# Master Plan for Developmental Services (MPDS): Recommendation Background and Technical Information Addendum

This document provides additional details and technical information to support implementation of some of the recommendations in the <u>Master Plan for Developmental</u> <u>Services Report (https://www.chhs.ca.gov/wp-</u>

<u>content/uploads/2025/03/MPDS</u> <u>ACommunityDrivenVision.pdf</u>]. The goal of the MPDS is to improve how California supports people with intellectual and developmental disabilities (I/DD) and their families into the future.

There are seven topic areas and 167 recommendations in the Master Plan. The report provides a summary of each recommendation. Recommendations are organized by topic area. The seven topics in the MPDS are:

- Topic 1: Systems Serving People with Intellectual and/or Developmental Disabilities (I/DD) Are Centered in Equity.
- Topic 2: People with I/DD Making Their Own Life Choices.
- Topic 3: People with I/DD Living in Inclusive Communities with the Resources They Need to Thrive.
- Topic 4: People with I/DD Getting Services They Need and Choose.
- Topic 5: People with I/DD Being Part of and Being Served by a Strong Workforce.
- Topic 6: Accountability and Transparency in All Systems That Serve People with I/DD.
- Topic 7: Informing the Future of the Developmental Services System.

Not all recommendations have additional detail or technical information in this addendum. The details and technical information provided in this document are meant to:

• Provide additional background or context for understanding recommendations which are more complicated.

#### and/or

• Provide technical information to support the successful implementation of recommendations.

# **Table of Contents**

Topic 1: Systems Serving People with I/DD are Centered in Equity
Topic 2: People with I/DD Making Their Own Life Choices
Use Supported Decision Making (SDM) More. Have Fewer Conservatorships
Making Choices in Regional Center Services
Topic 3: People with I/DD Living in Inclusive Communities With the Resources They Need to Thrive
Support Relationships as Part of a Full Life in the Community for People With I/DD 6
Make Sure People With I/DD Have Technology That They Need
Make Sure People With I/DD Can Participate in Community Programs, Services, and Activities
Make Sure People With I/DD Can Participate in Decision Making About Their Communities
Make Sure People With I/DD Can Get an Inclusive and High-Quality Education
Make Sure People With I/DD Have Transportation to Get Where They Need to Go11
Make Sure People With I/DD Have Money to Pay for Their Basic Needs
Make Sure People With I/DD Have a Home of Their Choice11
Make Sure the Justice System Works for People With I/DD14
Emergency Preparedness14
Topic 4: People With I/DD Getting Services They Need and Choose14
DDS and Regional Center Services14
Health Care and Wellness23
Health Care and Wellness- Behavioral Health Services
Health Care and Wellness- Dental Services
Transition Supports
Access to Other Services
Help Getting Services
Topic 5: People With I/DD Being Part of and Being Served by a Strong Workforce43
People Who Provide Services to People with I/DD43
Opportunities for People with I/DD44
Topic 6: Accountability and Transparency in All Systems That Serve People With I/DD45
Keeping People With I/DD Safe45
Hold Regional Centers Accountable
Make Sure the DDS System is Transparent
Topic 7: Inform the Future of the Developmental Services System
Funding for I/DD Services in California
Changes in Federal Funding

Gap Analyses	91
Data	92
Recommendation Needing Further Consideration	99

# Topic 1: Systems Serving People with I/DD are Centered in Equity

Recommendations in this topic area are focused on addressing fairness and equity in the systems that serve people with I/DD. No additional detail or technical information was developed for any of the recommendations in this topic section.

#### Topic 2: People with I/DD Making Their Own Life Choices

#### Use Supported Decision Making (SDM) More. Have Fewer Conservatorships.

These recommendations focus on making sure SDM is used more and conservatorships are used less. These recommendations build upon the work of an expert panel and its March 2023 report: Expert Panel: Review of California Developmental Services Conservatorship Program Report.<sup>1</sup> No additional detail or technical information was developed for any of the recommendations in this sub-topic section.

#### Making Choices in Regional Center Services.

These recommendations focus on making sure that people served by the regional center get to choose what goes into their Individual Program Plan (IPP).

Master Plan Recommendation: Use a Person-Centered Approach to Individual Program Planning (IPP) [page 34]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. These additional details support the piece of this recommendation which says that DDS should make sure that regional centers update the "exceptions process" as part of using a person-centered approach to IPP.

DDS should make sure that the IPP process is person-centered and consistent across regional centers. For this to happen, DDS should:

- Give regional center service coordinators the authority to approve the IPP as part of a collaborative planning process with the person or family served.
  - Make clear rules about what kinds of decisions service coordinators can make and how these decisions are made. This will make sure service coordinators' approval authority is clear and consistent across all regional centers. DDS should get input from diverse stakeholders to develop these clear rules. These rules should:
    - Clarify that service coordinators can approve services that meet a person's needs. This will make sure that services can be approved and authorized more quickly.

<sup>&</sup>lt;sup>1</sup> For more information about the Expert Panel: Review of California Developmental Services Conservatorship Program Report (https://www.dds.ca.gov/wpcontent/uploads/2023/03/ExpertPanelFinalReportMarch2023.pdf)

- Clarify that service coordinators should consider input from all members of the IPP team to make service approval decisions.
- Clarify that services can only be denied after all options and exceptions have been tried. There should be a clear timeline established and transparent process for denial of services. This will help to make sure there are not barriers to people accessing the services they need.
- Make sure that service coordinators are trained on how to interpret these new rules consistently.
- Make sure that regional centers:
  - Stop having service coordinators serve as "messengers" by sending information to managers, clinical teams, or committee that make decisions. This will make sure that decisions are made with the person served and the service coordinator in the room.
  - Update the "exceptions process." The exceptions process happens when a person's unique needs do not fit within the usual standards of getting services. The updated exceptions process should be more transparent and should work better for people served.
  - <u>Additional Details</u>: To make sure this happens, DDS and regional centers should:
    - Have clear explanations of the steps in the process and which regional center staff should be involved.
      - This will make sure the process is transparent.
    - Make sure that regional center staff work with the person served to explore how to creatively meet the person's needs.
    - Have an expectation that service decisions made in the process will be resolved in a timely manner.
    - Be supported with training that empowers service coordinators to support people served during the process.
      - High-quality training for service coordinators should also reduce the need to use this process.
  - Make it a practice to hold a meeting with people served and their circles of support to find creative solutions when a service is denied. This should happen before the regional center issues a Notice of Action. If a solution cannot be reached during the meeting, the regional center should continue with service coordination efforts to connect the person served to generic services or some other solution.

- Begin providing people served with access to services in a timely manner once a service approval agreement is reached.
- Provide people served with verbal and written explanations of all service approvals and denials. These explanations should be provided in a timely manner and in plain language so that people served can understand what is happening and why.

### Topic 3: People with I/DD Living in Inclusive Communities With the Resources They Need to Thrive

Support Relationships as Part of a Full Life in the Community for People With I/DD.

These recommendations focus on making sure that people with I/DD are able to build the kinds of relationships that are an important part of a full life in a community. No additional detail or technical information was developed for any of the recommendations in this topic section.

# Make Sure People With I/DD Have Technology That They Need.

These recommendations focus on making sure that people with I/DD are able to access and use the technology that they need.

