



Report on the

Needs of Aging Caregivers of Persons with Intellectual and Development Disabilities (I/DD) in Yolo County

Yolo County Commission on Aging and
Adult Services in collaboration with Alta
California Regional Center

Many Thanks to...

Supervisor Jim Provenza, Chair, Commission on Aging and Adult Services (CAAS)

Yolo County Commission on Aging and Adult Services (CAAS)

Members of the Ad Hoc Committee on Aging Caregivers of Persons with I/DD

- Seth Brunner (co-chair) Yolo County CAAS member
- Mary Nisson (co-chair) caregiver of person with I/DD
- Laurie Haas, Yolo County CAAS member and Manager Yolo County Public Guardian
- David Nisson person with I/DD
- John Decker, Director of Community Services and Supports, Alta California Regional Center (ACRC)
- Sydney Ruport, Community Services and Supports Specialist, Alta California Regional Center (ACRC)
- Ian Evan, Executive Director Yolo County Housing Authority
- Sheila Allen, Deputy to Supervisor Provenza and staff to Yolo County CAAS

Introduction

The purpose of the Yolo County Commission on Aging and Adult Services:

- Reviews and makes recommendations on specific issues and policy questions, relating to the aged, disabled, or other adults needing the protection of authority and state;
- Serves as the County's policy liaison to the Area 4 Agency on Aging;
- Reviews, considers, develops and advances plans for Board of Supervisors' consideration for better coordination of County resources devoted to the aged, disabled and other adults needing the protection of authority and state.

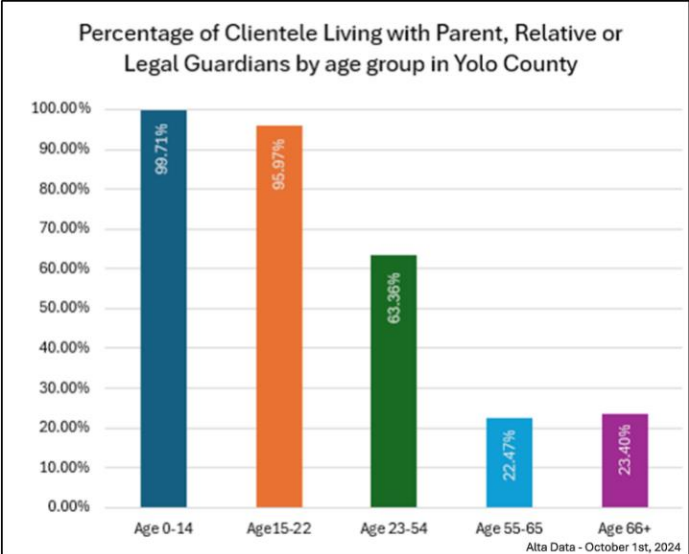
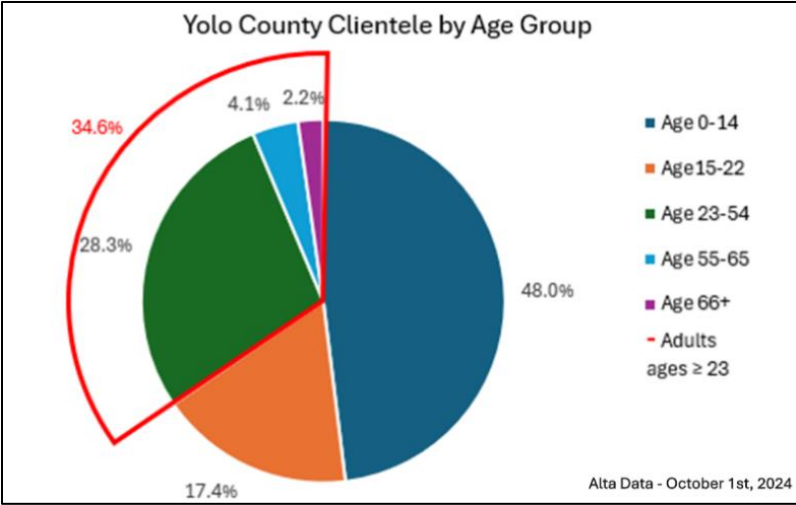
While much work has been done over the years on issues related to aging there has been a renewed focus on the similar and additional needs of persons with disabilities. The commission received public comment, followed by a presentation in February of 2022 from a local mother of a person with an intellectual disability. The comment and presentation highlighted the need to address both the challenges faced by aging caregivers of persons with I/DD and the need for affordable, supportive housing for persons with I/DD. The presentation led to the appointment of an Ad Hoc Committee to receive community input through a series of virtual and in-person meetings throughout Yolo County to hear about the needs of both caregivers, and those living with I/DD. This report summarizes the work of this Ad Hoc Committee and provides recommendations for actions to address these needs.



