




Alzheimer's Disease and Related Disorders Advisory Committee Meeting

CalHHS
California Health & Human Services Agency

Meeting Logistics

Join by smart phone, tablet, or computer:

https://us06web.zoom.us/w/86009181582

To join audio by telephone:

Tel: (888) 788-0099 | **Meeting ID: 860 0918 1582**

- **Live captioning** accessible via webinar (Zoom)
- **American Sign Language Interpretation** via webinar (Zoom)
- **Recording, Slides, and Transcripts** will be posted to the CalHHS Alzheimer's Disease & Related Disorders webpage post webinar

Public Comment

Time is reserved on the meeting agenda for public comment.

Attendees joining by webinar (Zoom), use the Q&A function to ask a question or select the raise hand icon. The moderator will announce your name and will unmute your line.

Attendees joining by phone, *press *9* on your dial pad to "raise your hand." The moderator will announce the last 4 digits of your phone number and will unmute your line.

Welcome & Introductions

Catherine Blakemore

Committee Chair

Family Member Representative

Today's Agenda

I. Welcome & Introductions

II. Down Syndrome and Alzheimer's Disease Presentations & Discussion

III. Public Comment

IV. Break – 30 min.

V. Alzheimer's Plan Updates - California Department of Aging and California Department of Public Health

VI. 2023 Committee Meeting Schedule & Topic Ideas

VII. Finalization of Recommendations & Items for CalHHS Secretary

VIII. Public Comment

IX. Closing Comments & Next Steps

Committee Member Introductions

Committee Chairs

- **Catherine Blakemore**, *Family Member Representative* (Chair)
- **Darrick Lam**, *ACC Senior Services, Family Member Rep* (Vice Chair)

Stakeholder Committee Members

- **Meg Barron**, *Alzheimer's Association, Consumer Organization Rep*
- **Julie Souliere**, *CA Health & Human Services Agency*
- **Dr. Sarah Tomaszewski Farias**, *UC-Davis, Alzheimer's Disease Diagnostic & Treatment Centers Rep*
- **Pam Montana**, *Consumer Rep*
- **Andrea Robert**, *Consumer Rep*

Committee Member Introductions

Stakeholder Committee Members (Cont.)

- **Dr. Dolores Gallagher Thompson**, *Stanford University, Social Research Rep*
- **Dr. William Mobley**, UC San Diego, *Academic Medical Research Rep*
- **Todd Shetter**, *ActivCare Living, Service Provider Rep*
- **Celine Regalia**, Collabria Care, *Alz. Day Care Resource Center Rep*
- **Dr. Wynnelena Canlas Canio**, *Kaiser Permanente, Mental Health Field Rep*
- **Barbra McLendon**, *Alzheimer's Los Angeles, Service Provider Rep*

Vacancy:

- *Elder Law Representative*

Presentation on Down Syndrome and Alzheimer's Disease

- ***Data and research –*** *William C. Mobley, MD, PhD*
- ***California data and Department of Developmental Services initiatives*** *– Lucy Esralew, PhD*
- ***Community services*** *– Lisa Rund, RN*
- ***Residential care model*** *– Todd Shetter & Kimberly Keane*
- ***Family caregiver's experience*** *– Marc Loupe*

The Oncoming Era of Treating to Prevent Alzheimer Disease in People with Down Syndrome (Trisomy 21)

William Mobley
Department of Neurosciences
UC San Diego

Disclosures

- Co-inventor on patent applications for γ-secretase modulators held by UCSD and MGH.
- SAB Member for Alzheon Inc, and Promis Inc. with stock options.
- SAB Member for National Down Syndrome Society.
- Former consultant for Cortexyme and Annovis-Bio and received stock.
- Consultant for AC Immune.

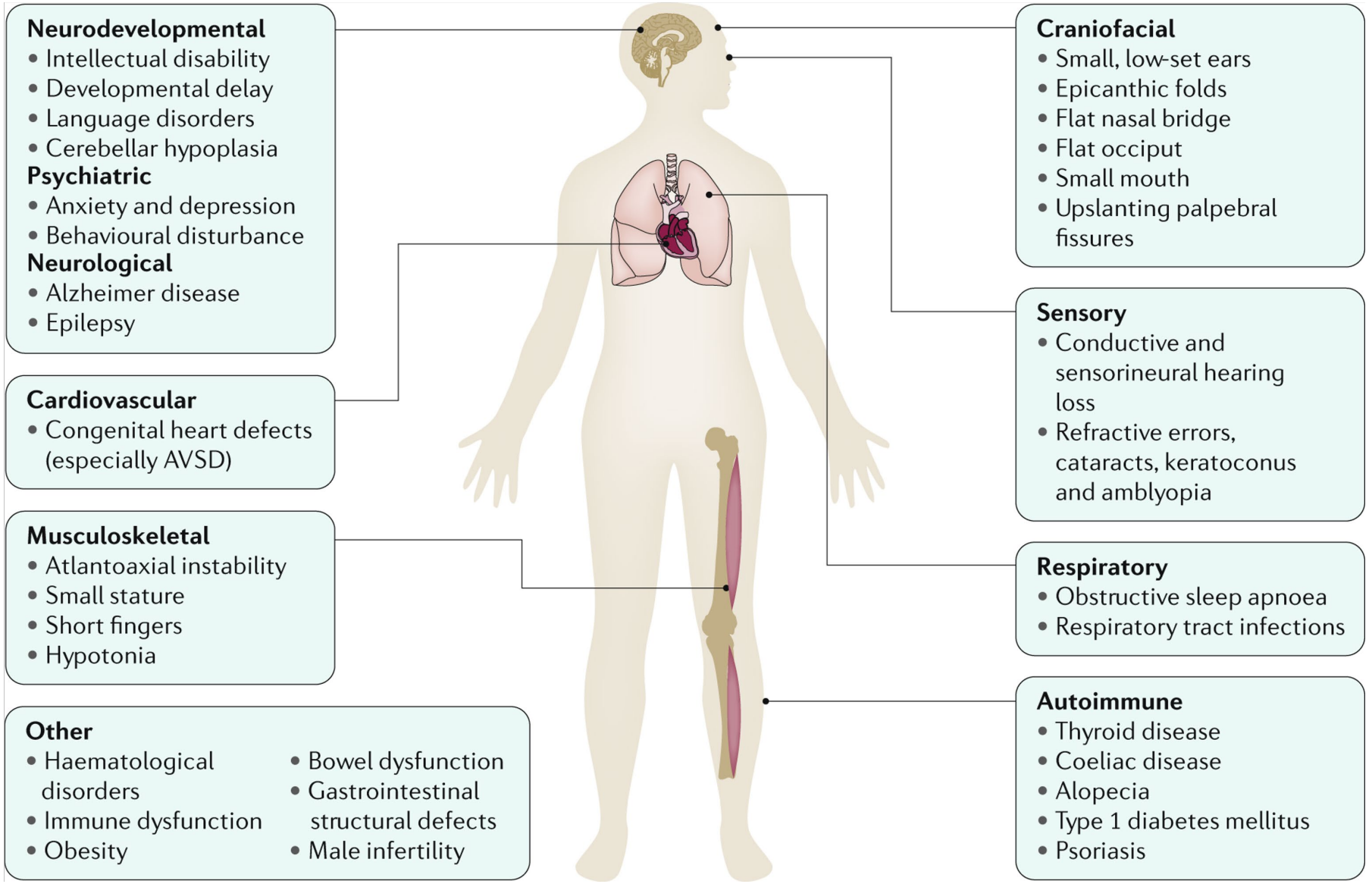
Overview

- Adults with Down syndrome (DS) face many health challenges.
- The most significant is Alzheimer disease (DS-AD).
- An extra copy of the gene for APP is necessary for DS-AD.
- Recent advances enable future trials to prevent DS-AD.
- It is essential to enhance health care services for the care of adults with DS and to equip them to deliver treatments proven safe and effective for preventing DS-AD.

Caring for Adults with DS

- Adults with DS experience a number of clinical challenges
- Changes in brain function are frequent.
- The most significant challenge is emergence of DS-AD.
- Clinicians with experience in the management of adults with DS are needed to address DS-AD and other conditions that impact learning, memory, and mood.
- Caregivers need to be able to engage physicians with expertise in DS to define problems and treatments.
- Clinicians must carefully consider the possible causes of neurologic dysfunction, including memory loss.

Adverse Impacts of DS on Health



Neurodevelopmental
- Intellectual disability
- Developmental delay
- Language disorders
- Cerebellar hypoplasia

Psychiatric
- Anxiety and depression
- Behavioural disturbance

Neurological
- Alzheimer disease
- Epilepsy

Cardiovascular
- Congenital heart defects (especially AVSD)

Musculoskeletal
- Atlantoaxial instability
- Small stature
- Short fingers
- Hypotonia

Other
- Haematological disorders
- Immune dysfunction
- Obesity
- Bowel dysfunction
- Gastrointestinal structural defects
- Male infertility

Craniofacial
- Small, low-set ears
- Epicanthic folds
- Flat nasal bridge
- Flat occiput
- Small mouth
- Upslanting palpebral fissures

Sensory
- Conductive and sensorineural hearing loss
- Refractive errors, cataracts, keratoconus and amblyopia

Respiratory
- Obstructive sleep apnoea
- Respiratory tract infections

Autoimmune
- Thyroid disease
- Coeliac disease
- Alopecia
- Type 1 diabetes mellitus
- Psoriasis