Master Plan Recommendation: Make Sure People With I/DD Can Access and Use Technology [page 43]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context.

DDS and regional centers should make sure that people with I/DD can get the technology they need. This means making sure that people served have access to:

- Internet. This should build on existing efforts in California to provide access to internet services, like the "Middle-Mile Broadband Initiative."<sup>2</sup>
- Cell phone services.
- Devices like laptops, tablets, and cellphones.
- Support to access AAC services and devices. "AAC" means using methods of communication in addition to or other than the spoken language. These communication methods can include gestures, pictures, symbols, electronic devices, and changes to the environment that make it easier for people to communicate.

<u>Additional Details:</u> Technology is necessary for people to participate in their communities. Reliable and affordable high-speed internet is needed to participate in most activities today. Having technology and high-speed internet is important for all communication and life activities, including connecting with family and friends, advocacy, work, learning, accessing healthcare, and buying

<sup>&</sup>lt;sup>2</sup> For more information on the Middle-Mile Broadband Initiative (https://middle-mile-broadband-initiative.cdt.ca.gov/)

goods. Access to technology can help better serve rural communities and underserved groups.

- Internet connectivity: The state should support people with I/DD and their families in getting needed technology, including internet or cellphone services. This will make it easier for people to access services and opportunities such as telemedicine, distance learning, jobs, or to be included in virtual communities and social media.
  - The state should explore non-Medicaid state and federal funding sources, and build upon its Broadband for All Initiative, to make sure that rural communities have stable internet connectivity (such as broadband connectivity). <sup>3</sup>
  - The state should consider tax incentives for internet providers to expand their services, to provide low-cost options, and to provide internet to underserved communities.
- Communication supports: DDS, regional centers, and DHCS should work together to increase access to effective communication supports. This can include:
  - Providing easy access to augmentative and alternative communication (AAC) evaluations and devices, including technologies such as tablets and smartphones. This should include ongoing services and supports to use and maintain AAC devices. If internet connectivity is required for use of a communication device or other technology, it should be included in the service.
  - Proactively working to increase the number of organizations that provide translation and interpretation services to people with I/DD whenever needed (this should include American Sign Language [ASL], cognitive interpretation, and more).
  - Providing training for people with I/DD on how to use their communication devices and supports. Provide training to supporters of people with I/DD, including support staff and other professionals (for example: healthcare and behavioral health professionals) on how to support people with I/DD's communication needs, learn people's communication methods and technologies, and improve their own skills as communication partners.
  - Making sure individuals with I/DD have access to these supports regardless of where they live.
  - Providing support to people with I/DD if they want and need to use artificial intelligence to help them communicate.

<sup>&</sup>lt;u><sup>3</sup> For more information about the Broadband for All Initiative (https://broadbandforall.cdt.ca.gov/)</u>

#### Master Plan Recommendation: Make Sure People With I/DD Can Choose to Access Some Services from Home [page 43]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context.

DDS and regional centers should give people with I/DD more access to services virtually and remotely by using Zoom and other tools. This would mean that people with I/DD could have the option to get some services they want and need from their home, instead of having to be present in person. DDS should make sure that virtual or remote services are the choice of the person served. This will make sure that services are not provided virtually or remotely just because it is easier for the service provider.

Better access to technology would help people get better access to services and opportunities. For example:

- Working from home.
- Learning from home.
- Seeing a doctor or therapist from home.
- Being a part of virtual communities, like social media.

#### Additional Details: DDS should make sure that:

- Safeguards are developed to make sure that getting services remotely is truly a person's choice.
- Virtual and remote services should be provided in a culturally responsive way and in the language preferred by the individual, with needed communication supports.
- In-person options and ways to receive services without using technology are always provided for those who prefer them, with needed supports.
- The vendorization process is streamlined to remove geographic barriers to supports which can be provided virtually or remotely.
  - This will help people to get remote services from providers statewide.
  - Traditional services are usually based on where a person lives or which regional center they are served by. This limits access to services for individuals in rural areas.

# Make Sure People With I/DD Can Participate in Community Programs, Services, and Activities.

These recommendations focus on making sure that people with I/DD and their families are able to participate in their communities. This means making it easier for them to be a part of community programs and activities, and to get services in the community. No additional detail or technical information was developed for any of the recommendations in this sub-topic section.

# Make Sure People With I/DD Can Participate in Decision Making About Their Communities.

These recommendations focus on making sure that people with I/DD understand how to participate in community processes like voting or volunteering for local organizations. The recommendations also focus on making sure that people in the community, like local officials, understand how to include people with I/DD in civic participation. No additional detail or technical information was developed for any of the recommendations in this sub-topic section.

# Make Sure People With I/DD Can Get an Inclusive and High-Quality Education.

This recommendation focuses on making sure that children and youth with I/DD are included in their schools and get the best possible education to meet their needs.

Master Plan Recommendation: Inclusive and Flexible Education [page 50]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. The California Department of Education (CDE) in partnership with Local Education Agencies should make sure that all children and young people with I/DD receive Free and Accessible Public Education.

There are many things the State should do to make sure that all children and youth with I/DD receive an inclusive and flexible education to meet their unique needs. For example, the State should:

- Make sure the educational system is based on the principles of "Universal Design for Learning." This is an approach to education that accommodates the needs and abilities of all students. It provides flexibility in how students learn.
  - This will help make sure that schools and other educational organizations are able to serve everyone, including people with I/DD, in an equitable and inclusive way.
  - The State should make sure that the California CDE and local partners should work with people with I/DD, their families, and other community partners to transition the public education system to the Universal Design for Learning. This process should also develop and implement ways to fix gaps and issues.
- Make sure that schools include and support youth with I/DD to participate in their Individual Education Program (IEP) process. Students should be supported to learn skills to advocate for themselves, make informed choices and practice self-determination.
- Make sure schools and teachers receive adequate supports, training, and resources to make inclusion a reality.
  - This includes making mental health supports, including counseling, in schools fully accessible to students with I/DD. This also includes bringing interdisciplinary teams together to support students who require supports from different professionals. Schools

should also make sure that career and college counseling and Think College options are inclusive if students with I/DD.

- Develop accountability measures for the public education system. This can include tracking information on graduation rates, transitioning into post-school education or jobs, and other outcomes for people with I/DD.
  - These accountability measures should build on or refine existing measures to make sure that data about all students with I/DD is collected.
- Make sure that school campuses are accessible for everyone.
- Make sure that schools have equal opportunities for everyone to participate in all school activities and events. This should include graduation activities and ceremonies, school clubs and more.

# <u>Additional Details:</u> DDS and CDE also have a role to play in implementing this recommendation. DDS and the CDE should:

- Develop a formal Memorandum of Understanding (MOU) or another formal agreement that will:
  - Clarify roles and responsibilities between the school system and I/DD system.
  - Identify which system is responsible for what services and which funding source/budget should pay for it.
  - Require and describe a process for collaboration and coordination at the state and local level.
  - Require and describe a process on how schools and regional centers/service coordinators should coordinate or collaborate on services and supports for school aged children to make sure continuity, consistency, and seamless services and supports.
    - This MOU should be informed by the recommendations of the gap analysis suggested in the recommendation titled "Gap Analysis on School for Children and Youth With I/DD." Which can be found in the "Gap Analyses" sub-topic of recommendations.
- Make sure that schools allow room for reasonable accommodations in all classes.
- Make sure that schools create a student advocate position (similar to regional center's consumer advocates) who can provide support for students with I/DD and their families in IEP meetings or finding resources.
- Partner with school systems and after-school programs to develop more inclusive before and after school support options for learning and skill development.

