - when muscles are stiff with awkward movement
- Dyskinetic - where there are issues controlling the movement of hands, arms, feet and legs, sometimes face and tongue
- Ataxic - when there are problems with balance and coordination
- Mixed - meaning multiple types of cerebral palsy, most common is spastic-dyskinetic

Autism

- Neurological, spectrum disorder that varies from person to person
- Challenges with expected social skills, differences in speech and communication, repetitive or restricted behaviors and/or interests
- Atypical ways of learning, paying attention, and/or reacting
- Often taught/pressured to “mask” their disability to better blend in socially

Down Syndrome

- Genetic condition where a person has an extra chromosome that alters how the brain and body develop
- Atypical physical features and challenges with development
- Typically affects IQ and can cause a shorter life expectancy
- Many individuals with Down Syndrome also have other medical conditions



California's Service Delivery System

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Early History of Care

Institutions & Developmental Centers

- State run homes/care facilities
- No schools or supports in community
- Poor conditions
- Segregated from community
- Lack of care
- Began closing in 1993
- Still exist for transitional care

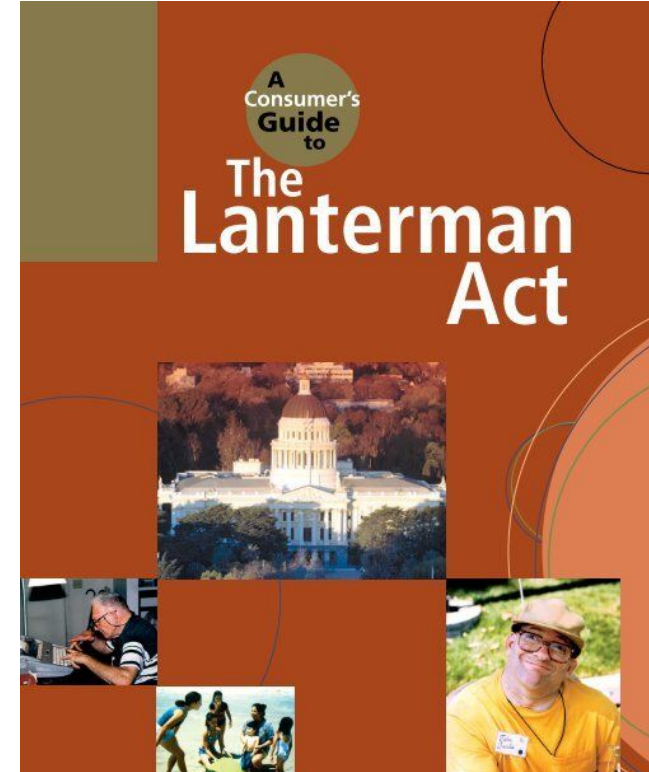


Early History of Care



The Lanterman Developmental Disabilities Services Act of 1969

- Established right to community supports and services
- CA is first and only state that recognized being supported in least restrictive environment possible “as a civil right and an individual entitlement.”
- Provides an entitlement to community supports and services, funded by the state.



Department of Developmental Services (DDS)



COVID-19 Vaccine & Testing
Information



State Budget Information



Developmental Services (DS) Task
Force



Early Start



Self-Determination Program



Regional Center Lookup



Service Access & Equity



Direct Support Professional (DSP)
Training



Regional Centers

Lanterman Act services are coordinated by the 21 regional centers throughout the state.

- Service coordinators work with the individual (and family/guardians if appropriate) to determine goals (e.g. more community integration, employment, live independently, improve health)
- The goals and needed supports and services are written in the Individualized Program Plan (IPP), which is a contract.
- The Regional Center pays local vendors to provide the supports and services identified in the IPP.

Your County Determines Your Regional Center (except in LA)

Enter Your ZIP Code to Find Your RC:



Zip code XXXXX is serv...