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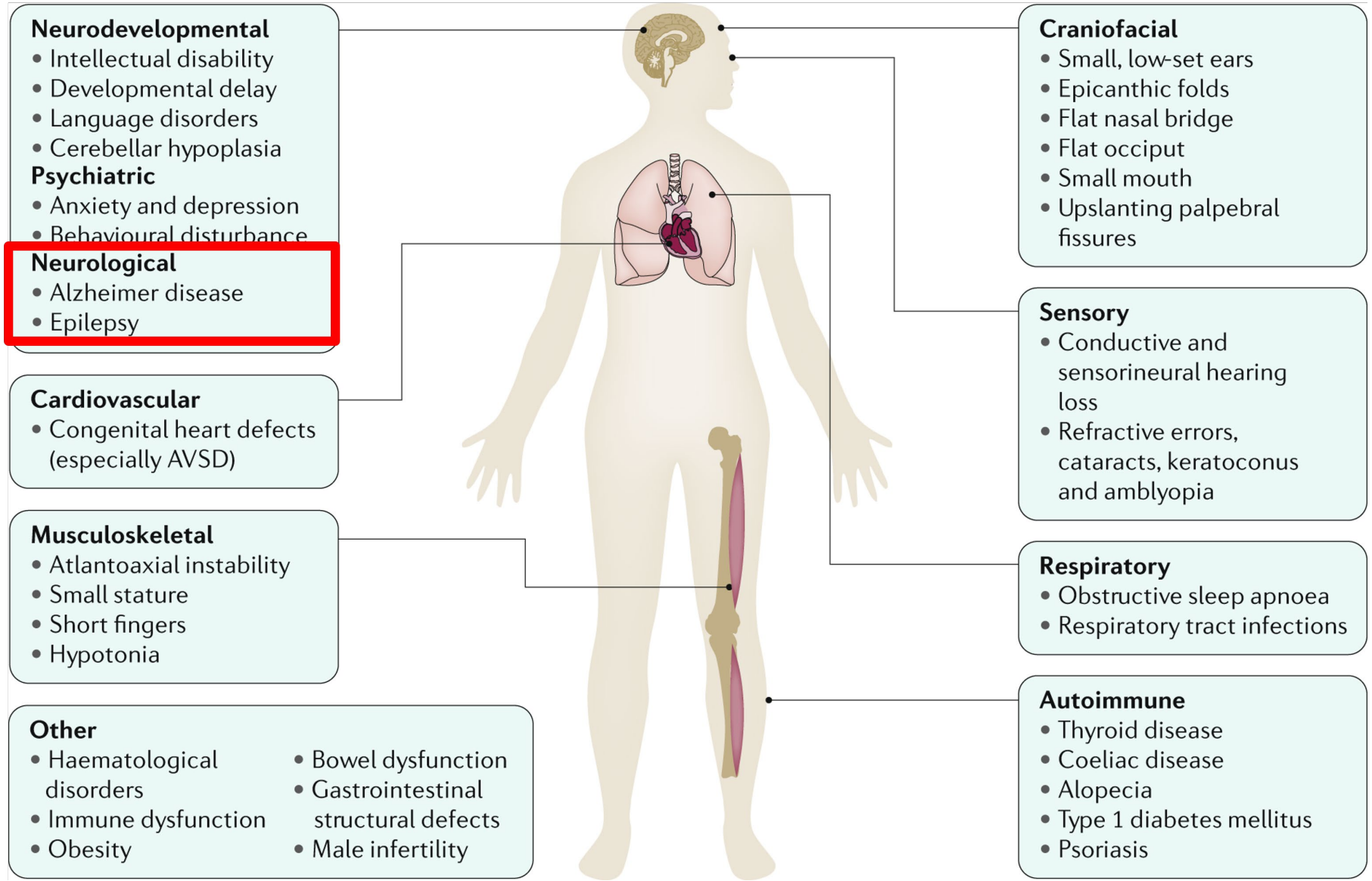

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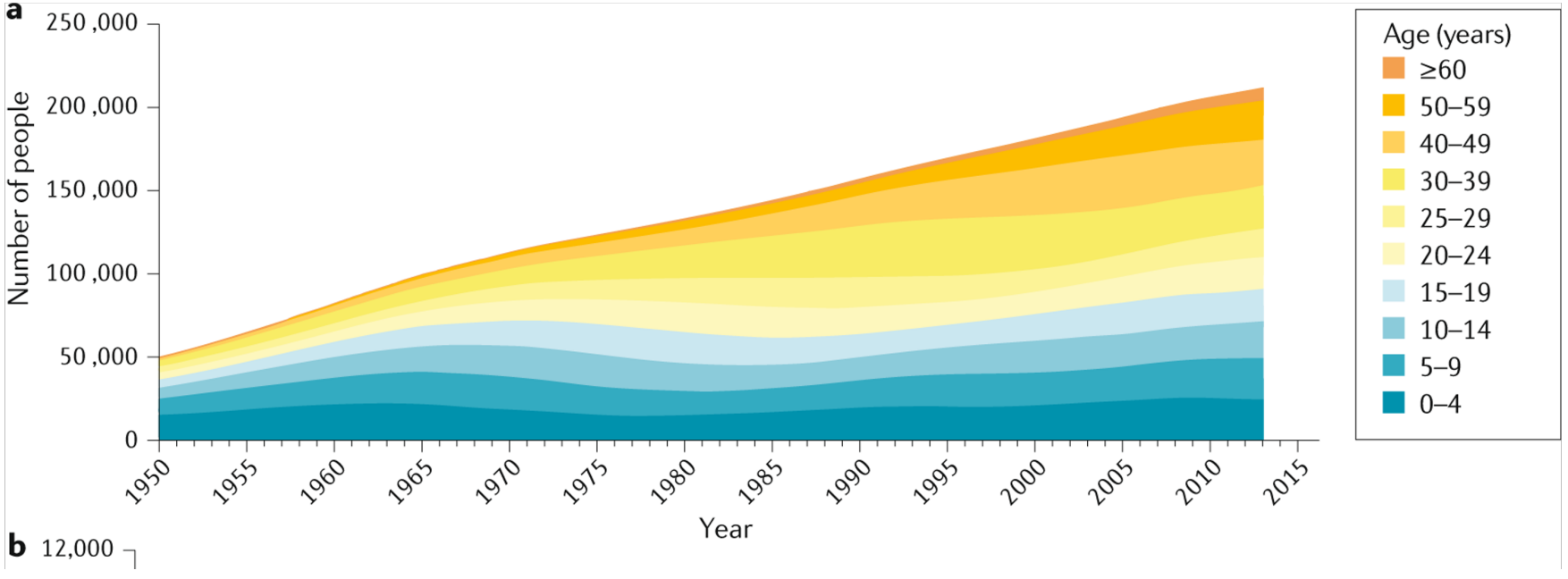
Increasing Longevity and Size of DS Population in US

Life expectancy of individuals with DS in the USA:

- 1950: mean of 26 years; median of 4 years
- 2010: mean of 53 years; median of 58 years



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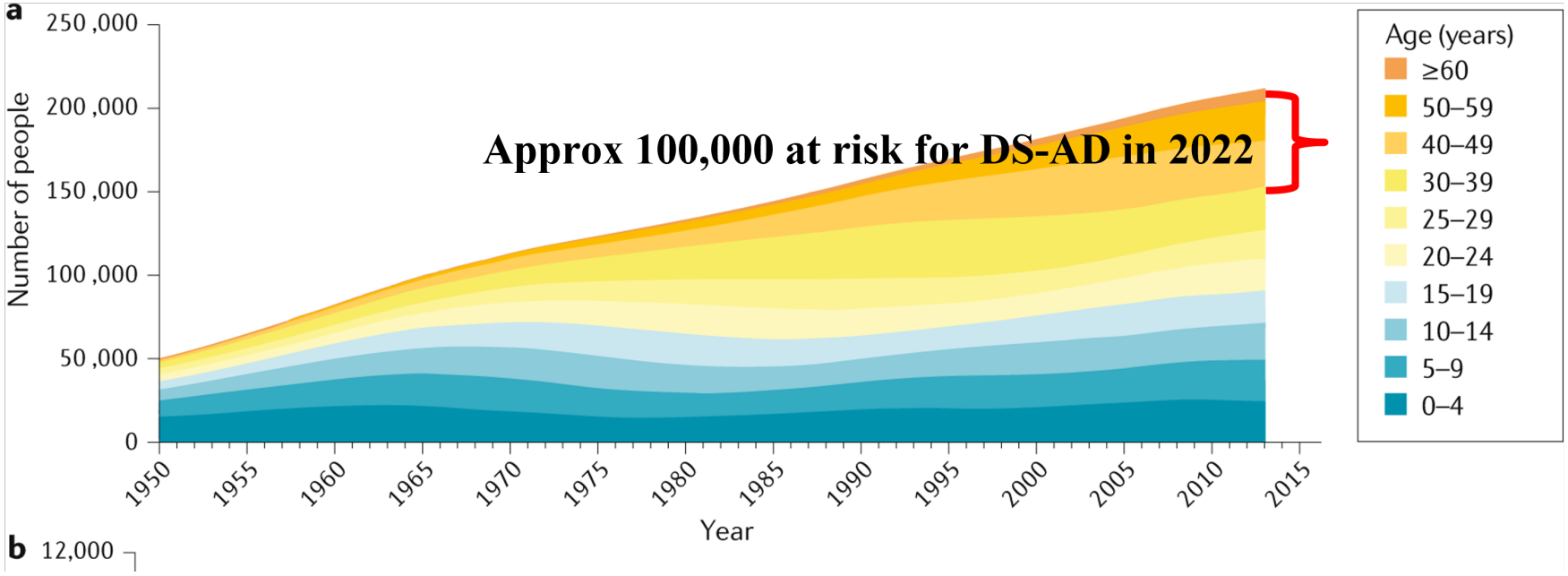
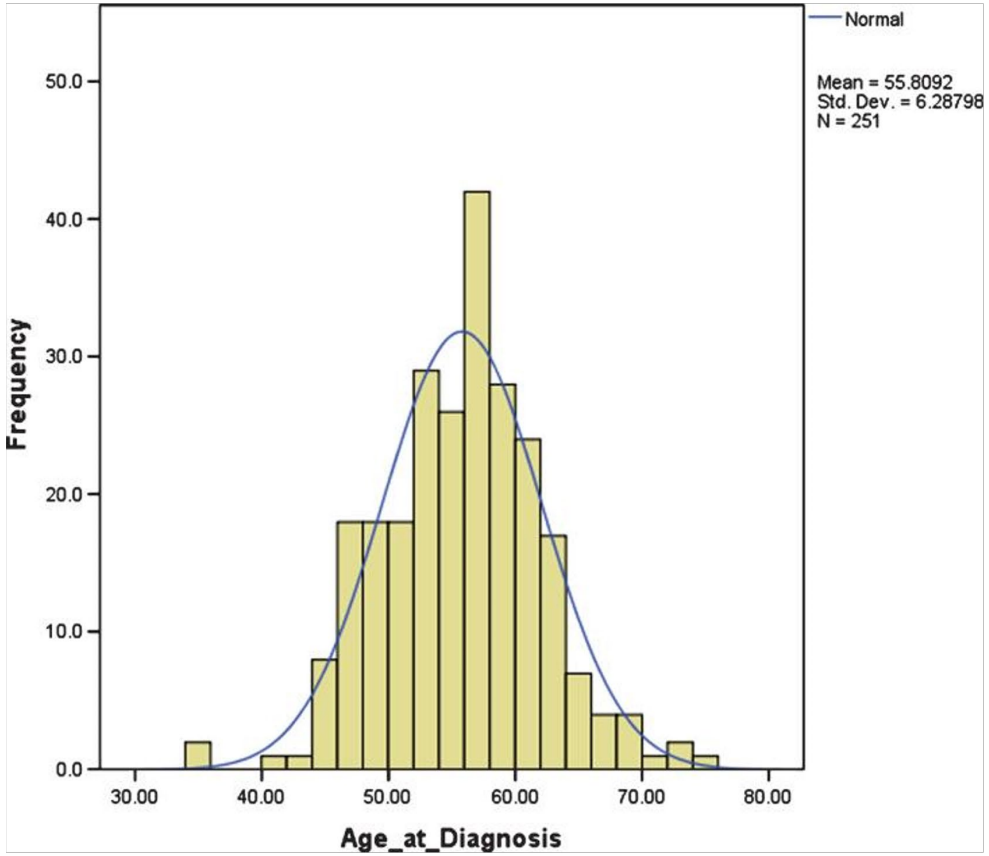


Antonarakis et al, Nature Rev, 2020

Alzheimer Disease(AD) in DS (DS-AD)

- AD much more frequent and earlier in DS (incidence > 90% over age 65).
- Dementia: cognitive or behavioral symptoms in two domains that: 1) interfere with the ability to function normally; and 2) represent a decline from a previous level of functioning and performing. DS-AD typically includes memory loss and changes in mood.
- Dementia occurs at a median age of ~55 years in DS.
- Neuropathological changes very similar if not identical to typical AD, and found in essentially all by age 40.