- Develop inclusive after school programs for youth ages 16-22, instead of day programs. This programming should support transition to post-school education and employment.
- Explore ways for school systems to use I/DD vendors to support inclusive before and after school programs.
- Make sure all school programing, including that which is funded through grants such as Expanded Learning Opportunities Grants, are fully accessible to students with I/DD with necessary accommodations and supports.
- Maximize use of Federal funding for Early Start and Special Education Grants.
- Partner with the school system and community-based organizations serving people with I/DD to develop better relationships and inclusive programs that provide supports to individuals and families.

#### Make Sure People With I/DD Have Transportation to Get Where They Need to Go.

Access to transportation helps people with I/DD fully participate in their community. Without reliable transportation, many people with I/DD are not able to get where they need to go. These recommendations focus on making sure that people with I/DD are able to access high-quality transportation options. No additional detail or technical information was developed for any of the recommendations in this sub-topic section.

# Make Sure People With I/DD Have Money to Pay for Their Basic Needs.

People with I/DD often do not have the resources they need to meet basic needs such as housing and food. This can be because they do not have enough money to pay for the things that they need. These recommendations focus on making sure that people with I/DD have enough money to pay for their basic needs. No additional detail or technical information was developed for any of the recommendations in this sub-topic section.

#### Make Sure People With I/DD Have a Home of Their Choice.

These recommendations focus on making sure that people with I/DD have supports that they need to find stable housing. These recommendations also focus on making sure that people with I/DD have accessible places to live.

Master Plan Recommendation: Build More Housing [page 56]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. The state and DDS should create more affordable and accessible housing for people with I/DD across California. To make sure that more affordable and accessible housing is available for people with I/DD, the State should:

- Make sure there is money in the state budget to build community-based affordable and accessible housing units for adults with I/DD.
  - For example, there is money in the state budget which is specifically used to fund housing for other at-risk groups like

veterans, seniors, and people with mental illness. A similar program should be established for people with I/DD.

- The state should give cities and counties money for making affordable housing available for people with I/DD.
  - For example, the state could give cities and counties money for making 15-30% of the units in each new development available as affordable housing for people with I/DD and for professionals who are hired in the developmental services industry.

To make sure that more affordable and accessible housing is available for people with I/DD, DDS should:

- Give more funding to existing programs that help build housing in communities. DDS should also explore new ways to use these programs.
  - DDS should increase funding for programs like Community Placement Plan (CPP) and Community Resource Development Plan (CRDP). DDS should also explore new ways to use these programs.
    - This could include using these programs to:
      - Develop integrated inclusive non-licensed community housing.
      - Maintaining existing housing.
      - Provide rent subsidies and more.
    - DDS should make sure that CPP and CDRP funding is distributed and used equitably across the state.
- Provide downpayment assistance or gap financing through their Housing Initiative program or seed funding for Adult Residential Facility (ARF)/Multiplex owners, community-based organizations, and families who can provide housing for people with I/DD.
- Set up a low-interest loan program and down-payment assistance to help people with I/DD and their families pay to build Accessory Dwelling Units (ADU). ADUs could be used to support long-term housing needs of individuals with I/DD. An ADU is a space where someone can live on a property that is separate from the main house. For example:
  - A basement apartment.
  - A garage that has been converted into an apartment.

Master Plan Recommendation: Make Sure People With I/DD can Access Legal Help for Housing Issues [page 59]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. The state should make sure people with I/DD can get quick, local, legal help if they need it.

People with I/DD can be underserved by the broader Legal Aid community. Specific to housing, certain Legal Aid organizations in California receive funding to serve the public with housing matters but the I/DD community remains underserved. This recommendation says that the state should:

- Increase funding for Legal Aid programs and advocacy organizations to:
  - Provide legal help for housing issues.
  - Provide advocacy to people with I/DD.
  - Stop local unfair housing practices.
- Create a way to count and report how many people need housing targeted legal help. This will help improve the State's housing rights protection, advocacy, anti-discrimination, fair-housing, and other important laws. This should include information about:
  - What type of help people need.
  - Actions needed.
  - Agencies or organizations involved.
  - Services provided.
  - Final outcomes.
- Complete a review to identify the barriers legal practitioners face when trying to serve people with I/DD. Then develop a plan to address these barriers. These barriers may be:
  - Knowledge of the law
  - Connection to expert resources
  - Experience working and communicating with people with I/DD

Master Plan Recommendation: Make Sure there is Enough Specialized Housing for People with I/DD [page 61]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should make sure that there are enough integrated inclusive housing options available.

These are housing options where people with I/DD can live with people who do not have disabilities and have access to, and participation in, the community and get special supports that they need. Integrated inclusive housing options include:

- Medical and behavioral homes.
- Foster homes.

DDS should make sure:

- Integrated inclusive housing options focus on personal choice, independence, and inclusion.
- Housing policies follow fair rules and meet the needs of all individuals.
- All residential settings fully comply with the settings requirements of Home and Community-Based Services (HCBS) final rule.

#### Additional Details:

• DDS should also make sure to provide regular compliance reviews and oversight of settings, with individual's and family input.

#### Make Sure the Justice System Works for People With I/DD.

When people with I/DD commit or are accused of crimes, they interact with the justice system just like anyone else would. The justice system has a lot of problems with equity and fairness, in general. People with I/DD may encounter even more unfairness in the justice system. These recommendations focus on making sure that the justice system works for people with I/DD. No additional detail or technical information was developed for any of the recommendations in this sub-topic section.

#### **Emergency Preparedness.**

People with I/DD should have plans and supports to stay safe during emergencies, just like other people in their communities. This recommendation focuses on making sure that people with I/DD have such plans. No additional detail or technical information was developed for any of the recommendations in this sub-topic section.

#### Topic 4: People With I/DD Getting Services They Need and Choose

The goal for this topic is that people with I/DD get the services and supports they need and choose, when they need them, so they can lead the lives they want.

#### DDS and Regional Center Services.

These recommendations are about things that DDS and regional centers should do to make regional center services work better for people with I/DD and their families.

Master Plan Recommendation: Make Sure Definitions of Services are Clear and Consistent [page 72]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should make sure all service definitions are easy to understand for individuals and family members. DDS should get help from an independent organization to develop and update definitions for services. These definitions should be available to:

- People with I/DD and their circle of supports. That organization should include people living with I/DD and people that understand the community, equity, and regional centers. These definitions should:
  - Describe things that must be included in each type of service, who is eligible to receive each service, and how services can be accessed.
  - Be used by all regional centers and providers.
  - Be easy for everyone to understand.
  - Be flexible so that they can accommodate the unique needs of individuals, including those in rural or other communities that might have resource constraints.

 Regional centers should be required to provide training about these definitions for regional center staff and people who support individuals and families. DDS should collect, analyze, and report data about people's experience receiving services.

<u>Additional Details:</u> Operational definitions of service types may evolve over time. They may evolve with changes in law, regulations, research, and good practice. They describe the current situation but may be important to inform advocacy for how the situation can be improved in the future.