Winters Community Aging
Caregivers Townhall

Background

Alta California Regional Center (ACRC) operates as a not-for-profit organization under contract with the California Department of Developmental Services. Its primary role is to determine eligibility and coordinate services for individuals with developmental disabilities, as outlined by the Lanterman Act. Throughout 10 Northern California counties, ACRC serves over 32,000 clients and their families. Within Yolo County, there are more than 2,100 ACRC clients. There are around 730 adult clients over the age of 23 living in Yolo County, comprising nearly 35% of the total ACRC Yolo County clientele. Out of the approximate 730 individuals, about 410, or around 56%, of them live with a parent, relative, or legal guardian.



Adults with I/DD who depend on family for much of their care and safety are at risk if these caregivers are no longer available. Alta Regional Centers recognize this issue and have started to take a closer look at addressing it. John Decker, Director of Community Services and Supports for ACRC notes, “Adults with I/DD have significant support needs and most frequently live with family caregivers. Research shows that planning team meetings, coordinated by I/DD professionals, are not resulting in functional plans that prepare adults with I/DD for the inevitable loss of their primary caregiver. When that caregiver dies or is incapacitated the adult with I/DD becomes **homeless**”.

In June of 2021, ACRC held a virtual public information meeting to introduce the **Coordinated Future Planning Initiative**. This initiative seeks to enhance housing stability and prevent homelessness for adults with intellectual and developmental disabilities (I/DD) who are living with elderly caregivers. The number of adults with I/DD aged 60 and older in the US is projected to dramatically increase in the coming years, rising nationally from 640,000 in 2010 to 1.2 million by 2030. The goal of the Coordinated Future Planning Initiative is to train Alta staff to work with families and clients at an annual visit to create and transcribe a plan for if a caregiver is no longer available.

Issue Brought to Commission on Aging and Adult Services

Meeting of the Yolo County Commission on Aging & Adult Services
February 2, 2022

The Crisis of Aging Parents Still Caring for Adults with Intellectual Disability and/or Developmental Disabilities (I/DD)

Mary Nisson

"Family Advocate" (Parent of a Yolo County Adult with Developmental Disabilities)
Founder, *Developmental Disability Future Planning Groups – Yolo County (DDFP-Yolo)*
Founder, *Developmental Disability Future Planning Group – California*

The issue of aging caregivers for individuals with I/DD is a relatively new problem. Up until the latter part of the 20th century, the usual practice was to place individuals with intellectual and developmental disabilities in institutions. Families having a child with such disabilities were frequently recommended to admit them to state-run hospitals or other specialized establishments instead of caring for them within their own homes. However, following years of advocating for deinstitutionalization, most individuals with I/DD currently reside within the community. On February 2, 2022, Yolo County resident and parent of an adult child with I/DD, Mary Nisson, presented to the Yolo County Commission on Aging & Adult Services addressing the issues of local aging caregivers.

Ad Hoc Committee Creation and Key Findings

The Yolo County Commission on Aging and Adult Services formed an I/DD Ad Hoc Committee which included representatives from the Commission on Aging and Adult Services, ACRC and Ms. Nisson and her son. The mission of this ad hoc committee was to convene town hall meetings throughout Yolo County aimed at better understanding the issues that are affecting the community, particularly the issue of aging caregivers of individuals with I/DD and discussing opportunities to address these issues.