DS Markedly Increases Risk of AD



Sinai et al., JAD, 2018

Cumulative risk by age 65 is estimated to be 90%.

McCarron et al., J Intellect Disabil Res, 2014.

DS-AD

- More frequent and earlier in adults with DS (incidence may exceed 90% beyond age 65).
- Dementia: cognitive or behavioral symptoms in two domains that: 1) interfere with the ability to function normally; and 2) represent a decline from a previous level of functioning and performing. AD typically includes memory loss.
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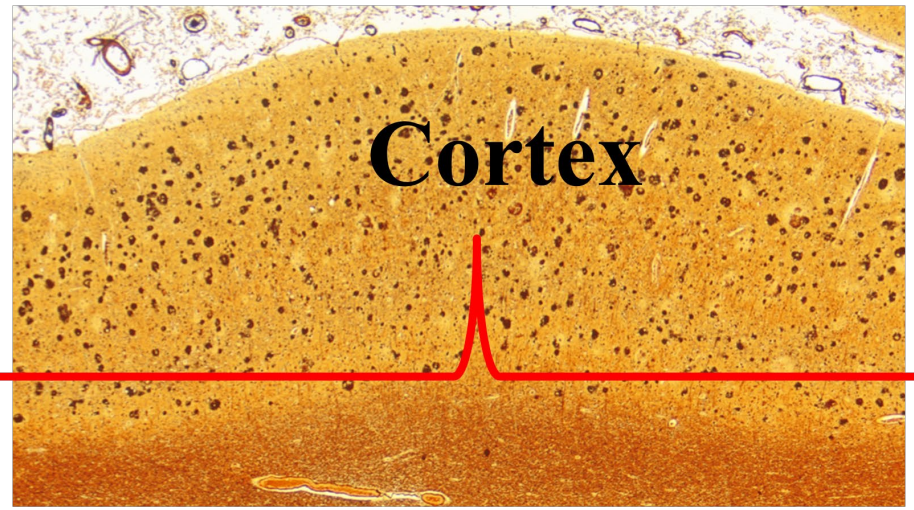
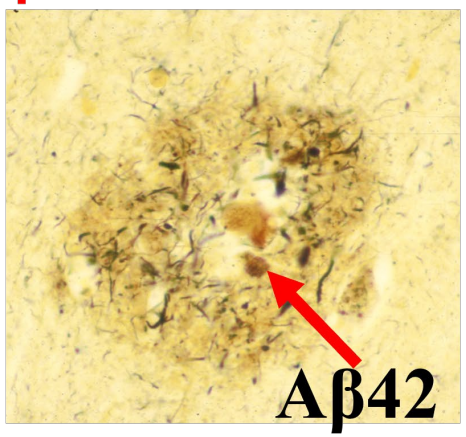
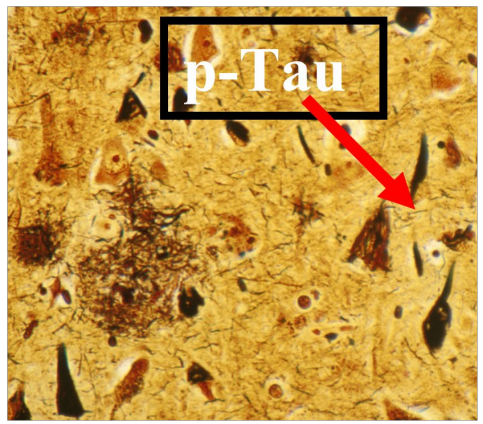
Neuropathology: AD-DS

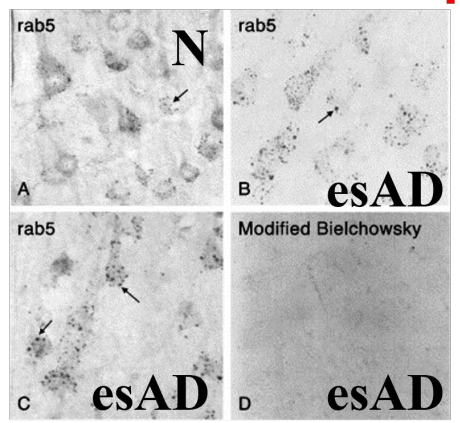




Amyloid plaque



Neurofibrillary tangle



Enlarged Endosome

(Cataldo et al., N'biol Aging, 2004)

DS-AD

- Genetics points to increased APP gene dose as necessary for DS-AD.
  - *Increased APP gene dose in DS-AD*.

    -Prasher et al., 1998

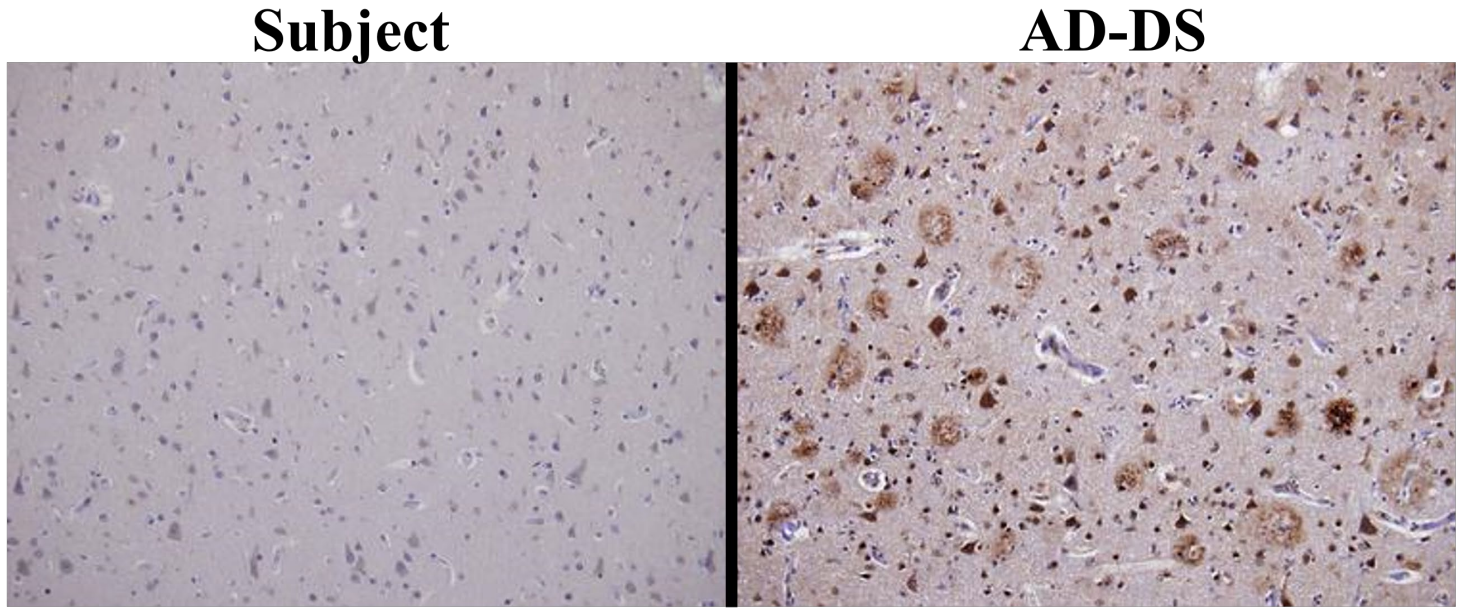
    -Korbel et al., 2009

    -Doran et al., 2016
- Relevant cell biological phenotypes are induced by increased expression of the APP gene.
- The APP gene has several products.

APP Gene Dose in DS: Doran et al., 2017

- Elderly man with DS and partial trisomy of chromosome 21 (pTs21); he had the normal two copies *APP*.
- Between 66–72 years: neuropsych testing, neuro exams, amyloid PET imaging, plasma amyloid-β (Aβ) measurements.
- Intellectual disability was mild. Serial tests showed less than a 3% decline. No dementia.
- PiB-PET scans negative and plasma $A\beta_{42}$ lower than values for demented or non-demented adults with DS.

APP Gene Dose in DS: Doran et al., 2016



- Brain showed a single neuritic plaque; neurofibrillary degeneration consistent with normal aging.
- Findings support obligatory role of APP for DS-AD.

DS-AD

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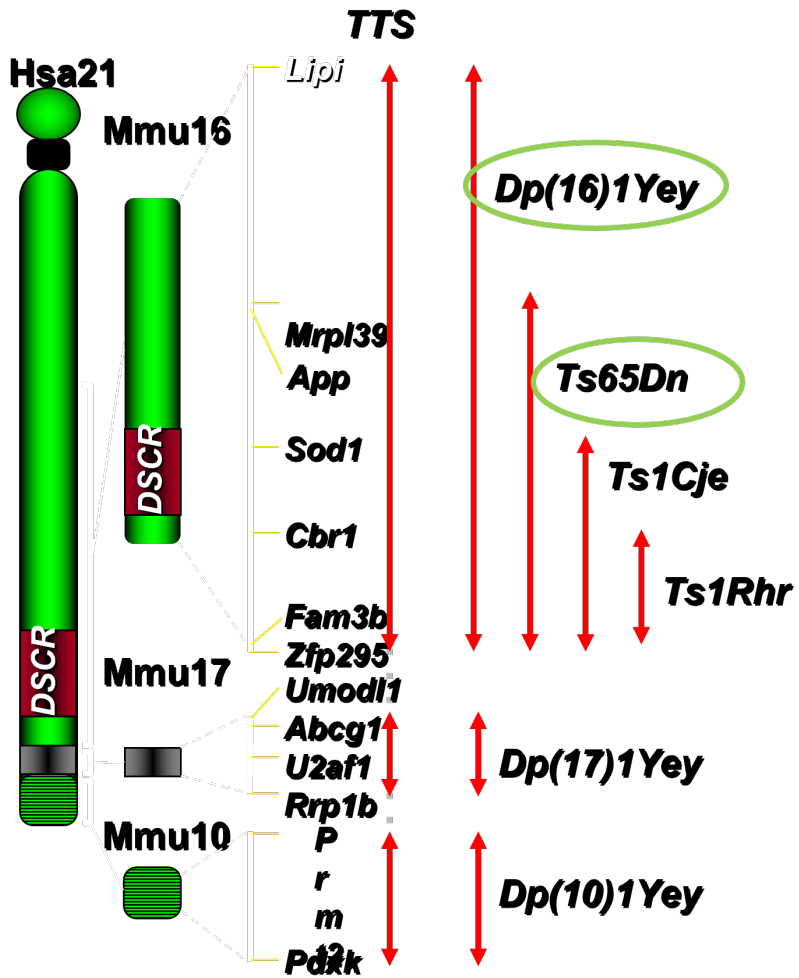
Exploring Pathogenesis in Mouse Models of DS