- Operational definitions of service types should clearly set out which elements are core and universal to each service type as well as where any element of a service might differ by regional centers. Definitions should allow for enough flexibility to make sure that services and support can be tailored to meet the needs and promote a good quality of life for each individual person. The definitions are not meant to limit available services but should be seen as a basic list of the most common ones.
- Operational definitions of service types should clearly describe the following elements:
  - Who can receive the services and where support can be provided (eligibility and location).
  - Whether the service type can be provided as self-directed support or through self-determination program.
  - What activities, tasks, interactions, and life areas can be supported by the type of service.
  - Any limitations to the support that can be provided by this type of service.
  - How the services can be accessed.
  - What those receiving services and their families would experience if the service was being provided according to legislation and good practice.
  - Where a service type is funded under an HCBS waiver, it is very clear what that service needs to be doing to be in line with HCBS values and standards.
  - Sources used and where to find more information.
- Two versions of operational definitions of service types should be created:
  - The primary audience for operational definitions of service types should be regional centers and providers. The definitions should be detailed and specific enough to make sure there is clarity, minimize misunderstanding and therefore promote consistency across regional centers and providers.
  - Plain language versions of operational definitions of service types should be provided in a range of different languages. Eligibility

criteria should be included in the plain language versions so that individuals and family can be very clear as to whether they might be eligible for this service type.

- Both versions should have clear, consistent, and equitable language that accommodates cultural sensitivity, linguistic accessibility, accessibility for people with a range of disabilities, sexual orientation, and gender identity inclusivity.
- Operational definitions should be accompanied by a clear statement of data that is needed and collected in order to know:
  - Whether individuals and families are experiencing services the way they should be according to the definitions.
  - Whether having operational definitions have had an impact on the equity, quality, and outcomes of services.
- Training should be available and required on operational definitions for regional center leadership, service coordinators, providers, and direct support professionals.
  - Training (content and process) on new operational definitions should be informed by the experiences of providing and receiving the training on the four existing operational definitions that will be conducted as part of the Provider Application and Validation for Enrollment (PAVE) Service Outcomes project.
  - Training should be customized for each of these different audiences to make clear what they need to do to make sure services are provided according to the definitions.
  - Regional center leadership should be involved in the development and training of service definitions for their staff.
  - Refresher/updated training should be provided on an ongoing basis and provided when operational definitions are changed.
  - Service coordinators should be trained to promote creativity and flexibility in customizing services to meet individual needs, while clarifying that the listed services are not exclusively tailored for any one person.
- There should be a process for developing and updating operational definitions that are accurate, clear and deliver a service system that is equitable, fair, and transparent. The process should consider using a similar process used to develop PAVE operational definitions of service types. This would ideally include:
  - A thorough environmental scan of legislation, regulations and guidance and existing definitions and good practice descriptions available nationally and internationally, is conducted.

- The environmental scan could be usefully supplemented by consultation with subject matter experts on each service type.
- A first draft of the definition is produced based on the environmental scan, including the sources used.
- The first draft is sent to a group of stakeholders to assess the accuracy of information and the completeness of sources used.
  - This group should, at a minimum, include the Department of Developmental Services, the Association of Regional Center Agencies, advocacy organizations, self-advocates and families, and others with expertise in each type of service for which definitions are being written and relevant state and federal regulation.
- Feedback from this stakeholder group is used to produce a second draft.
- The second draft of full operational definition is sent to directors of all 21 regional centers and feedback sought.
- A plain language version is developed in collaboration with a group of self-advocates and families.
  - Consider working with the State Council on Developmental Disabilities to carry out this stage.
- A third draft of both full definition and plain language version is made available to wider community and feedback sought in a number of different ways. Feedback meetings and surveys should allow people to focus on one service type at a time.
- Version 1 of Operational Definition finalized, translated, and made publicly available.
- The process of developing and updating the operational service definitions should be independently facilitated.
  - This independent review body should be representative of the community and involve self-advocates.
- Operational service definitions require a process for consistent review and the ability to revise the definitions as needed over time. It is important that service definition language is precise and clear. Service definition language should not constrain what services are offered, and the language should be transparent about what services are available.

Master Plan Recommendation: Make Sure Day Programs are Person-Centered [page 73]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should work with people with I/DD, their families and other community partners to make sure day-programs are person-centered. This could include developing day programs that are individualized.

#### Additional Details:

- DDS should make sure that community inclusion and participation opportunities and supports are available to all individuals, regardless of the setting they live in.
- Day services should include helping people explore and seek employment in the community.
- Meaningful day activities must be supported with access to transportation.
- Day programs must receive adequate funding and rates to provide individualized person-centered services, including to individuals with significant needs (including medical and behavioral needs). This will help prevent adverse selection.

Master Plan Recommendation: Improve Support Services That People With I/DD Receive at Home [page 73]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context.

DDS should improve the support services that people with I/DD receive when they live in their own home or their family homes. People need flexible supports that are responsive to their needs. Supports and services should be provided when and where people need them. Services should follow the individual through their life and should not be disrupted by life transitions.

The services that are available do not work well for many people with I/DD. The services are complicated, disjointed, and they limit rather than support access. Some of these services are provided by regional centers. Some of these services are provided by other agencies and programs. These services depend on a person continuously meeting criteria set by the system. These criteria can include where they live or how old they are.

These services include:

- Independent Living Services (ILS).
- Supported Living Services (SLS).
- In-Some Supportive Services (IHSS).
- Personal care services.
- Personal attendant services.

Short-term improvements to these services should focus on expanding the SLS program and making sure that people with I/DD can access person-centered SLS.

Long-term improvements should redesign the services which are provided to people who live in their own or family home. DDS should work with individuals, families, and other community partners to redesign services for individuals who live in their own or family homes using a flexible unified approach. <u>Additional Details:</u> DDS should work on short-term and long-term improvements to the services people receive when they live in their own or family homes.

Short-term recommendations include improvements to Supported living Services (SLS) and Enhanced Supported Living Services.

Long-term recommendations include redesign of services for people who live in their own or family homes to create a seamless and flexible system of supports.

Short Term Improvements:

- <u>Supported Living Services</u>. Supported Living Services (SLS) are a broad range of services to adults with developmental disabilities who choose to live in their own homes. The person served can own or lease their home in the community.
  - SLS may include:
    - Help with selecting and moving into a home
    - Choosing personal attendants and housemates
    - Getting 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 their 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 services because there are not enough providers.
    - This also impacts the quality of services being provided. Because SLS is provided in a person's own home, SLS providers and services are presumed to be compliant with HCBS rules.
    - Additionally, SLS is not available if a person chooses to live with their family based on their preferences and culture. Many families prefer to stay together according to their traditions.
    - This service helps prevent people from moving to more restrictive settings.
  - DDS should work with regional centers to:
    - Recruit providers of SLS services so that people do not have to wait to receive them.

- Create ways to make sure services are high quality, personcentered, and culturally informed.
- Develop a way to make sure that SLS is following HCBS rules, even though SLS settings are people's own homes and presumed to be HCBS compliant.
  - Consider using a client Advisory Council or another method to identify, review, and resolve problems.
- Make SLS services available to people living with family without having to move out of family homes.
- Develop a standard definition of SLS so that the service is provided consistently across the state.
- Make sure that individuals have transparency into what SLS providers are billing for. This will help make sure those services have actually been provided.