During the February 22, 2022, Yolo County Board of Supervisors Meeting, Supervisor Jim Provenza reported to the full Yolo County Board of Supervisors on the moving presentation from Mary Nisson and the creation of the I/DD Ad Hoc Committee. Supervisor Provenza announced that the Yolo County Commission on Aging and Adult Services would report back to the full Board on this topic with recommendations for action.

Town Hall Meetings

Each town hall included a brief introduction of the Yolo County Commission on Aging and Adult Services and the purpose of the Ad Hoc Committee on Aging Caregivers of Persons with ID/DD. The local representative of the Board of Supervisor, Adult Regional Services and Yolo County Housing were present to directly hear the community input and to directly answer questions.

The first town hall meeting was held in **Davis on April 19, 2023**. Participants attended in person and online. The meeting was attended by parents/caregivers of people with I/DD, employees of local social services, service providers, members of local advocacy groups, numerous adult Yolo County residents with I/DD, committee members and Supervisor Provenza. There were several recurring concerns that community members brought up throughout the meeting:

- Proper housing for the individual with I/DD throughout their lifetime and once the caregivers have passed on.
- Alternative housing models such as grouped housing with shared support personnel.
- Adequate services (day programs, work programs, transportation, etc.).
- Financial/Legal services to ensure the individual with ID/DD is protected when the caregivers have passed on.
- Rising costs and decline of available resources (e.g., paid caregivers).

Because housing was one of the primary concerns raised, the I/DD task force engaged Yolo County Housing about participating in future town halls. Ian Evans, Executive Director of Yolo County Housing Authority became a part of the ad hoc committee.

The second town hall meeting was held in **Woodland on July 12, 2023**. Community members participated online and in person. The meeting was attended by parents/caregivers of people with I/DD employees of local social services, service providers, members of local advocacy groups, committee members and Supervisor Provenza. Recurring concerns at this meeting included:

- Affordable housing that meets the needs of the individual with ID/DD.
- Adequate services (day programs, work programs, transportation, etc.).
- Support for “intricacies” such as ID renewal, insurance, annual check-ups, etc.
- Emergencies/passing of caregiver before plans are finalized.



Woodland Town Hall (L to R - Supervisor Jim Provenza, ACRC Housing Specialist Rhonda Phillips, Yolo County Housing Executive Director Ian Evans)



Davis Town Hall (L to R – ACRC Director of Community Services John Decker, ACRC Housing Specialist Rhonda Phillips, Supervisor Jim Provenza)

The town hall meetings in Davis and Woodland were well received, so additional meetings were then planned for West Sacramento, Esparto, Winters, and finally a fully virtual meeting. Much like the first two meetings, the subsequent meetings were led by representatives from the Commission on Aging and ACRC. The meetings were attended by a combination of employees of local social services, service providers, members of local advocacy groups, and parents/caregivers of individuals with I/DD.

The town hall meeting held in **West Sacramento occurred on March 27, 2024**. Participants attended in person. Recurring concerns throughout this meeting included:

- Issue of police and how they can learn about I/DD, especially how to interact and respond to those that are non-verbal.
- Adequate services (day programs, work programs, transportation, etc.).

- Local awareness of available services.
- The need for more service coordinators that are immersed in the various languages and cultures of the area.
- Ongoing funding for housing for individuals with I/DD.
- A particular issue was raised about a local program for the I/DD population that was popular before the pandemic but has struggles since. The sense transportation was the primary barrier. ACRC staff and West Sacramento Community Center staff pledged to work together to address this local issue.