[Alta California Regional Center](#)

[Central Valley Regional Center](#)

[Far Northern Regional Center](#)

[Golden Gate Regional Center](#)

[Inland Regional Center](#)

[Kern Regional Center](#)

[North Bay Regional Center](#)

[Redwood Coast Regional Center](#)

[Regional Center of Orange County](#)

[Regional Center of the East Bay](#)

[San Andreas Regional Center](#)

[San Diego Regional Center](#)

[Tri-Counties Regional Center](#)

[Valley Mountain Regional Center](#)

Common Types of Supports and Services Funded by Regional Centers

- Respite Care
- Day Programs
- Housing Services (group homes)
- Supported Employment Services
- Transportation
- Rehabilitation/Therapies
- Independent Living
- Supported Living
- Social Recreation
- Early Intervention (ages 0-5)



Other Common Supports and Services Not Funded by Regional Center

- In Home Supportive Services (IHSS)
- Special Education
- SSI/SSP
- Medi-Cal



Reminder About Federal Disability Laws

Americans with Disabilities Act (ADA)

- Integration and Accessibility
- “Full and equal enjoyment of the goods, services, facilities, privileges, advantages, or recommendations offered by a place of public accommodation”
- Reasonable accommodations must be provided

Rehabilitation Act, Section 504

- “All federally funded programs and activities must be readily accessible to and useable by people with disabilities.”



Legal Provisions

Mandated Reporting

Welfare & Inst Code § 15630 (a):

“A person who has assumed full or intermittent responsibility for the care or custody of an elder or dependent adult, whether or not they receive compensation, including administrators, supervisors, and any licensed staff of a public or private facility that provides care or services for elder or dependent adults, or any elder or dependent adult care custodian, health practitioner, clergy member, or local law enforcement agency, is a mandated reporter.”

Mandated Reporting

What situations/events need to be reported?

- Physical/Sexual/Financial abuse
- Neglect
- Abandonment
- Isolation
- Abduction (taking the person out of the state against his or her will)
- Other behavior that causes physical harm, pain, or mental suffering
- Deprivation by a caregiver of things or services that the elder or dependent adult needs to avoid physical harm or mental suffering
- Chemical Restraint (medications, drugs, alcohol)

****Understand and acknowledge that reporting abuse may not lead to stopping that abuse****

Mandated Reporting

- Advocates are not explicitly listed and are not required to report unless
 - Explicitly providing health or social services to dependent adults
 - Required due to their profession/licenses (e.g., LCSW, psychologist, clinical therapist)

****Reporting if not required could be a violation of VAWA confidentiality provisions****

Best Practices in Reporting

- Be clear
 - Know your roles and responsibilities
 - Know your protocols and process
- Provide notice of responsibilities
 - Intake/counseling scripts
 - Posted reminders
- Meaningful safety planning
- Know your resources
- Acknowledge survivor's choices and center survivor involvement and autonomy as much as possible

Basic Principle: “Presumption of Competence”

- Adults (18+) are “presumed to be competent” and are legally able to manage their own lives unless a court decides otherwise.
- This applies to the vast majority of adults with I/DD. Approximately 15% of adults with I/DD are conserved after a court ruling.
- Anyone claiming to have legal authority over another should have legal documentation to prove this, documents must detail the specific powers the conservator holds.

What is a Conservatorship?

- A legal arrangement decided by a judge to appoint another person to make some or all decisions for a person who is considered impaired.
- There are different kinds of conservatorships. An individual may have one or both kinds of conservators; one person can fulfill both roles.
 - “Conservator of the person”
 - “Conservator of the estate”
- Conservators are supposed to support the wishes of the person with I/DD and encourage their maximum potential. The court monitors the conservator.

What is a Conservatorship?

- Most people with I/DD do **NOT** have conservatorships.
- A court monitors the conservator and the conservatorship.
- Law enforcement or APS will inform conservator, staff are not legally permitted to inform conservator.
- Sometimes conservators need to be involved in signing contracts including consent forms and liability waivers.

Limited Conservatorships

A Limited Conservatorship identifies certain areas of control. The Court may grant the conservator the authority in one or more of the specific areas (domains):

1. Decide where the conservatee lives.
2. Have access to the conservatee's confidential records.
3. Make all decisions concerning the conservatee's education and vocation.
4. Restrict the conservatee's right to enter into a contract.
5. Give or withhold consent for the conservatee's medical treatment.
6. Restrict the conservatee's social and sexual contacts and relationships.
7. Give or withhold consent to the conservatee's marriage.