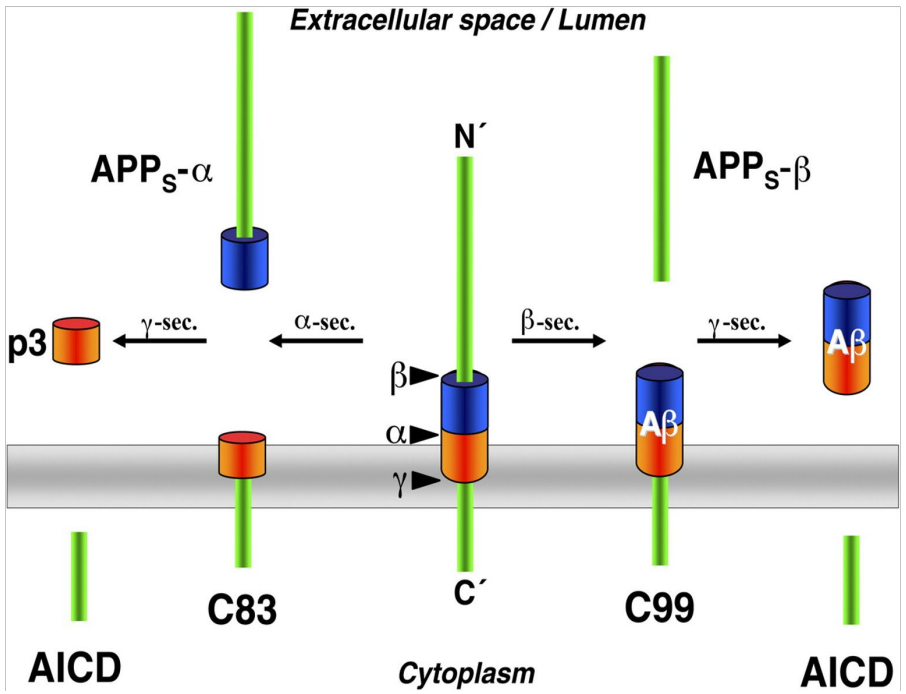


Pathogenesis Studies in Mouse Models

- Increased APP gene dose results in increased levels of APP and its products.
- Dp16 mice show:
  - age-related degeneration of neurons affected in DS – BFCNs, LCNs, ECNs.
  - dysregulation of endosome structure and transport.
  - increased phosphorylation of tau.
- Increased APP dose is necessary for all changes.

APP and its Products

APP Gene → APP mRNA → Fl-APP → APP-CTFs → **Aβ**



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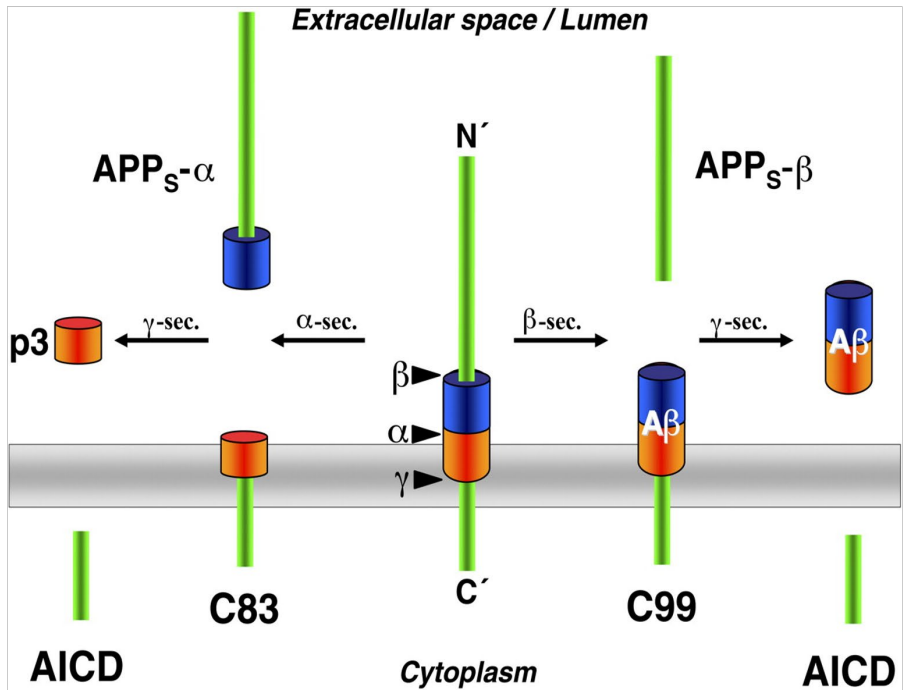

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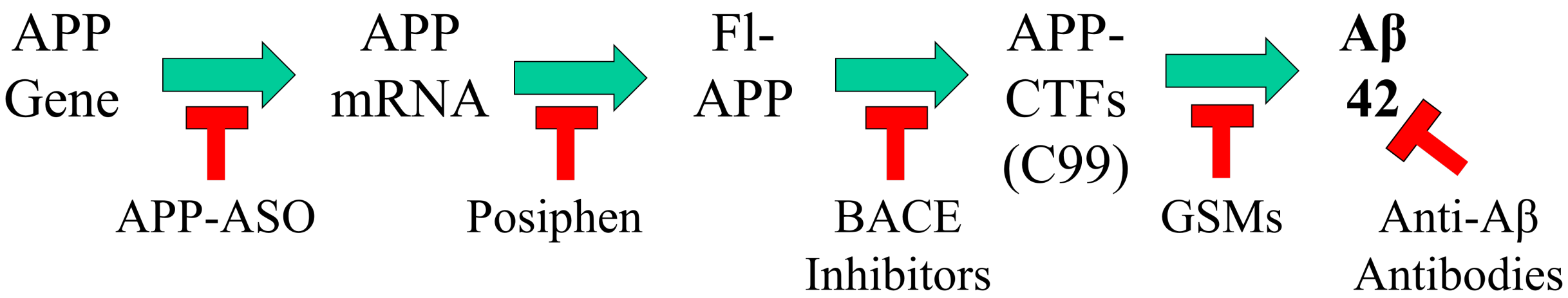
Targeting APP Gene Dose in DS: Several Approaches



Clinical trial networks now established to carry out studies in DS. Use measures to evaluate changes in cognition, function in adults with DS and employ biomarkers used in AD trials.

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Possible Causes of Memory Problems

Condition	Presentation
Sensory deficits	Hearing loss Vision loss, low vision, depth perception changes
Metabolic disturbances	Electrolyte abnormalities Hypoglycemia/hyperglycemia B_{12} or folate deficiencies Undetected thyroid dysfunction Anemia Toxic levels of antiepileptic or psychoactive medications Toxic adverse effects of certain medications (eg, hyperammonemia in chronic valproic acid use)
Coexisting mood disorder	Either newly detected or subacute worsening of baseline mood disorder Note: Depression can cause symptoms that seem similar to dementia

Possible Causes of Memory Problems

Condition	Presentation
Sleep problems	Sleep apnea and other undetected sleep disorders
Seizures	Undetected or worsening seizure disorders
Pain	Undiagnosed pain or undertreated pain
Mobility problems	Mobility disorders and loss of functionality
Psychosocial or environmental stressors	Changes in routines, death or impairment of family members or close acquaintances, new regimen at home or in the workplace, reactions to threatening situations
Others	Conditions that may be associated with cognitive deficit (stroke, chronic subdural hematoma, brain tumors, multiple sclerosis, human immunodeficiency virus, and cryptococcal infection)
Additional considerations: prevalent conditions in adults with Down syndrome	Vision impairment :cataracts and keratoconus

Clinical Care for Adults with DS: Limited Availability

- Specialty centers improve care for patients with DS.
- While the number of adults with DS is increasing, there was unknown capacity for specialty centers.
- Conducted a national survey of staff of specialty clinics, reviewed online clinic listings, and calculated the number of adults with Down syndrome seen.
- Analysis identified the percent of adults with Down syndrome who could have their medical care needs met in a current specialty clinic.

Santoro et al., 2021. Am J Med Genet A

Clinical Care for Adults with DS: Limited Availability

- Fourteen specialty clinics provided care for 4038 DS adults.
- Reported gaps included: limitations of existing clinics, need for additional clinics, and health professionals with expertise in DS.
- Survey-respondent clinic capacity would meet needs of only 3% of adults with DS.
- Online data for twenty-five adult DS clinics indicated capacity to care for 6517 adults with DS, meeting the needs of only 5%.

Santoro et al., 2021. Am J Med Genet A

Clinical Care for Adults with DS: Conclusions

- Additional clinic capacity is needed to meet the needs of adults with DS.
- Survey of existing clinics provides guidance to create additional clinics, including: must-have team members, current sources of clinic financial support, and gaps in current clinical care.
- Creating a more robust clinical care network is essential for meeting the needs of adults with DS.
- This is especially urgent given the impact of Alzheimer disease in this population and the oncoming era of effective treatments.

Overview

- Adults with Down syndrome (DS) face many health challenges.
- The most significant is Alzheimer disease (DS-AD).
- An extra copy of the gene for APP is necessary for DS-AD.
- Recent advances enable future trials to prevent DS-AD.
- It is essential to enhance health care services for the care of adults with DS and to equip them to deliver treatments proven safe and effective for preventing DS-AD.