The town hall meetings held in **Esparto on April 3, 2024**, at RISE, Inc. and **Winters on May 2, 2024**, at the Winter Branch Library had themes that pertained to the more rural areas of Yolo County in addition to the themes seen in the earlier town hall meetings. Participants attended in person with Supervisor Frerichs in attendance in Winters and Supervisor Barrajas in Esparto. Recurring concerns throughout these meetings included:

- Transportation to the rural areas of Yolo County.
- Lack of accessible services in rural areas.
- Non-accessible/damaged sidewalks.
- Affordable supportive housing.
- Caregiver/staff retention and training.
- Local awareness of available services.
- How to address future planning/care coordination if caregiver is already passed.
- Needs assessment needed for the area.
- An outcome of the Esparto meeting included informational pamphlets and interest in ACRC working with RISE and Winters Healthcare to identify more persons that would qualify for ACRC benefits.

The final town hall meeting was held virtually via Zoom on May 22, 2024. Recurring concerns throughout this meeting included:

- Need for housing specialists to assist with finding appropriate housing.

- Ongoing concerns about unmet needs.
- Service Coordinators not being aware of or not sharing all information regarding available services.
- Lack of availability and very long wait lists for affordable housing (especially for clients trying to stay in the same town to stay close to family and services).
- Community integration.
- Jobs for individuals with I/DD.
- Lack of transportation options in certain areas.

Progress for the Coordinated Future Planning and Coordinated Family Support

John Decker, the Director of Community Services at ACRC, presented introductory information at each townhall about what can be done to begin addressing the concerns of community members and the issue of aging caregivers. John discussed training for ACRC employees on how to better engage with families to address caregiver succession, Coordinated Future Planning and Coordinated Family Support (CFS). Coordinated Family Support is a new service that can come into a family home and help aging caregivers plan and arrange for the supports needed for their loved one.

<https://www.dds.ca.gov/services/coordinated-family-support-service/>. The importance of documentation and creating a plan that is detailed on the wants/needs of the individual when the aging caregiver is no longer able to support them was stressed in the town hall meetings and is the basis of Coordinated Future Planning. Future planning for caregiver

succession is a necessary part for all members of an individual's care team to take part in to ensure that the individual will continue to thrive when the primary caregiver is no longer able to support them.

Beginning next year, any Alta recipient living in a family home and 22 years will be asked at their annual meeting with their service coordinator “do you want to provide a caregiver succession plan?” Additionally, regional office can help find housing and pay rental stipend for a person “at risk” for homelessness.

Aligning with the Coordinated Future Planning Initiative, the California Assembly Human Services Committee authored AB3291 which was signed into law on September 22, 2024. See: https://digitaldemocracy.calmatters.org/bills/ca_202320240ab3291

This legislation is already helping to move forward the issue and idea brought to the Commission on Aging by Mary Nisson. The Commission on Aging will continue to monitor its implementation.

Impact of Collaboration

ACRC reports that the monthly meetings with the I/DD Ad Hoc Committee of the Yolo County Commission on Aging & Adult Services and the information gathered during the town hall meetings led to additional partnerships and opportunities both in Yolo County and statewide:

- Established relationship with Yolo County Housing Executive Director Ian Evans and introduced to the California Affordable Housing Agency (CalAHA) (Yolo County Housing is a member)
- 8/22/23 - Developed a statewide contract for CalAHA to provide technical assistance to all 21 regional centers throughout California to aid in the development of additional multifamily housing projects.
- 12/1/23 – ACRC vended Redwood Transportation to support regional center clients in Yolo County. (*Redwood Transportation attended the 7/12/23 Town Hall in Woodland and expressed interest in serving ACRC clients*)
- 3/14/24 - ACRC invested \$1,850,000 into Danco Communities Lake Washington Housing Project in West Sacramento – 152 units of affordable housing with 19 units set aside for individuals with IDD.
- 9/2/24 – ACRC applied for funding from the State of California to support the Brinshore Development, Operative Office, and New Hope Community Development Corporation 641 5th Street development in West Sacramento – 36 units of affordable housing with 8 units set aside for individuals with IDD.
- 9/2/24 – ACRC applied for funding from the State of California to support Mercy Housing Bretton Woods Senior Apartments in Davis – Phase 1 – 75 units of affordable senior housing with 10 units set aside for individuals with IDD.