#### Enhanced Supported Living Services:

- Enhanced Supported Living Services are an alternate to residential care models. When people with I/DD 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 the support of the 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 SLS providers are not limited by the rules of Community Care Licensing 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 an individual's experiences and preferences.
  - DDS should work with regional centers to:
    - Continue to develop and expand the 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 recruit Enhanced SLS providers. Develop policies and measures to prevent Enhanced SLS from turning into unlicensed group homes.
- Pay providers in a way that is enough to cover the cost of services and prevent adverse selection (providers not wanting to serve people with more needs). Rates should pay for different staff with different training that is needed to meet the needs of individuals. Rates need to be higher when providers serve people with more support needs.
- Provide information to people with I/DD and families about this option.
- Make Enhanced SLS service available to people living with family without having to move out of the family home.
- Evaluate this service option to serve youth with I/DD.
- Explore how Enhanced SLS supports could be used in foster home settings for children with complex needs.

#### Long-term redesign of services for people who live in their own or family home:

- DDS should work with individuals, families, and other community partners to redesign services for individuals who live in their own or family homes using a flexible unified approach. This service approach should reflect these recommendations:
  - Services should be based on a person's needs and preferences, rather than their age, where or with whom they live, or other criteria. This includes people who live independently, with family, or with other people of their choosing.
    - This means that the services a person receives are put together based on the person's needs and preferences using person-centered planning process that looks at the whole person and their life goals.
    - Access to services should not be based on a "package" of services available to them because they live with family or independently.
  - Services should include and expand on the scope of services and supports currently available through SLS, Enhanced SLS, ILS, and other services available to individuals who live in their own or family home.
    - Available supports should include services that enable people with significant support needs to live in the home of their choice in the community, similar to the current Enhanced SLS model.

- Services should bring in additional supports, if the individual needs them to meet their accessibility, medical or behavioral needs. This way everyone can have the supports they need to live in the community.
  - Individuals with complex behavioral or medical needs should be able to receive the right supports through this service in their own homes and communities.
- Services should be person-centered and culturally responsive and should support a person's communication and language needs, including AAC and sign language.
- The services should evolve as a person goes through their life and life transitions without disruption, or as their needs change.
- Services should follow the individual where they go, either at home or within the community. This means supports are not tied to a person's home or another specific location, like day program center.
  - Services can follow the person as they participate in the community, civic life, work, advocacy, and more. This should be supported with access to transportation.
- Services should have enough providers so that people do not have to wait to receive them. This means DDS and regional centers should be working proactively to recruit providers.
- Services should have a reimbursement structure that pays providers enough.
  - Rates should reflect the cost of services and prevent adverse selection.
  - Rates should reflect various levels of staff qualifications and training that are needed to meet different needs of individuals.
  - Rates need to be tiered based on the person-centered support needs of the individual being served.
  - Additional funding needs to be made available to provide training on a regular basis for staff serving those with higher support needs (behavioral, medical, and other needs).
- Services should be high quality, person-centered, and culturally and trauma informed. There should be ways to measure this.
- There should be ways to make sure that services are following Home and Community Based Settings rule requirements (HCBS rules), even though home settings are the person's own or family homes and presumed to be HCBS compliant. DDS should consider using a client Advisory Council or another method to identify,

review, and resolve issues related to complying with rule requirements.

- DDS should develop standard definitions and rules for this service approach so that the service is provided consistently across the state.
- People receiving services should be able to know what providers are billing for. This will help make sure that services have actually been provided.
- People with I/DD and families should be given information about this option in plain language, in different languages and modalities.

# Health Care and Wellness.

These recommendations focus on making it easier for people with I/DD to get the health care services they need. The recommendations also focus on making sure that the health care services provided to people with I/DD are high quality.

#### Master Plan Recommendation: Make Sure People With I/DD Do Not Face Discrimination From Health Care and Behavioral Health Systems [page 76]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. The State and DHCS should make sure that health care systems do not discriminate against people with I/DD.

This recommendation includes health care and behavioral health services that DHCS funds and oversees. People with I/DD are sometimes denied services because they have a disability. This is called discrimination. Many people with I/DD experience discrimination when trying to get health care services and behavioral health services. When people with I/DD cannot get the health care and behavioral health services they need, they cannot live the lives they want and fully participate in the community. It can also make it harder and more costly for DDS and regional centers to serve people. To prevent discrimination, there are many things that the State and DHCS should do. For example:

- DHCS should change contracts and agreements with organizations and providers in their system to make it clear that they cannot discriminate against people with I/DD. DHCS should create measures and ways to hold them accountable to those expectations.
  - DHCS should create explicit expectations around compliance with measurements, accountability, and enforcement mechanisms in contracts with Managed Care organizations, counties, regional centers, providers, and other system partners.
- The State should create a responsible organization where people can report when they experience discrimination and barriers to health care services. This organization should look at data, review, and investigate reports, and help to address and resolve issues.
  - This could look like an ombudsperson program.

- This organization should review and investigate reports and help address and resolve issues.
- This organization should also look at data and see if there are any trends or gaps. This will help create more information on what people experience.
- Data should be gathered, analyzed, and used to make systems better and help eliminate discrimination. When providers deny services to people with I/DD, they should provide an explanation. This organization should review this explanation to make sure it is not discriminatory.
- DHCS should provide outreach and education to health care and behavioral health providers to transition to compliance with antidiscrimination laws. including:
  - Provide outreach and education, including information about providing accommodations, if needed, to individuals with I/DD.
  - Provide technical assistance, training, and outreach to help health care and behavioral health professionals and organizations understand their rights, responsibilities, and mandates to serve individuals with I/DD.
- DHCS should engage self-advocates, family members, DDS, and community partners to develop strategies to make sure antidiscrimination laws and rules are followed.
- DHCS should also develop and regularly report on data and measures specific to disparities, access, and utilization for the I/DD population compared to the population without disabilities.
  - Data must be broken out by race, ethnicity, gender, language, and other demographic characteristics.
- Disability, including I/DD, is a protected class under Americans with Disabilities Act (ADA), and individuals with I/DD are protected under ADA and other federal statutes and rules including Section 504 of the Rehabilitation Act and Section 1557 of the Affordable Care Act. <sup>4 5</sup>
  - DHCS should also regularly report on the status of Final Rules implementation (Final Rule implementing Section 504 of the Rehabilitation Act and Final Rule implementing the antidiscrimination provisions under Section 1557 of the Affordable Care Act).

 <sup>&</sup>lt;sup>4</sup> <u>For more information about protections against disability discrimination</u> (<u>https://www.hhs.gov/about/news/2024/05/01/hhs-finalizes-rule-strengthening-protections-against-disability-discrimination.html</u>)
 <sup>5</sup> <u>For more information about nondiscrimination protections</u>

<sup>(</sup>https://www.hhs.gov/about/news/2024/04/26/hhs-issues-new-rule-strengthen-nondiscriminationprotections-advance-civil-rights-health-care.html)

# Master Plan Recommendation: Make Sure There are Enough Health Care

**Providers to Support People With I/DD [page 78].** Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DHCS and DDS should provide resources and funding to make sure there are enough providers for people to choose from across the State.