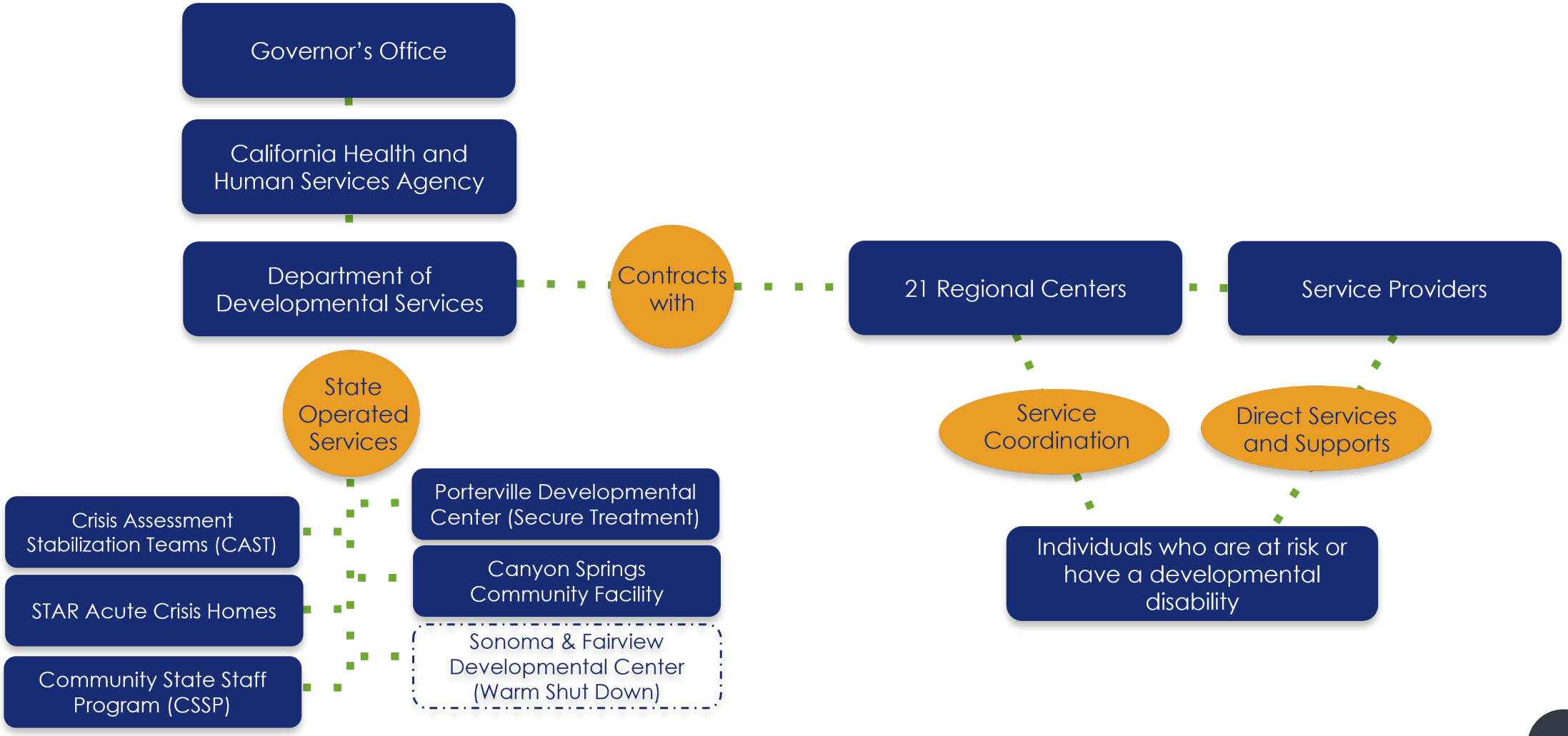
Alzheimer's Disease and Related Disorders Advisory Committee

Dr. Lucy Esralew, Senior Psychologist Supervisor
Office of Statewide Clinical Services

December 8, 2022

Department of Developmental Services

System Organization



DDS Vision

*People with intellectual and developmental disabilities experience **respect** for their culture and language preferences, their choices, beliefs, values, needs, and goals, from a **person-centered** service system made up of a network of community agencies that provide **high quality, outcome-based** and **equitable services***

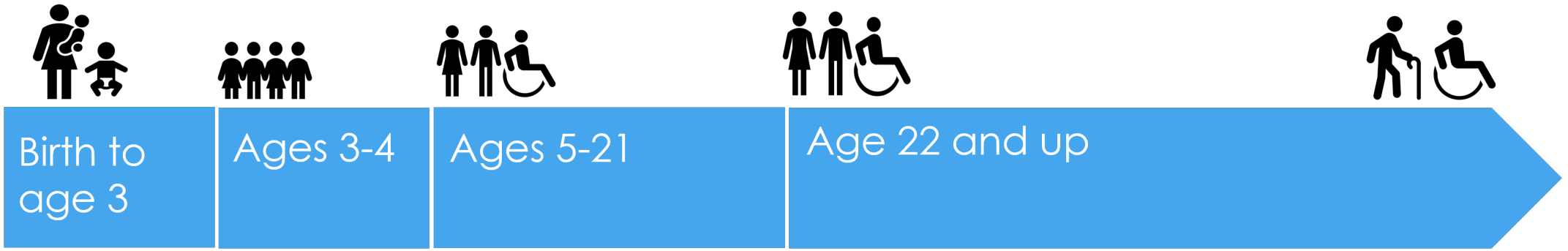
Eligibility for Lanterman Act Services

California law defines developmental disability as disability that originates prior to age 18, is expected to be lifelong, and constitutes "substantial disability" for that person

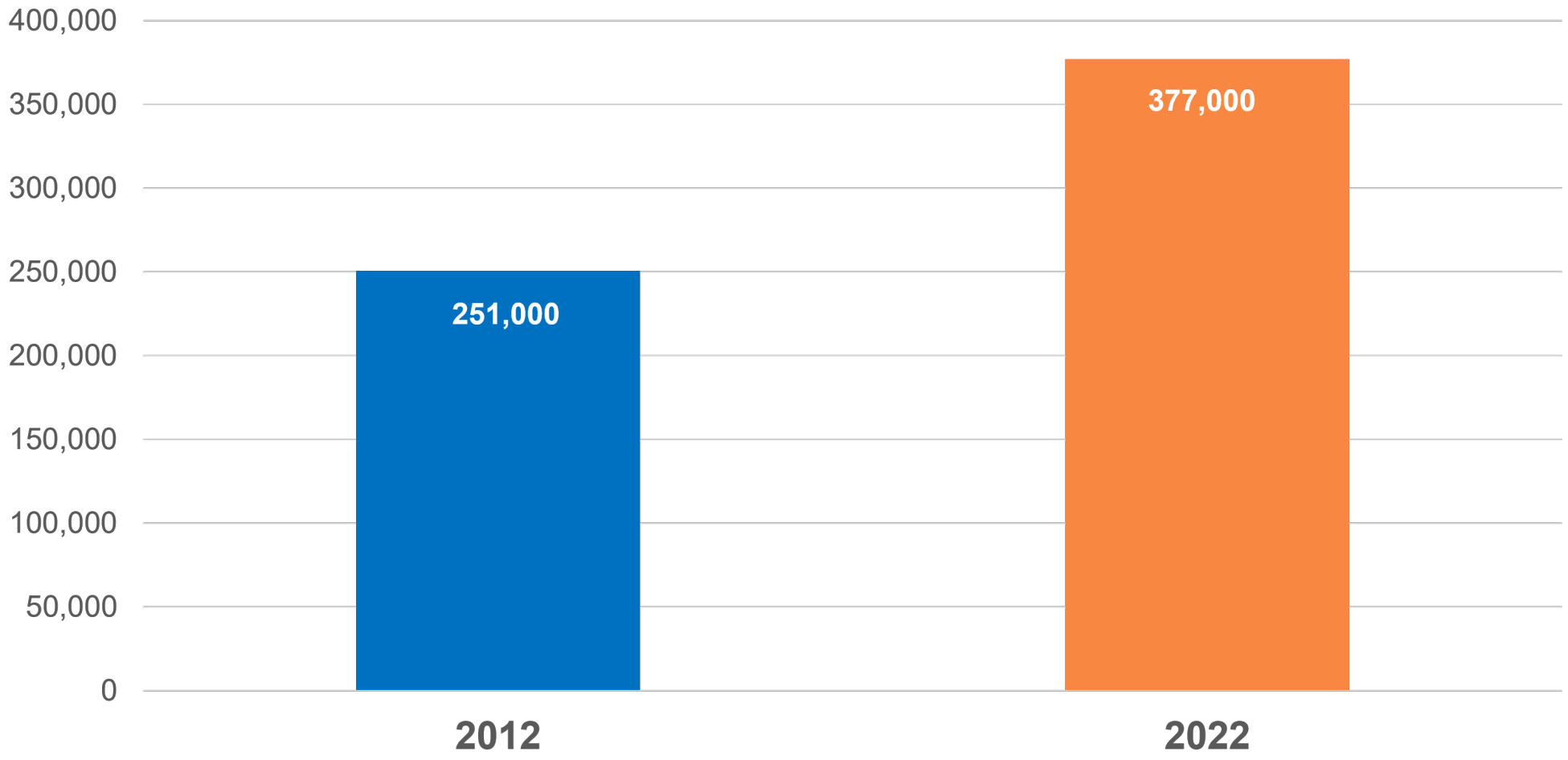
Categories that qualify a person for Lanterman Act services include intellectual disability, autism, epilepsy, cerebral palsy, and/or other disability that closely resembles ID and/or individual requires similar services

