Workgroup 5 Workgroup Focus Area:

Individuals Receive Quality, Life-Long, Person-Centered Services from Systems with Adequate Resources

Workgroup 5 Priority:

> Priority 3: Innovate and expand person-centered and culturally informed service types that support community living and can be covered by Medicaid or other systems, such as housing or transportation, to promote inclusive systems and communities.
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> Priority 3 simplified version: Create new and expand person-centered and culturally informed services (such as housing, transportation, education, local resources, and more) that support people to live in their community how they want. Make sure Medicaid or other programs can pay for these services.

Universal Goal:

Californians with intellectual and developmental disabilities get innovative, person-centered, and culturally informed services from all systems, community organizations, and their communities. This supports people with I/DD to live in their community how they want.

Systems and services are well funded by Medicaid or other programs and funding sources.

Problem Statement

Some important services and supports, like help with affordable housing, are not enough for all people who need them. It is even harder for people with I/DD to receive those services.

California is facing an affordable housing crisis as home values and rents have become among the highest in the nation. The affordable housing crisis disproportionately impacts people with IDD as the vast majority live on fixed incomes that are at or near poverty level thresholds.

When people with I/DD are excluded or have a hard time getting services and supports from other systems or organizations that are supposed to serve them, I/DD system has to fill in the gap or provide more costly services. These services may not be eligible for Medicaid/federal match. This can impact DDS budget.

Some services and supports can still make it harder for people with IDD to be included in the community or make their own choices. These service models can feel like old-style institutions. More innovative models are needed that do not put people with I/DD into separate places where they can only be with other people with disabilities and paid staff.

Students with I/DD are not provided equitable opportunities to be fully included in educational process. Special Education system needs an overhaul.

Root Causes of the Problem

Who is left behind:

- People with I/DD trying to access non-disability specific systems, like schools, transportation, housing.
- People with complex needs that require services and supports from multiple systems.
- Students with complex needs do not get access to meaningful education opportunities with needed supports. This leads to lack of opportunities later in life, like employment. Lack of access to equitable education sets trajectory for the rest of person’s life.
- People who speak languages other than English or whose native language is not English.
- People who need information in plain language or in ways other than writing.
- Individuals living in rural communities.

- Self-advocates with little to no natural supports.
- Immigrant communities who speak English but are unfamiliar with the system's processes.
- People from different cultural backgrounds where other factors pose as barriers such as guilt, shame, fear of stigma, fear of government, fear of green card issues, fear of "public charge" implications, etc.
- Individuals involved with the juvenile justice or criminal justice system.
- Individuals who are conserved.
- Unhoused individuals with I/DD.

Root Causes:

- Insufficient federal and state funding for essential supports like affordable housing.
- Vast systems that are inaccessible, culturally biased, and too complex to navigate.
- Duplication of services, or no appropriate services exist to meet needs.
- Lack of data being collected regarding services desired, service satisfaction across all areas.
- Lack of access to services or chosen services.
- Lack of access to affordable housing, transportation, technology, the internet.
- Lack of consistent expectations and accountability for providers.
- Systems are not developed in person-centered manner.

Recommendation #1 - Supported Living Services

Why are we making this recommendation?

Supported Living Services (SLS) consist of a broad range of services to adults with developmental disabilities who choose to live in their own homes. Person can own or lease their home in the community.

SLS may include:

- assistance with selecting and moving into a home
- choosing personal attendants and housemates
- acquiring household furnishings
- common daily living activities and emergencies
- participating in community life
- managing personal finances, as well as other supports.

Typically, a supported living service agency works with the individual to establish and maintain a safe, stable, and independent life in his or her own home. But it is also possible for some individuals to supervise their services themselves, to secure the maximum possible level of personal independence.

Currently, people have to wait to access SLS service because there are not enough providers. This also impacts quality of services being provided. Because SLS is provided in person's own home, SLS providers and services are presumed to be compliant with Home and Community Based Settings rule.

What we recommend:

Develop enough providers of SLS services so that people do not have to wait to receive it.