This recommendation includes providers in the I/DD system, health care system, and behavioral health system. DDS and DHCS should develop ways to pay I/DD, health care, and behavioral health providers so that people with I/DD can get services they need in a timely way. Providers should be paid enough to provide accommodations and accessibility supports people need.

DDS and DHCS should recognize adverse selection as a form of discrimination. Adverse selection is when providers only agree to serve people with fewer support needs. DDS and DHCS should develop funding models for I/DD, health care, and behavioral health providers that reflect the level of need of people with I/DD and the cost of services that meet their needs. This will prevent adverse selection.

Additional Details: DHCS and DDS should:

- Hold Managed Care organizations and regional centers accountable to make sure there are enough providers across the state so that people get services when they need them.
- Create expectations and provide resources for regional centers to recruit and develop new providers.
- Develop and regularly report on measures related to provider availability across the state, including linguistical and culturally specific capacity.
- Collect data on what families, individuals, and community partners are experiencing with primary care physicians, emergency departments, urgent care services, access, what areas they feel are being missed or deficiencies that exist in services.
- Develop flexible funding models for I/DD, healthcare, and behavioral health providers so that people with I/DD can get timely services they need and get disability related accommodations and accessibility supports they need. Use these resources to recruit providers who can serve people with I/DD in a culturally appropriate and person-centered way.
  - Services across I/DD, healthcare, and behavioral health systems should be adequately resourced to provide individualized supports, allow providers to collaborate effectively, and implement innovative solutions that could improve quality of life outcomes.

The state should:

• Study what is stopping new providers from joining the field. This will help to understand how to expand available services.

- This can include review of risks for Private Attorneys General Act litigation, worker compensation costs, insurance costs, and funding mechanisms.
- Consider doing a state-sponsored vendor collective for insurance.
  Supporting small businesses as providers will help create more options for more culturally competent vendors that individuals and families can trust.

#### Master Plan Recommendation: Make Sure Healthcare Service Systems Coordinate to Support People with I/DD [page 79]. Details for this

recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. CalHHS should make sure that all of the systems that provide health care services to people with I/DD work together.

Different systems have different rules and ways for people to get needed supports. This can make it very difficult for people with I/DD and their families to know how to get the services and supports they need. It is important that the systems work together to make getting services easier. This will help make sure that people with I/DD and their families can get all of the services that they need from the different systems that serve them. There are many things CalHHS should do to make sure that health care systems work together. CalHHS should:

- Require that DHCS and DDS set up agreements that make it clear how they coordinate all services that people with I/DD and their families need.
- Require that DHCS and DDS create ways to coordinate services and supports across systems using person-centered principles and practices. This includes sharing data and information.
- Require that DHCS and DDS work together to make it clear how people with I/DD and their families will get specific services. This will require making sure that people can get services from DHCS and DDS that might be similar, but which might meet different needs.
  - For example, DHCS Enhanced Care Management (ECM) and Community Supports services from DHCS.

#### <u>Additional Details:</u> Some people have complex medical or mental health needs. They need more help from healthcare and behavioral health professionals and providers.

- Individuals with I/DD and their families need help getting supports from different systems and providers.
- DHCS and DDS should work together to make sure that systems they oversee and fund support people with I/DD and families with robust coordination and navigation of services they provide. I/DD, healthcare and behavioral health systems should connect and coordinate with each other to ensure holistic and seamless supports.
  - DHCS and DDS should establish formal agreements between Managed Care organizations, regional centers, and counties to:

- Define roles and responsibilities of Managed Care organizations, counties, and regional centers for coordination and navigation of services. This needs to reflect Lanterman Act expectations of regional centers and service coordinators' role in providing individuals with I/DD end to end navigation and cross system coordination of support services throughout their lifespan. This also needs to require collaboration from other systems.
- Create ways to coordinate services and supports across systems using person-centered principles and practices. This includes sharing of data and information.
- Make Enhanced Care Management (ECM) available through Medi-Cal to all individuals with I/DD. Make ECM part of formal agreements and require ECM to coordinate with regional centers and Counties Behavioral Health programs. Clearly distinguish ECM from service coordination provided by regional centers.
- Make Community Supports services provided by managed care organizations available to people with I/DD. Develop ways to make sure they do not duplicate services provided by regional centers.
- DHCS and DDS should develop a way for healthcare, behavioral health, and I/DD systems to work together as a multi-disciplinary team to support individuals with complex cross-system needs using a whole person approach. Multidisciplinary teams should include other team members as needed.
  - DHCS and DDS should develop and implement incentives for healthcare, behavioral health, and I/DD providers to proactively support people with complex cross-system needs.
- Make sure systems recognize that individuals with I/DD can have a full range of human experiences, including physical health, mental health and substance use conditions and are entitled to receive necessary services and supports to meet all their needs.
- Healthcare, behavioral health, and I/DD systems need to stop using the concept of "primary diagnosis" to deny or limit access to needed supports.
- Develop and implement accountability and performance metrics which provide information on how well the regional centers, Managed Care organizations, and counties are doing in supporting navigation, coordination, and communication.

- Establish incentives and enforcement approaches to make sure people receive high quality navigation and coordination supports.
- Establish better, easy-to-use ways to communicate between the regional centers, service providers, individuals and families.
   Communication needs to be supported in the language preferred by the individual and their family and should be in plain language.
  - Establish customer service standards that guide regional centers and providers in how to better support individuals and families. This includes a timeline to return phone calls or emails, not to use complex "phone trees" (Phone tree - an automated telephone system that directs callers according to options selected in response to recorded questions) – people should be able to get a live person to respond and help them get to the right place to have their questions answered.
  - Use technology to communicate where it is helpful. Always make available ways to communicate that do not involve technology.

#### Health Care and Wellness- Behavioral Health Services.

These recommendations focus on making sure that people with I/DD can access the behavioral health services that they need. The recommendations also focus on making sure that behavioral health services for people with I/DD are high-quality.

Master Plan Recommendation: Make Sure People With I/DD and Behavioral Health Needs Get Enhanced Care Management (ECM) and Enhanced Service Coordination [page 84]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS and DHCS should develop and implement a statewide approach to provide ECM and enhanced service coordination.

- DHCS should make a new population of focus for the ECM Medi-Cal benefit. A "population of focus" for ECM means a group of people who have specific needs which ECM would help with. ECM is a service that provides a Lead Care Manager to coordinate health and health-related care and services. ECM helps connect people with complex needs to care that they need, wherever they are. Making people with I/DD who also have behavioral health needs population of focus for ECM would help make sure that people with these kinds of complex needs can get care coordination support.
- DDS and regional centers should include people with I/DD with complex behavioral health needs in lower regional center caseloads ratios for individuals with complex needs. This should specifically include people who are "at risk" of needing crisis services or for whom the crisis services are not available. DDS and regional centers should also include

placement in Institutions for Mental Diseases as a criteria for complex needs and lower caseload ratios.