Lanterman Developmental Disabilities Services Act

Supporting Individuals Across the Lifespan

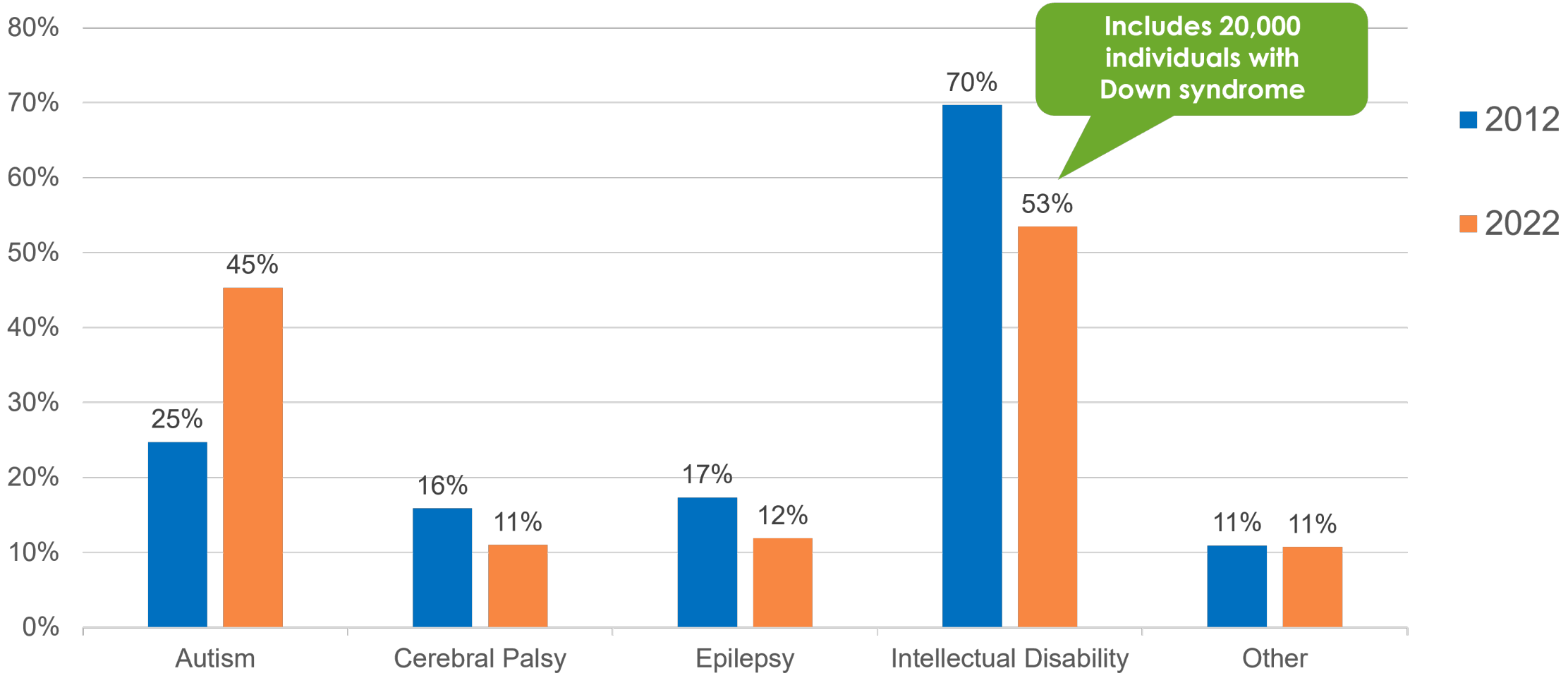


Consumer Population – 10 year view



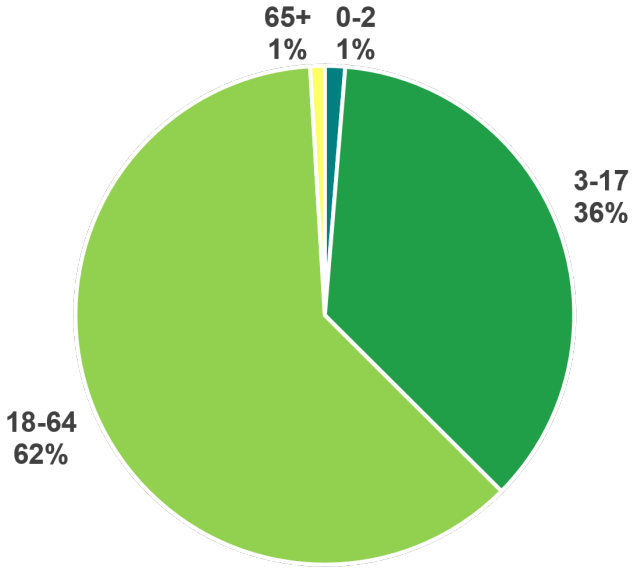
Includes Early Start (0-2) and Lanterman (3+)

Consumer Population by Diagnoses – 10 year view

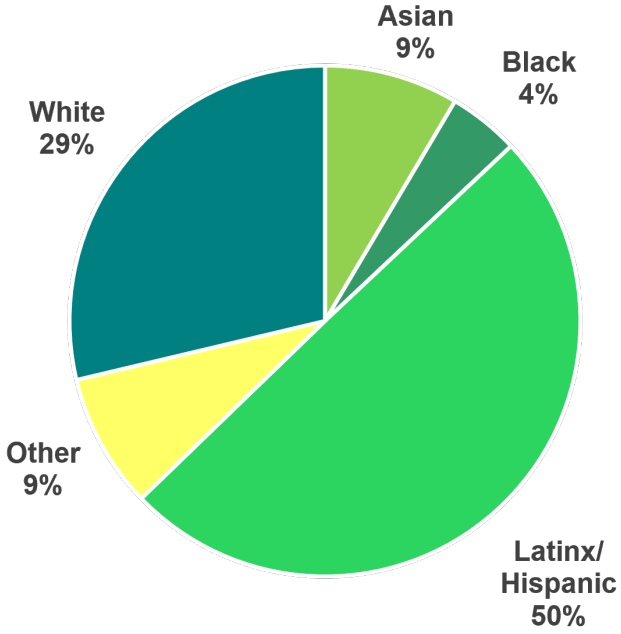


Regional Center Consumers with Down Syndrome

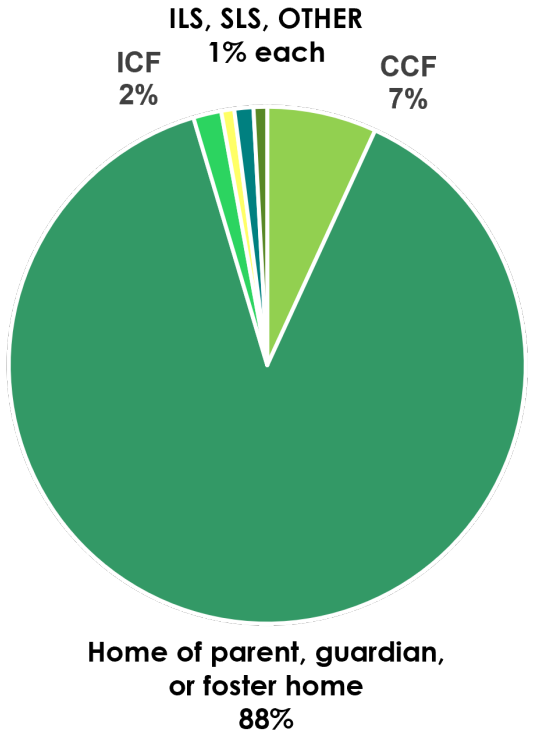
AGE



ETHNICITY



RESIDENCE TYPE



ICF: Intermediate Care Facility
ILS: Independent Living Service
SLS: Supported Living Services
CCF: Community Care Facility

Down Syndrome

- The most frequently occurring chromosomal disorder and the leading cause of known genetic intellectual and developmental delay
- Most individuals with Down syndrome lead typical lives in their communities
- Individuals with Down syndrome are living longer, leading to increase in population over the next 20 years
  Average life expectancy in 1980s was only age 28 and in 2020 was age 60
- Longer life expectancy increases risk for certain conditions of older adults
- Approximately 50% of persons with Down syndrome have a congenital heart defect, increases risk for early onset dementia
- More likely than their non-Ds peers to exhibit "accelerated aging" during ages 40-50

Down Syndrome and Alzheimer's Disease

- Chromosome 21 plays a key role
- Approximately 70-90% of older individuals with Down syndrome will eventually develop Alzheimer's Disease and/or a related disordered
- Individuals with Down syndrome are at higher risk for Alzheimer's disease after age 50
- Individuals with Down syndrome may exhibit signs of Alzheimer's disease in their late 40's
- Signs of Alzheimer's Disease are apparent approximately 20-25 years before the average age of onset in the population without I/DD
- Decrease in functioning progresses more quickly

DDS Initiatives

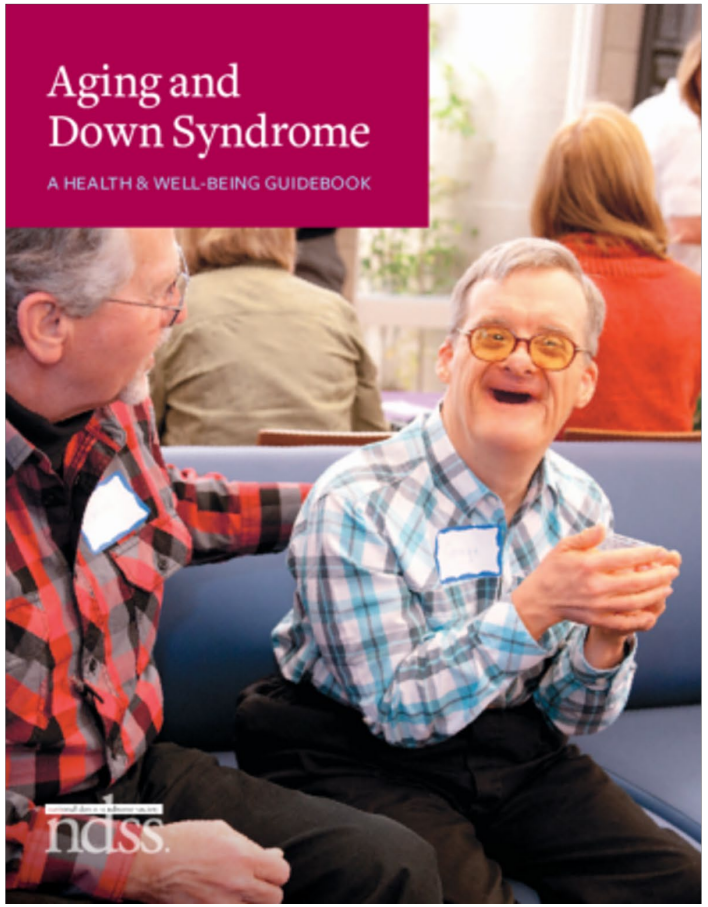
Aging Inclusion Specialist

- Leadership and subject matter expertise
- Inform on and develop policies, resource materials, trainings and supports consistent with the Lanterman Act, Governor Newsom's Master Plan for Aging, and other federal and state statutes and regulations

Coordinated Family Supports

- New service model to provide supports to adults living in their family homes
- Improve service equity and meet evolving needs of adults and their families without having to move from the family home (supports aging in place)
- Pilot beginning in 2023

Information



Aging and Down Syndrome: A Health & Well-Being Guidebook

National Down Syndrome Society (NDSS)

Resources & Links

- Lanterman Act and Related Laws - CA Department of Developmental Services
- Laws & Regulations - CA Department of Developmental Services
- Regional Center Map
- Regional Center Lookup Tool
- Regional Center Eligibility & Services
- Regional Center Services & Descriptions (available in multiple languages)
- Resources for Families, Parents & Caregivers
- Family Resources Centers Network of California
- Stakeholder Events
- Developmental Services Task Force

Thank you!

www.dds.ca.gov

info@dds.ca.gov

Dementia in Intellectual/Developmental Disabilities (I/DD) at San Andreas Regional Center

A Snapshot

Health Services Unit

Lisa Rund, RN Health Services Associate Coordinator

lrund@sarc.org 408-341-3885

The Lanterman Act

The Lanterman Developmental Disabilities Services Act of 1969 established eligibility requirements and outlines how regional centers work

It says people with I/DD have a right to services and supports to help them live the most independent and productive lives possible in the least restrictive environment

Regional Centers are private, non-profit community agencies

For individuals, the RCs:

- Diagnostic assessment
- Determine eligibility for services
- Facilitate Individualized Family Service Plan (IFSP) ***Birth through 2***
- Facilitate Individual Program Plan (IPP) ***3 years & older***
- Service coordination
- Authorize funding of services, when generic resources are unavailable

For their communities, the RCs:

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

What services are provided and how it works

- Regional Centers (RC) provides service coordination and develops an individual program plan (IPP) with the individual and their planning team
- After generic resources have been explored and exhausted, service providers who are "vendored" with the RC may be identified to meet the needs of the individual
- The RC authorizes services for the individual and payment to vendored service providers
- Services may include family respite, adult day programs, employment supports, residential services, and transportation, among others