Create ways to make sure services are high quality, person-centered, and culturally informed.

Develop a way to make sure that SLS is following Home and Community Based Settings rule requirements (HCBS rule), even though SLS settings are person's own homes and presumed to be HCBS compliant. DDS should consider using a client Advisory Council or another method to identify, review, and resolve problems.

Make SLS service available to people living with family.

Recommendation #2 – Enhanced Supported Living Services

Why are we making this recommendation?

Enhanced Supported Living Services is an alternate to residential care models. When people with IDD are asked where they want to live, most say they prefer their own home, rather than a group home. Enhanced SLS makes this possible even for individuals with complex behavioral or medical needs by providing the right supports in their own homes and communities.

DDS is only beginning to develop this service model. This service is highly flexible and individualized to meet each person's unique needs. If this service was more readily available in more places, individuals who have to move from place to place to get the supports they need could stabilize and stay in their own home and communities with support of right providers. Enhanced SLS can also prevent long hospital stays and placement disruptions. When individuals experience a crisis and go to the hospital, this service helps them return home quickly, rather than waiting weeks or months and sometimes years waiting for a new placement. It prioritizes stability, keeping individuals connected to their communities and supports.

Enhanced Supported Living Services providers are not limited by the rules of Community Care Licensing (CCL) allowing them to support individuals who may not qualify for medical or behavioral group homes. This approach can use trauma-informed and culturally responsive practices to make care respectful of individual's experiences and preferences.

DRC Report for reference is available here.

<u>What we recommend:</u>

Continue to develop and expand Enhanced Supported Living Services model to provide individualized, trauma informed, culturally responsive services to individuals who choose this option in their own or family home.

Proactively develop Enhanced Supported Living Services providers.

Provide information and educate individuals and families about this option.

Explore how Enhanced SLS supports could be adjusted to be used in long term single foster home settings for those children with complex needs that cannot stay at home but want to remain near their families and communities.

Recommendation #3 – Innovative service models where people share resources and services.

<u>Why are we making this recommendation?</u>

<u>What we recommend:</u>

DDS should work with individuals with I/DD and families to think about and develop innovative service models where people can share resources and services. This can include sharing staff or hours of support, for example “time banks”. Such models can be called co-op model. These models could be more resource effective and maybe easier for people to get assistance from providers who are not their parents or relatives.

Recommendation #4 – Day Programs

<u>Why are we making this recommendation?</u>

Today many day programs do not provide individualized, person-centered services that help people with I/DD to fully participate in the community. They are often done in separate places and buildings. They are often done in large groups that only include people with disabilities and paid staff. Activities may not reflect interests and preferences of people participating. They frequently do not provide meaningful opportunities to engage with the community.

What we recommend:

Develop and create programming that is individualized, person-centered, is culturally responsive and provides opportunities for person to authentically participate in and contribute to their community. Ensure that community inclusion and participation opportunities and supports are available to all individuals, regardless of the setting they live in.

Access to meaningful day activities must be supported with access to transportation.

Recommendation #5 - Technology

Why are we making this recommendation?

Technology of all kinds is critical to all people to be able to participate in community. Reliable and affordable high-speed internet, or electronic connectivity, is fundamental for any activity today. Access to technology and high-speed internet is vital for all communication and life activities, including connecting with family and friends, advocacy, work, learning, healthcare, buying goods. Assistive technology and environmental accessibility adaptations (such as ramps) can be critical in helping people be independent and to participate in the community. Technology can help better service rural communities and underserved groups.

What we recommend:

Support individuals in getting needed technology, including internet or cell services, to better access services and opportunities such as telemedicine, distance learning, jobs, or to access and be included in virtual communities and social media. Explore non-Medicaid funding sources, state and federal funds to get rural communities stable connectivity (such as USDA broadband connectivity for rural areas). Consider tax incentives for internet providers to expand their ranges or satellite providers to provide low-income options.