- Additional Details:
  - To support the implementation of this recommendation, DDS should Amend WIC 4640.6 (6)(C). Suggested amendments are presented with <u>italics and underlining.</u> Suggested amendments include:
    - (6) (A) Notwithstanding paragraphs (1) to (3), inclusive, an average service coordinator-to-consumer ratio of 1 to 25 for all consumers with complex needs.
    - (6) (B) The coordinator-to-consumer ratio specified in this paragraph shall not be authorized for a consumer for more than 12 months after the consumer is no longer receiving the services described in clause (i) or (ii) of subparagraph (C), after the consumer is no longer placed in a facility described in clause (iii), (iv), (v), (vi), (vii), or (viii) of subparagraph (C), or after the department has made the determination described in clause (ix) of subparagraph (C), unless an extension is granted. An extension shall be based on a new and complete comprehensive assessment of the consumer's needs. An extension may be granted one time and shall not exceed six months.
    - (6) (C) For the purposes of this paragraph, a "consumer with complex needs" means a consumer who is <u>at risk of needing</u>, <u>eligible for but has not received</u>, <u>or receiving</u> any of the following:
      - (i) Receiving regional center-funded mobile crisis services by a department-approved vendor or has received those services within the past six months.
      - (ii) Receiving state-operated crisis assessment stabilization team services or has received those services within the past six months.
      - (iii) Placed in a community crisis home, as defined in Section 4698.
      - (iv) Placed in an acute crisis home operated by the department, pursuant to Section 4418.7.
      - (v) Placed in a locked psychiatric setting or has been placed in a locked psychiatric setting in the past six months.

- (vi) Placed in an institution for mental disease, as described in Part 5 (commencing with Section 5900) of Division 5.
- (vii) Placed at the Canyon Springs Community Facility operated by the department.
- (vii-viii) Placed out of state as a result of appropriate services being unavailable within the state, pursuant to Section 4519.
- (<u>viii- ix</u>) Placed in a county jail and eligible for diversion pursuant to Chapter 2.8 (commencing with Section 1001.20) of Title 6 of Part 2 of the Penal Code or found incompetent to stand trial as described in Section 1370.1 of the Penal Code.
- (ix x) A person the department has determined cannot be safely served in a developmental center, as described in Section 6510.5. <u>or another state</u> <u>operated facility</u>.

# Health Care and Wellness- Dental Services.

These recommendations focus on making sure that people with I/DD can access the dental services that they need. The recommendations also focus on making sure that dental services for people with I/DD are high-quality. No additional detail or technical information was developed for any of the recommendations in this sub-topic section.

# Transition Supports.

These recommendations focus on making sure that people with I/DD get the supports they need during life transitions.

Master Plan Recommendation: Make Sure People with I/DD Have Transition Supports [page 89]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS and regional centers should provide transition supports to people with I/DD before any transition begins. This makes sure that all people making a transition will have the support that they need.

Transition supports should include:

- The option of a Person-centered Plan (PCP) by a provider they choose.
- Someone to help them, who they can choose. This person is called a "navigator."
  - Navigators can help by:
    - Attending planning meetings.
    - Completing service applications.
    - Identifying service options.

- People should have the option to choose a navigator who is a peer with I/DD.
- Information about the life transition and what happens next. DDS should work with diverse stakeholders, including self-advocates, to develop information for each major life transition. This information must:
  - Be designed with the "end-users" in mind. The end users are individuals and their families. End-users may also be communitybased organizations, navigators, and service coordinators.
  - Include information about the individual's rights.
- The option of a PCP and planning services by a provider they choose as part of each transition. DDS has proposed a waiver amendment to allow for a PCP during life transitions. This recommendation would expand upon that effort as follows:
  - DDS should develop information about PCP with diverse stakeholders, including self-advocates. The information must be in plain language. It must be translated into the languages spoken by individuals and their families.
  - DDS should define a PCP as planning tool based on core PCP principles, such as:
    - The PCP focuses on the whole person.
    - The PCP focuses on life goals and dreams. This means longterm goals, how to achieve them and ways to address barriers.
    - The PCP identifies what the person needs to prosper. This includes the kinds of supports the individual chooses to reach their goals.
  - The PCP plan waiver service should also provide additional options for the development of the PCP. For example, the PCP could be developed by:
    - A natural support
    - A regional center service coordinator
    - A qualified vendor (as allowed by the proposed waiver amendment)
    - Another qualified individual who provides PCP services through Participant-directed services

Master Plan Recommendation: Support Transitions From High School [page 93]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. Regional centers should provide all high school students with the transition supports they choose. These supports should start at age 14. This will make sure that there is time to plan before the person leaves school. The supports will continue until the person receives the services they have chosen to receive after high school.

- <u>Additional Details:</u> One barrier to implementing this recommendation may be Welfare and Institutions Code Section 4648.55(d) which prohibits regional centers from purchasing day program, vocational education, work services, independent living program, or mobility training and related transportation services for a consumer who is 18 to 22 years of age, inclusive, if that consumer is eligible for special education and related education services and has not received a diploma or certificate of completion absent narrow circumstances. The amendment below is intended to address this barrier. Suggested amendments are presented with <u>italics and underlining.</u>
  - 4648.55(d) amendment: (d) An exemption to the provisions of this section may be granted in <u>either of</u> the following circumstances:
    - (1) For participation in a paid internship or competitive integrated employment that is an outcome of a paid internship described in subdivision (a) of Section 4870 if the IPP planning team determines that the consumer could benefit from participation in a paid internship or competitive integrated employment. Participation in a paid internship or competitive integrated employment that is an outcome of a paid internship does not preclude a consumer from continuing to receive public education services to the extent those services are determined to continue to meet the consumer's needs.
    - (2) For participation in a paid or unpaid internship, volunteer opportunity or competitive integrated employment that occurs before or after school or during breaks in the school year, if the IPP planning team determines that the consumer could benefit from participation.
    - (3) For participation in community activities that occur after school hours or during breaks in the school year, if the IPP planning team determines that the consumer could benefit from the participation.
    - (4) For participation in an independent living program or services provided before or after school hours or during breaks in the school year that will assist in consumer in achieving their preferred post-secondary goals if the IPP planning team determines that the consumer could benefit from the service.
    - (25) On an individual basis in extraordinary circumstances to permit purchase of a service identified in subdivision (a). An exemption shall be granted through the IPP process and shall be based on a determination that the generic service is

not appropriate to meet the consumer's need. The consumer shall be informed of the exemption and the process for obtaining an exemption.

 In addition, the DDS guidance about waiting lists for post-secondary transition services should collect data about the timeliness of providing post-secondary services and develop strategies to address any delays in receiving services that are greater than 30 days.

Master Plan Recommendation: Help Plan for the Future for People with I/DD who Live with an Aging Caregiver [page 100]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS and regional centers should help people with I/DD and their families plan for long-term housing and residential care needs.

This recommendation means making a plan for where a person with I/DD will live when their parent or other family caregiver is no longer able to live with and care for them. This planning should happen before aging caregivers can no longer provide support. The plan should be included in the person with I/DD's IPP.

#### Additional Details: This planning should use tools like:

- Legacy homes.
- Special needs trusts or pooled trusts.
- Future planning programs.
- Regional centers should help families coordinate the supports they need as they make plans for using their home to provide the housing and services that their loved one with I/DD might need during their lifetime.

#### Access to Other Services.

These recommendations are about services that people with I/DD use that are not specific to the developmental services system. These services are called "generic services." These recommendations are focused on making it easier for people to get generic services that they need and choose from different service systems.