The Court is required to consider the least restrictive options for the individual.



Language & Terminology

Language Matters!

Person-first language

"person with a disability"

e.g. "They are a person with autism."

- Centers the person, not the disability
- Counters ableism and the use of diagnoses as derogatory language

Identity-first language

"disabled person"

e.g. "They're autistic"

- Recognizes that disability is a part of the person's identity
- Positions disability to be the same as any other identity category

Language Matters!



Preferred Terminology

- Disability
- Intellectual disability
- Neurodiversity
 - Neurotypical
 - Neurodivergent

Language Matters!

Terms to Avoid

- The R word
- Functioning labels
- Mental age correlation
- Euphemisms
- “On the spectrum”

Other words to avoid?



Language Matters!



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Reclaiming Terms:

- Terms that once had a negative meaning, given a positive or neutral identity
 - Eg. Crip, crippling (from Crippled)
- Not for everyone to use



Ableism



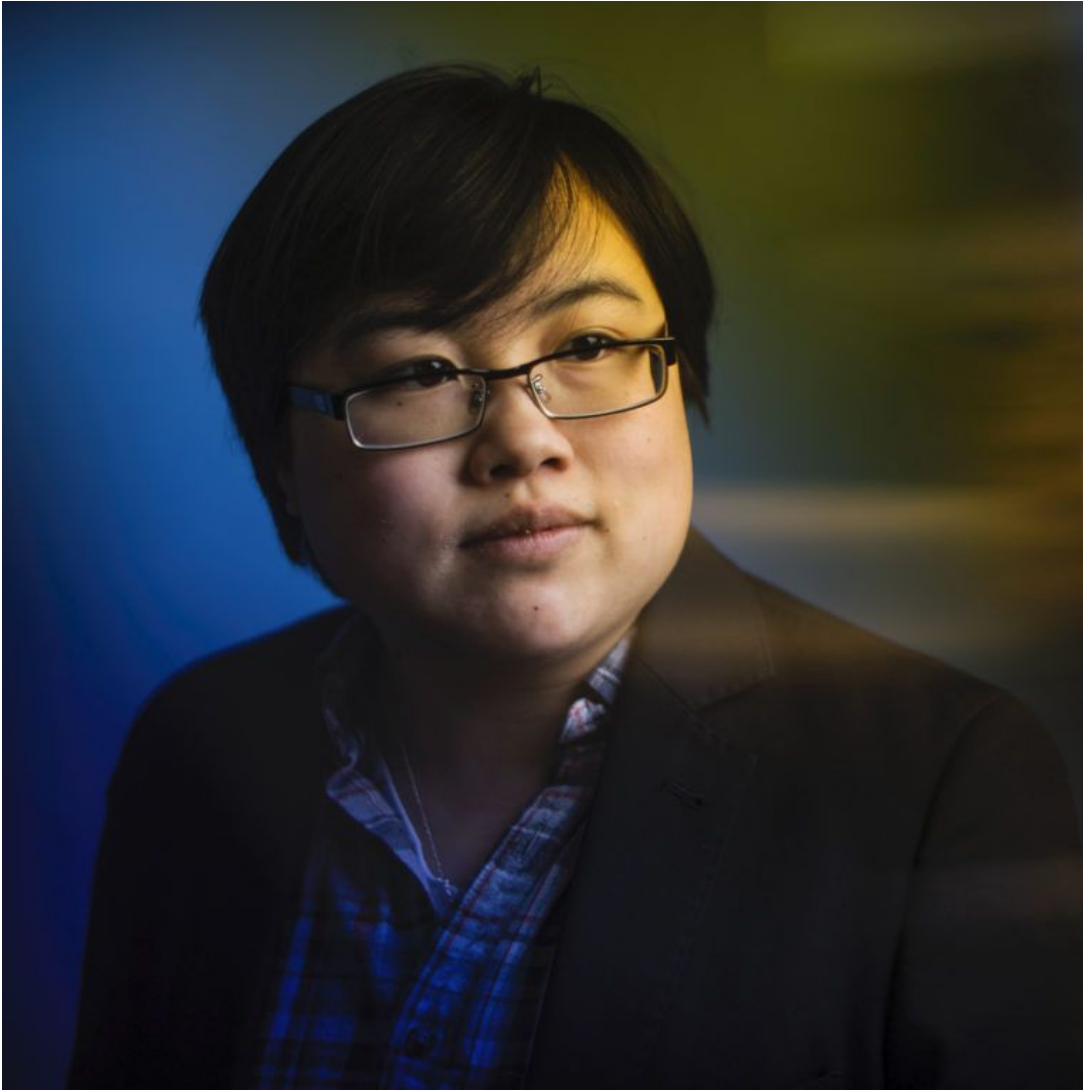
"A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism."