San Andreas Regional Center

- Serves about 18,000 people with I/DD of all ages
- Covers 4 counties: Santa Clara, Santa Cruz, Monterey, San Benito
- Works with community partners to support individuals to access generic resources and other specialists for dementia care
- Working to build internal resources through education and information
- Looking to broaden and elevate the education outside the RC for the benefit of the people served by SARC

www.sanandreasregional.org

Importance of education, information, building partnerships

- Internally to SARC Service Coordinators
- Vendored service providers in all settings, including families
- Health care providers- individual cases as well as outreach from SARC to Social Work and Case Management departments in hospitals, SNFs, subacutes, and FHCs (federally qualified health clinics)
- Other agencies such as Medi-Cal managed care plans, social services, local law enforcement
- Parents Helping Parents, a local organization that provides support and education for families of people with I/DD

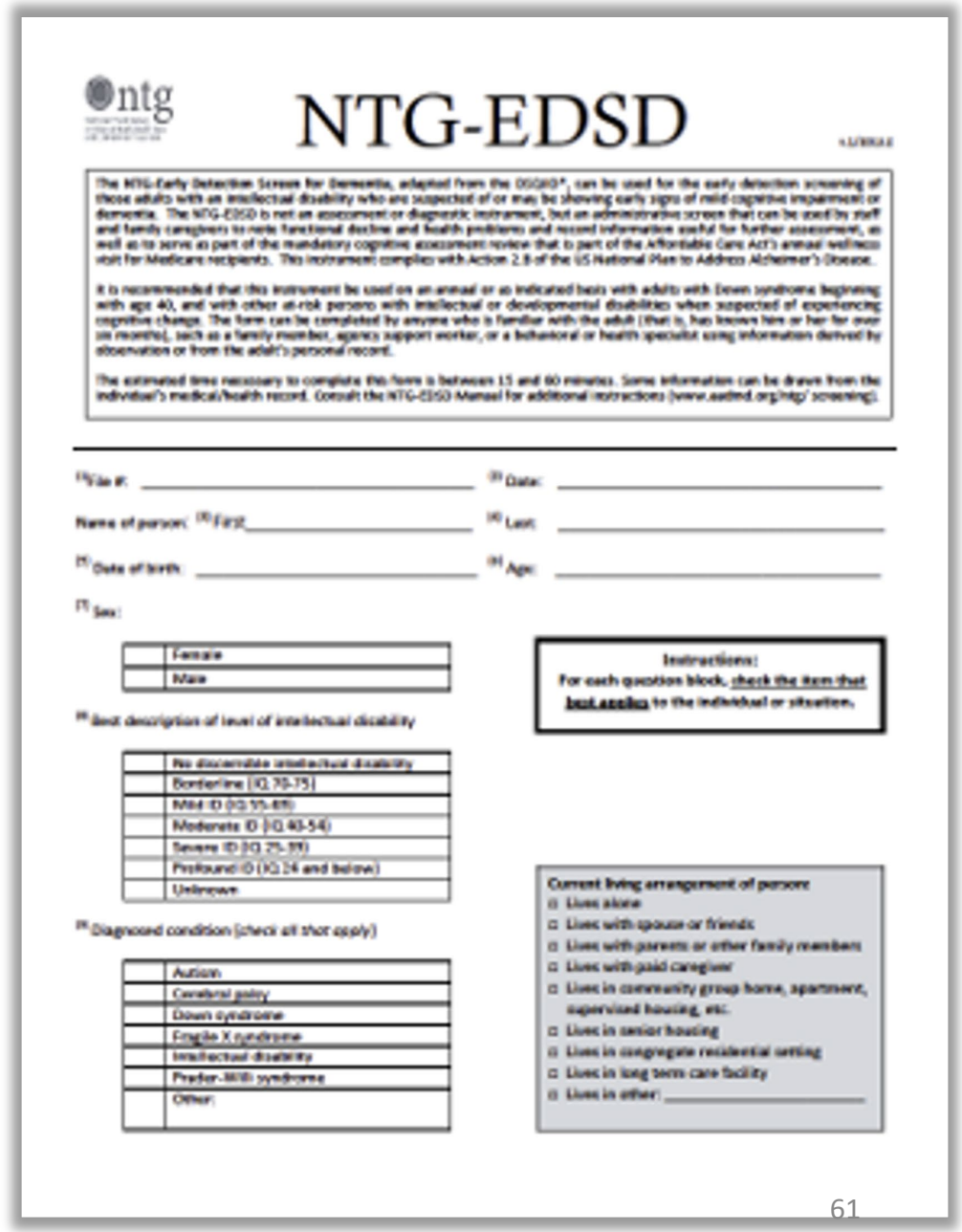
What we teach

- Importance of knowing the individual's baseline state of being so that changes are observed, reported, and documented
- Early identification of observed changes allows for correct diagnosis to be made by the professional
- Define key terms: dementia, DD, ID, MCI, normal aging
- Different types, stages of dementia
- Signs of dementia, diagnosis, treatment
- Providing care through the stages

We now have a tool to look at decline in people with ID/DD

Early
Detection
Screen for
Dementia

https://www.the-ntg.org/ntg-edsd



ntg

NTG-EDSD

The NTG-Early Detection Screen for Dementia, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/screening).

[1] File #: _____ [2] Date: _____

Name of person: [3] First _____ [4] Last _____

[5] Date of birth: _____ [6] Age: _____

[7] Sex:

	Female
	Male

Instructions:
For each question block, check the item that best applies to the individual or situation.

[8] Best description of level of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

[9] Diagnosed condition (check all that apply)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

Current living arrangement of person:
- ☐ Lives alone
- ☐ Lives with spouse or friends
- ☐ Lives with parents or other family members
- ☐ Lives with paid caregiver
- ☐ Lives in community group home, apartment, supervised housing, etc.
- ☐ Lives in senior housing
- ☐ Lives in congregate residential setting
- ☐ Lives in long term care facility
- ☐ Lives in other: _____

Person-Centered Planning

- Must tailor care to meet the needs of the individual, to enter THEIR reality
- These needs and abilities change as time goes on, sometimes unpredictably
- This requires us to be educated, trained, flexible, and creative in our approach

For More Information

- Alzheimer's Association e-learning
  http://www.alz.org/care/alzheimers-dementia-care-training-certification.asp#elearning
- UCLA resources and video series for caregivers
  https://www.uclahealth.org/medical-services/geriatrics/dementia/patient-resources
- National Institute on Aging
  https://www.nia.nih.gov/alzheimers/topics/alzheimers-basics
- National Task Group on Intellectual Disabilities and Dementia Practices
  Caring for a Family Member with ID and Dementia (the-ntg.org)

Thank you for this opportunity to advocate for an often-overlooked segment of the population in California. Your time and attention is appreciated, as well as your efforts for inclusion at all levels.

Noah Homes and

ActivCare Living:
A Special Memory Care

Partnership

ActivCare® LIVING
Residential Memory Care

NOAH HOMES®

Establishing a Collaborative Partnership

- In November 2021, ActivCare Living set out on a mission to address the shortage of Memory Care options for adults with intellectual and developmental disabilities.
- This will offer a pathway to those with Down syndrome and dementia to live in one of **two** ActivCare communities in San Diego County.

Noah Homes and ActivCare Living:

A Collborative Partnership

The below text was pulled from both organizations' websites.

ActivCare® Living
Residential Memory Care

"We cherish our residents and strive to bring fulfillment to their lives daily. **To provide meaning and purpose each day, we build a routine and provide an environment where they can be successful.**

The ActivCare program of structured activities i**s designed to maintain the highest possible functioning level of each resident while enhancing their self-esteem**."

Noah Homes®

"Our goal is to **maximize each individual's independence in a community environment that fosters dignity and respect, as well as personal and spiritual growth.**

Noah Homes is an oasis of peace as well as a hub of activity, offering residents continued opportunities for personal growth and fulfillment."

ActivCare Living: A History

- Recognizing the need for a specialized memory care community, the first ActivCare was opened in 1988 in California with assistance from Alzheimer's disease specialists and family caregivers.
- For more than 30 years, ActivCare has led the industry in providing personalized memory care and enhancing the quality of life for its residents and their families.

ActivCare Living: A Future

- Now, ActivCare is once again expanding its mission to enhance the quality of life for those with memory loss and embrace an underserved population affected by dementia – individuals with intellectual and developmental disabilities, particularly Down syndrome.

- This is an opportunity to further strengthen our innovative care practices, expand our connections with other leaders in our field, and provide even more ways for those living in their communities to feel useful and have a greater sense of belonging.

Visiting ActivCare Rolling Hills Ranch

- Noah Homes toured an ActivCare Living location for the first time over three years ago, and we were truly impressed with what we observed.
- It is a beautiful inclusive community with **dedicated caregivers** who **encourage residents to engage in activities and programs that help stimulate cognitive functioning and increase self-confidence, much like Noah Homes!**

ActivCare in Action: Virtual Tour of ActivCare Rolling Hills Ranch

Please click image to view video.

The Folks Meet New Friends

So, what's going on now?

(Continued)

ActivCare's first new resident

Please click image to view video.

- Our first residents moved into ActivCare 4S Ranch on August 1 and ActivCare Rolling Hills Ranch on September 1.
- Currently, 3 residents in total are living in ActivCare communities.
- A total of 40 accommodations are available in San Diego County.

So, what's going on now?

Teri is enjoying her new home!

Population We Serve

Individuals with intellectual and developmental disabilities who can still benefit from our social programs and:

- Have a diagnosis of dementia and/or cognitive decline, or
- Are inappropriately placed in skilled nursing facilities, or
- Are living at home with family who can no longer provide appropriate care and support, or
- Exceed Level 3 care who may require additional safety features and nursing support

THANK YOU!

ActivCare® LIVING
Residential Memory Care

ActivCare 4S Ranch

10603 Rancho Bernardo Road

San Diego, CA 92127

(858) 485-8001

ActivCare Rolling Hills Ranch

850 Duncan Ranch Rd

Chula Vista, CA 91914

(619) 482-8000

NOAH HOMES®

Marc Loupe – Family Caregiver's Experience

California Department of AGING

Down Syndrome and Alzheimer's Disease – Discussion & Public Comment

Facilitated by
Catherine Blakemore
Committee Chair
Family Caregiver Representative

Public Comment

Attendees joining by webinar (Zoom), use the Q&A function to ask a questions or select the raise hand icon. The moderator will announce your name and will unmute your line.

Attendees joining by phone, *press *9* on your dial pad to "raise your hand." The moderator will announce the last 4 digits of your phone number and will unmute your line.