Increase access to effective communication, including communication supports. This can include:

- Easy access to augmentative and alternative communication (AAC) evaluations and devices, including mainstream technologies such as tablets and smart phones
- Easy access to ongoing services and supports to use AAC devices and expand person's ways to communicate
- Proactively work to increase the number of organizations that provide translation and interpretation services to people with IDD whenever needed (e.g., ASL, cognitive interpretation, etc.)
- Proactively increase the number of trainings for direct support staff and other professionals (including healthcare and behavioral health professionals) to support people with IDD's communication, learn people's communication methods and systems, and improve their own skills as communication partners

Make choice of virtual and remote supports more available to those who want them. Consider virtual and/or hybrid model for people whose work takes them out of town. Virtual and remote services should be made available based on person's preferences and not for provider/vendor convenience. In-person options and options to receive services without using technology should always be made available for those who prefer them.

Remove geographic constraints, such as limits that come from current vendorization process, and increase ability to get remote services. Traditional services are location -dependent, limiting access to individuals in rural areas.

Make technology that helps people be more independent more easily accessible to those who need it.

Make it easy and fast for people to get assistive technology they need. This includes clarifying roles and responsibilities of different entities and funding sources to provide assistive technology.

Provide supports to make sure there are enough vendors with necessary skills to provide assistive technology, equipment (like wheelchairs), and environmental accessibility modifications (like ramps, or wider doors) timely.

Expand access to innovative technology, such as "smart homes", to help people be more independent in their own homes and make them be less dependent on help of staff. Research, explore, and pilot independent living with use of technology.

Provide supports and learning opportunities to help individuals, their families, and their support staff to improve their skills in using technology. This can include learning about technology like "Zoom" than can help people in their daily lives. Sometimes this is called "digital literacy".

Develop a Life Tracker System that supports individuals from birth through end of life. In Life Tracker all systems of support are tied together, and there is technological innovation that helps alert to lags in response time, service. Life Tracker has client portal access. This portal can be similar to "My Chart" where individual can communicate with RC and providers. It also supports communication with the different system community partners and provides each system of support (Behavioral health, Regional Centers, School, Department of Rehabilitation (DOR) etc.) their unique areas of access to track, deliver and monitor services.

Recommendation #6 – grants and other funding sources

Why are we making this recommendation?

There are funding sources, such as grants, that people and organizations can apply for to do projects and try out new ideas. These funding sources are not Medicaid, but can help with money for innovative ideas and doing things to improve services and supports.

What we recommend:

Explore and prioritize use of grant funding to do and pilot innovative projects and service delivery models.

Provide advance notices to community partners, potentially eligible or interested in applying, about federal or other funding opportunities or grants. Partner with researchers, universities, also specifically UCEDDs, to explore innovative models and opportunities.

Recommendation #7 – Specialized remote/virtual supports

Why are we making this recommendation?

Several states have developed and implemented a model where people with I/DD can get remote/virtual supports with physicians that are specialized in supporting people with IDD. This can help states save money on emergency and crisis services, while providing services specialized for people with IDD. When people and their families receive medical care from professionals that understand their needs, trips to the ER, costly hospitalization and first responder calls dimmish. (Example of this model in Missouri: https://stationmd.com/modmh/)

What we recommend:

Partner with Managed Care and community-based organizations to provide I/DD-specialized telehealth services to individuals with I/DD. This allows individuals to connect quickly with a doctor at any hour of the day, 365 days a year, for any medical concern or for disability-specific advice.

Specialized virtual doctor or psychiatric appointments can help reduce costs associated with first responder calls, Emergency department, urgent care usage and hospitalizations. This further addresses issues for rural families and individuals that cannot access the same resources as populated areas, by giving them access to experts in their own home and communities.

Recommendation #8 - School System

Why are we making this recommendation?

AAIDD:

All children and youth with intellectual and/or developmental disabilities (IDD) must receive a free appropriate public education that includes fair evaluation, ambitious goals, challenging objectives, the right to progress, individualized supports and services, high quality instruction, and access to the general education curriculum in age-appropriate inclusive settings. Parents and families must be supported as essential partners in the education and transition to adult life of their children.