- Talila A. Lewis


The Arc
California

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<https://affecttheverb.com/disabledandhere/>



“Ableism as a form of oppression is inextricably intertwined with, interconnected with, necessary for, and dependent upon every other form of oppression that exists.”

- Lydia X. Z. Brown, Disability Rights Activist



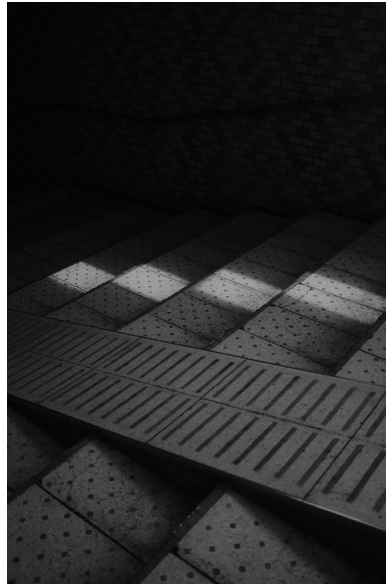
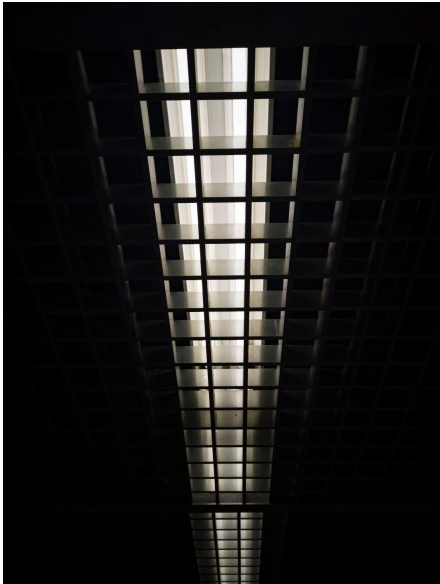
“While I don’t believe that we can separate ourselves from our privileges, we can leverage them toward justice.”

- Leah Lakshmi
Piepzna-Samarasinha, Disability
Justice Activist & Author

Ableism

Physical - ways that ableism shows up in physical spaces

- What are some physical barriers to accessibility?



Ableism

Personal - negative or harmful beliefs, attitudes, language and behaviors

- What are some of the ways you've seen personal ableism demonstrated?



Ableism

Systemic - how policies, procedures, laws contribute to inequity

- What are some examples you've seen of system wide inequity?



Ableism and Sexual Health

Ableism in Sex Education



disabled bodies are often seen as inherently desexualized and infantilized



disabled students are often excluded from health class or other sexual education opportunities



labeling disabled persons as "mentally children" who are incapable of feeling sexual feelings, having sex, and/or cultivating and maintaining a romantic relationship



'inappropriate' body parts (penis, vagina, breasts, etc.) are often removed from communication devices

Ableism in Sex Education



belief that cognitive disabilities prevent understanding sexuality



curriculum is inaccessible (no braille, lacking captions and/or ALT text)



lack of disabled people in positions of power (i.e. policy makers, leaders, curriculum makers)



lack of representation in sex education curriculum



lack of disabled sex educators

Breakout Room

- What is one of the ways that you have seen ableism show up in your work? (physical, personal, systemic)
- Share an experience when you were corrected about an ableist term and how you responded.
- How do you think learning about the landscape of disability services in California can help you going forward?

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