Break

The meeting will resume at 12:20pm

Alzheimer's Plan Updates

Susan DeMarois

Director

California Department of Aging

Our Path Forward: Final Report Issued November 2020

Recent Activities

- Recognition of National Alzheimer's Disease Awareness and Family Caregivers Months
- ACL grants received – CAlz Connect and No Wrong Door
- Cal-COMPASS awards
- CalGrows Innovation Fund applications
- MHSOAC Older Adult Behavioral Health
- ADRC Advisory Committee
- American Society on Aging

Alzheimer's Plan Update: California Community Program for Alzheimer's Services and Support (Cal-COMPASS)

Michelle Johnston

Program Director, Dementia Initiatives

California Department of Aging

Cal-COMPASS Pilot Project Overview

- **Purpose**: Support existing licensed Adult Day Programs and Adult Day Health Care centers in providing dementia-capable services to prevent institutionalization and advance health equity.
- **Total budget**: $4.5 million + $300,000 for evaluator
- **Award amounts**: $350,000 - $750,000 per awardee
- **Timeline**: Nov. 2022 – Dec. 2023

Cal-COMPASS Goals

Provide dementia capable, person-centered support for persons living with Alzheimer's or other dementias and their caregivers

- Leverage state and local partnerships/initiatives
- Create a statewide learning community
- Implement best practices and test strategies
- Build Alzheimer's and dementia-capable care providers
- Create uniform measures and evaluate outcomes
- Ensure that services meet the needs of communities disproportionately impacted by dementia

Goals Identified by Proposers

- Increase persons served
- Enhance programs
- Staffing, training and workforce development
- Assessment, evaluation and documentation
- Caregiver education and support

Cal-COMPASS Awardees

Organization	License Type(s)	County
Alzheimer's Family Center	ADHC	Orange
Choice In Aging	ADHC/ADCRC	Contra Costa
City of Sacramento, Triple R Adult Day Centers	ADP/ADCRC	Sacramento
Collabria Care	ADHC/ADP/ADCRC	Napa
Hearts and Minds Activity Center	ADP/ADCRC	Santa Clara
Innovative Health Care Services (Peg Taylor Center for ADHC)	ADHC/ADCRC	Butte
OPICA ADP & Counseling Center	ADP	Los Angeles

ADHC – Adult Day Health Care; ADP – Adult Day Program; ADCRC – Adult Day Care Resource Center

Cal-COMPASS Next Steps

- Learning Community has begun to meet
- Reviewing ADCRC materials
- Contracting with outside evaluator
- Finalizing set of deliverables for new model
- Dividing into workgroups

Alzheimer's Plan: CAlz Connect Update

Tanya Bautista

Bureau Chief, Supportive Services

California Department of Aging

Calz Connect Overview

Funding

Administration for Community Living (ACL), Alzheimer's Disease Program Initiative (ADPI) grant for state entities

Objectives

- Create and sustain a dementia-capable home and community-based services system for people living with Alzheimer's disease and related disorders and their caregivers, using a no wrong door (NWD) approach.
- Ensure access to a comprehensive, sustainable set of quality services/interventions that are dementia-capable and provide innovative services to people with dementia and their caregivers.

Project Partners

Pilot counties

- Ventura (Area Agency on Aging)
- Marin (Center for Independent Living)
- Imperial (Area Agency on Aging)

Additional partners

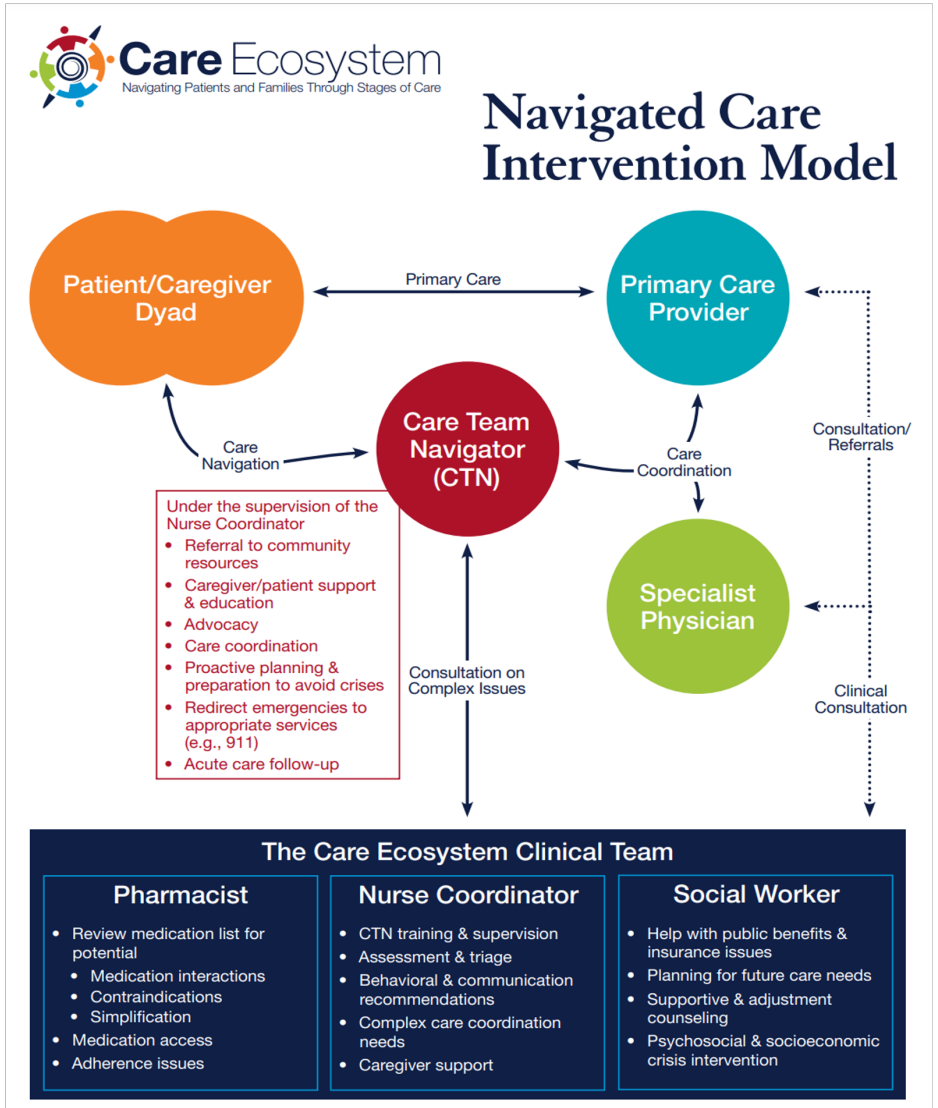
- Clinical supervision (nursing, social work and medication management)
- Evaluator

Approach

Offer UC San Francisco's evidence-based Care Ecosystem program outside of a healthcare setting

- Staffed by bilingual Community Health Workers trained as Care Team Navigators (CTNs)
- CTNs provide specialized dementia education, work with the family to develop a plan of care, connect families with community services/supports, and aid in care transitions
- Contract for clinical supervision

UCSF's Care Ecosystem Model



Source: UCSF Care Ecosystem, https://memory.ucsf.edu/research-trials/professional/care-ecosystem

Approach (continued)

Pilot a dementia-capable Consumer Navigation Contact Center

- Promote to health care system (community clinics, hospitals, doctors, health plans), especially Medi-Cal providers
- Help bridge the divide between medical and social services – more person-centered
- Increase accessibility and equity amongst the communities hardest hit by dementia

Project status: planning stage

Desired Outcomes

- **Person-level**: improve the quality of life for individuals living with dementia and decrease caregiver burden.
- **System level**: development of dementia capacity in California's project sites, and eventually throughout California's NWD system.
- **Sustainability goals**:
  - Adopt the piloted Contact Center as an established, sustainable community resource throughout California.
  - Ensure best practice resources that will inform related statewide dementia-capable No Wrong Door systems and programs.

Alzheimer's Plan: California Department of Public Health Updates

Lauren Groves

Chief, Chronic Disease Control Branch

Center for Healthy Communities

California Department of Public Health

Report to the California Health and Human Services Agency Alzheimer's Disease and Related Disorders Advisory Committee

Lauren Groves, MPH, Chief
California Department of Public Health
Chronic Disease Control Branch
Alzheimer's Disease Program

California Alzheimer's Disease Centers

- Improve dementia health care delivery - provide specialized training and education to health care professionals
- Advance the diagnosis and treatment of ADRDs
- $281,000/Year/Center

California Healthy Brain Initiative

- Advance cognitive health as an integral component of public health
- Implement the CDC Healthy Brain Initiative 2018-2023 Road Map
- $10 Million over 3 years – Two Cohorts

California Research Projects

- Scientists engaged in the study of Alzheimer's disease and related disorders

- Encompasses areas of basic science, diagnosis, treatment, epidemiology, health disparities, behavioral management, drug therapies and caregiving

- $8.7 Million – 7 2022 Projects

Public Awareness Campaign

- Vendor Proposals in Review
- Campaign:
  - Focused on public education
  - Addressing Signs and Symptoms
  - Target At Risk Populations
  - Multilingual, multicultural, and intergenerational
- $8.5 million expected to be funded

Dementia Friendly Communities

- Focus on prevention of dementia
- Long-term, place-based interventions to support healthy behaviors
- Blue Zone County Pilot
- $1.7 Million dollars

Caregiver Training Program

- Focusing on unpaid family caregivers
- No cost, online, multi-lingual
- Includes partnership with local community organizations
- $3.4 million between northern and southern CA

Standards of Dementia Care

- Standard of Dementia Care Model
  - Public Health Risk Reduction
  - Post Diagnosis Resources for Providers
- Risk Calculator
- $3.825 Million

State Dementia Services Coordinator Summit

- Hosted by Alzheimer's Association
- October 25-26, 2022
- Washington DC

ALZHEIMER'S® ASSOCIATION

- Importance of establishing a State government response to Alzheimer's
- The future of Alzheimer's treatments
- The Public Health approach to Dementia
- Supporting Caregivers

Questions?

Alzheimer's Disease Program, CDCB, CDPH

AlzheimersD@cdph.ca.gov

2023 Meeting Schedule & Topic Ideas

Catherine Blakemore

Committee Chair

Family Member Representative

2023 Meeting Schedule

February 2, 2023

May 4, 2023

August 3, 2023

November 2, 2023

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10 am – 2 pm

Finalization of Recommendations & Items for CalHSS Secretary

Catherine Blakemore

Committee Chair

Family Member Representative

Public Comment

Attendees joining by webinar (Zoom), use the Q&A function to ask a questions or select the raise hand icon. The moderator will announce your name and will unmute your line.

Attendees joining by phone, *press *9* on your dial pad to "raise your hand." The moderator will announce the last 4 digits of your phone number and will unmute your line.

Closing Comments & Next Steps

Catherine Blakemore

Committee Chair

Family Member Representative

Thank you!

CalHHS
California Health & Human Services Agency

CALIFORNIA ALL

Visit the CalHHS Alzheimer's Disease & Related Disorders Advisory Committee webpage for:

- More information about the Committee
- Upcoming meeting dates
- Presentations, recordings, and transcripts of past meetings