People with IDD continue to face many barriers in their education. Lifelong education is essential for all individuals with IDD to have rich lives and to be part of their communities. The Individuals with Disabilities Education Act (IDEA) states: “Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.”

Many students with IDD are kept in separate classrooms or schools, with few or no opportunities to learn, be with their peers without disabilities, and fully participate in school life. Many students with IDD leave school unprepared for further education, employment, and independent living in the community. Many students and families are not included in assessing student’s needs and their Individualized Education Programs (IEPs) process.

Outdated, inaccurate beliefs about students with IDD lead to low expectations, segregated classrooms, inappropriate disciplinary practices, and diminished accountability for students with disabilities.

What we recommend:

Educational system and educator workforce development must be based on the principles of Universal Design for Learning to ensure that schools and educational organizations are competent to serve everyone, including individuals with I/DD, in an equitable and inclusive way. "Universal design for learning" framework for teaching and learning treats students' varied physical, intellectual, and learning needs as the norm, not an exception.

Schools and teachers should receive adequate supports, training, and resources to make inclusion a reality. This includes making mental health supports in schools fully accessible to students with I/DD.

There should be accountability measures for public education system which can include metrics on graduation rates, transitioning into post school education or jobs, and more.

We recommend a gap analysis of the ways people with developmental disabilities are served by the school system in California. A gap analysis is a way to make sure that we know the ways the school system is and isn't working, so that it is easier to fix or change it. This study will help us see where schools are doing well and where schools are not providing fully inclusive, person-centered learning experience for students with I/DD. This study should be done with input from individuals with I/DD and their families.

California Department of Education and local partners should work with individuals with I/DD, their families, and other community partners to develop and implement ways to fix gaps and issues and to transition public education system to the Universal Design for Learning.

Develop formal Memorandum of Understanding (MOU) or another formal agreement that will:

1. Clarify roles and responsibilities between school system and I/DD DDS system.
2. Identify which system is responsible for what services and which funding source/budget should pay for it.

3. Require and describe a process for collaboration and coordination at state and local level
4. Require and describe a process on how schools and RCs/service coordinators should coordinate/collaborate on services and supports for school aged children to ensure continuity, consistency, and seamless services and supports.

Funding and accountability: ensure all school programing, including that is funded through grants such as Expanded Learning Opportunities Grants, is fully accessible to students with I/DD with necessary accommodations and supports.

Partner with school systems and after-school programs to develop more inclusive before and after school support options for learning and skill development.

Maximize use of Federal funding for Early Start and Special Education Grants. Partner with school system to develop better relationships and inclusive programs that provide supports to individuals and families.

Recommendation # 9 - transition out of institutional settings

Why are we making this recommendation?

California has closed large state operated institutions for people with intellectual and developmental disabilities and supported many individuals move into the community. Many people remain in institutional settings like private Intermediate Care Facilities (ICFs), nursing homes, and other more restrictive settings that do not have to comply with Home and Community Based Settings (HCBS) rule requirements.

The "**Home and Community Based Settings Rule (HCBS Rule)"** is a federal rule that ensures people with disabilities who receive Medicaid services can live in the community, make their own choices about their care, and have the same rights as anyone else when accessing support services. It protects their freedom to live as independently as possible in their own homes or community settings.

The rule protects individual choice. People receiving services get to decide where they live, what activities they do, and who provides their services, based on their individual needs and preferences. HCBS rule protects people's right to live among others without disabilities in the community, not segregated in specialized facilities. HCBS rule protects people's right to privacy and control. This includes things like being able to lock your door, have visitors, and manage your own schedule. It also ensures that individuals are actively involved in planning their own support services, ensuring they are getting what they need.

What we recommend:

Using the experience and lessons learned from closing state operated institutions, DDS will develop and implement a plan to support individuals to move from institutional settings into community settings with appropriate supports.

Recommendation # – Contingency planning for potential budget cuts at the federal level

PLACEHOLDER

Recommendation # – Housing and houselessness supports – PLACEHOLDER

Learning session is being scheduled.

Recommendation # – Transition models for individuals who are supported by aging caregivers – PLACEHOLDER