ACRC continues to regularly engage with Yolo County Housing to determine additional ways the regional center can support affordable housing development for regional center clients that reside in the county. CalAHA has helped ACRC, as well as several other regional centers, make connections with housing authorities throughout California, with the goal of establishing similar collaboration as ACRC has with Yolo County Housing.

Recommendations

Moving forward, several things can be done to further prepare and support aging caregivers. The Yolo County Commission on Aging and Adult Services recommends:

RECOMMENDATION 1: The Yolo County Board of Supervisors advocate at state and federal for additional funding to build more housing development to address the needs, especially for set asides for persons with disabilities including federal housing vouchers for consumers/clients.

At a time when the State budget is uncertain, advocacy to maintain and enhance funding allocations for continued ACRC investment in housing units for their populations will be critical to addressing one of the biggest priority areas identified during the town halls. ACRC will be unable to continue investing in meaningful housing projects throughout Yolo County without this funding, especially as costs to build affordable housing continue to rise.

RECOMMENDATION 2: The City Aging Commission representatives work with their city council for streamlined review and approval of housing projects, and mitigation of regulations. This is a particular impediment in Davis with additional Measure J/ requirements that significantly extends the timeframe (e.g.: Shriner's project includes I/DD housing set aside units and will not come before the voters for some time yet)

RECOMMENDATION 3: The establishment of a permanent subcommittee of the Yolo County Commission on Aging and Adult Services with the task of meeting regularly with a representative of ACRC and Yolo County Housing regarding continuing and permanent investment analysis and funding applications for supported, low-income housing units for adults with I/DD and follow up on these recommendations.

RECOMMENDATION 4: Receive quarterly updates from Alta Regional Center to the YCCAAS (that includes housing and new resources that are available) to assist with the dissemination of this information to the local communities.

RECOMMENDATION 5: Request Yolo Housing Authority and Yolo County include information on Alta Regional on their websites.

RECOMMENDATION 6: Request annual report to Yolo County Housing Commission on the special housing needs of the I/DD population.

RECOMMENDATION 7: Follow up on connections of Alta Regional to RISE, Inc., Yolo Healthy Aging Alliance and other rural partners to increase utilization of Alta services in rural Yolo County and support aging caregivers.

RECOMMENDATION 8: Work with Yolo Healthy Aging Alliance to connect aging caregivers of persons with I/DD to local programs and services. Suggest a focused resource fair and invitation to Alta Regional to join the YHAA Collaboration Committee.

RECOMMENDATION 9: Work with Yolo County Transportation and local jurisdictions to assure Alta Regional has contracts with all available transportation such as BeeLine (Yolo County), Via (West Sacramento), Davis Community Transit (Davis) and that community members are aware of these options.

RECOMMENDATION 10: Because the crisis facing aging caregivers is enmeshed with the uniquely complex crises impacting their family member with I/DD, it is strongly advisable for Yolo County to establish a department (or identify where in the Yolo County structure) with a vision of maximizing health, safety, and independence so that adults with I/DD and their aging caregivers can avoid homelessness and transition into new and separate living arrangements in a manner that protects their ability to thrive. Perhaps the office could include, among other professionals, employment of a dedicated grant writer to work with Yolo County Housing and ACRC.

Members of the Yolo County Commission on Aging and Adult Services

K Kevyne Baar	District 2
Sue Tarleton	District 3
Elaine Roberts Musser	District 4
James Bohon	District 5
Dawn Myers	At Large
Seth Brunner	At Large
Jim Daniel	At Large
Kim Britt	CAO Designee
Laurie Haas	Public Guardian
Regan Overholt	Woodland Commission on Aging
Rosey Ramsey	West Sacramento Parks, Recreation & Intergenerational Services Commission
Supervisor Jim Provenza	Yolo County Board of Supervisors Representative