Master Plan Recommendation: Make Sure Regional Centers Provide Generic Services that Have Waitlists [page 104]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. CalHHS and DDS should propose changes to the Lanterman Act. These changes would allow regional centers to pay for a generic service when the service cannot be provided by a generic services agency within 30 days (or sooner in an emergency or other immediate need putting the individual's health and safety at risk). This is sometimes called "gap" funding. If the person is on a waiting list, the service is not available to them. CalHHS and DDS should also develop ways for regional centers to be reimbursed for the cost of the generic services they pay for.

#### Additional Details:

- CalHHS and DDS should also develop pilot programs to reimburse regional centers for generic services. For example:
  - A program allowing regional centers to pay for Applied Behavior Analysis (ABA) services when there is a waitlist for generic services. Then to be paid back by managed care providers.
  - DDS and DHCS should also pilot a program allowing regional centers to initially pay for ABA services and then to be paid back by managed care providers.
- DDS should propose changes to Welfare and Institutions Code Section 4646.4 to expand a regional centers' ability to provide gap funding. One approach to these changes is identified in the next recommendation.
- CalHHS, working with its departments and diverse stakeholders, should develop or refine current processes to resolve payment disputes between departments and CalHHS.
  - For example, similar to WIC 4659.7, this should allow for resolution of disputes about which entity is required to pay for a specific type, frequency or duration of service specified in an individual's IPP or Individualized Family Service Plan (IFSP). It should also require the regional center to provide the service that is in dispute and seek reimbursement for the cost of the service as part of the dispute resolution process.
- Use of gap funding could be initially implemented as a pilot.
  - For example, a regional center could purchase those generic services which are eligible for funding under the Medicaid State Plan and any of the state's Medicaid Waivers.
  - This option would allow for cost neutrality as the services would be eligible for federal Medicaid funds regardless of which entity provided/funded the services.

Master Plan Recommendation: Make it Easier for People to Get Generic Services [page 105]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. CalHHS and DDS should change the Lanterman Act to remove the requirement that people with I/DD and their families must appeal a generic services denial.

This recommendation says that CalHHS and DDS should also create a way to resolve disagreements between systems about which system should pay for a generic service. This will make it easier for people with I/DD and their families to get the generic services that they need. DDS should also make sure that:

- If a person served wants to appeal a denial, the regional center should help them get an attorney or agency to help.
  - If the attorney does not work for a legal aid program and requires payment, the regional center should pay for the attorney.

- For example, a school district denies behavioral support during school. The child is not successful in school because of their behavior and the parent wants to appeal the decision.
- The regional center cannot use information it learns when helping a person access a service or benefit against the person.
  - For example, if the regional center is helping a person served to write a letter to support an SSI appeal and they learn something about the person's disability, they cannot use that information to change the person's regional center eligibility.
- Additional Details:
  - DDS should specify that an individual served by the regional center does not have to appeal a denied generic service when the generic agency made its decision using its eligibility, assessment, or planning processes.
  - To implement these recommendations, Welfare and Institutions Code Section 4646.4(a) and WIC 4659 should be amended. Suggested amendments are presented with <u>italics and underlining.</u> Suggested amendments are:
    - 4646.4. (a) Regional centers shall ensure, at the time of development, scheduled review, or modification of a consumer's individual program plan developed pursuant to Sections 4646 and 4646.5, or of an individualized family service plan pursuant to Section 95020 of the Government Code, the establishment of an internal process. This internal process shall ensure adherence with federal and state law and regulation, and if purchasing services and supports, shall ensure all of the following:

(1) Conformance with the regional center's purchase of service policies, as approved by the department pursuant to subdivision (d) of Section 4434.

(2) Utilization of generic services and supports if appropriate, in accordance with all of the following:

(A) The individualized family service planning team for infants and toddlers eligible under Section 95014 of the Government Code may determine that a medical <u>or other generic service</u> identified in the individualized family service plan is not available <u>when the service is not provided</u> within <u>630</u> calendar days, <u>or sooner if there is an emergency that impacts</u> <u>the consumer's health and safety</u>, through the family's private health insurance policy or health care service plan or under the Medi-Cal program <u>or</u> <u>another generic services agency</u>, and therefore, in compliance with the timely provision of service requirements contained in Part 303 (commencing with Section 303.1) of Title 34 of the Code of Federal Regulations<u>, the service</u> will be authorized for purchase-of-service funding by the regional center.

(B) The individual program plan team under Section 4646 may determine that a medical <u>or other generic</u> service identified in the individual program plan is not available <u>when the service is not provided</u> within <u>630</u> calendar days, <u>or sooner if there is an emergency</u> <u>that impacts the consumer's health and safety</u>, through the family's private health insurance policy or health care service plan or under the Medi-Cal program <u>or another generic services</u> agency and therefore, in compliance with paragraph (1) of subdivision (d) of Section 4659, <u>the service</u> will be authorized for purchase-of-service funding by the regional center.

(C) For purposes of this paragraph, a regional center shall authorize the provision of medical <u>or other</u> <u>generic</u> services through the purchase of services during any <u>plan or other generic services agency</u> delays<u>-including the appeals process</u>. A consumer or, when appropriate, the parent, guardian, or conservator or authorized representative, shall not be required to appeal the denial of services from another agency that has a legal responsibility to serve all members of the general public and is receiving public funds for providing those services in order for a regional center to purchase those services as part of a consumer's IPP.

• Delete WIC 4659(c)and (d).

(c) Effective July 1, 2009, notwithstanding any other law or regulation, regional centers shall not purchase any service that would otherwise be available from Medi-Cal, Medicare, the Civilian Health and Medical Program for Uniform Services, In-Home Support Services, California Children's Services, private insurance, or a health care service plan when a consumer or a family meets the criteria of this coverage but chooses not to pursue that coverage. If, on July 1, 2009, a regional center is purchasing that service as part of a consumer's individual program plan (IPP), the prohibition shall take effect on October 1, 2009.
(d) (1) Effective July 1, 2009, notwithstanding any other law or regulation, a regional center shall not purchase medical or dental services for a consumer three years of age or older unless the regional center is provided with documentation of a Medi-Cal, private insurance, or a health care service plan denial and the regional center determines that an appeal by the consumer or family of the denial does not have merit. If, on July 1, 2009, a regional center is purchasing the service as part of a consumer's IPP, this provision shall take effect on August 1, 2009. Regional centers may pay for medical or dental services during the following periods:

- (A) While coverage is being pursued, but before a denial is made.
- (B) Pending a final administrative decision on the administrative appeal if the family has provided to the regional center a verification that an administrative appeal is being pursued.
- (C) Until the commencement of services by Medi-Cal, private insurance, or a health care service plan.
- (2) When necessary, the consumer or family may receive assistance from the regional center, the Clients' Rights Advocate funded by the department, or the state council in pursuing these appeals.

### Help Getting Services.

These recommendations focus on ways that people with I/DD and their families can get help with getting services.

#### Master Plan Recommendation: Make a Single On-Line Application for Services

**[page 110].** Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. CalHHS should work with its departments and diverse stakeholders to develop a single on-line application for the health and human services the individual needs and chooses.

When developing this system, CalHHS should consider current systems which provide some of the expected functionality and assess whether the functionality of those systems can be expanded. Examples of existing systems include:

- BenefitsCal.
- The San Diego Community Integration Exchange, which is part of its 211 system.

The goal of the single on-line application would be to create a unified, accessible platform that allows people with I/DD, families, or caregivers to access all eligible services from any CalHHS department regardless of the department they first contacted. The system should:

- Provide a seamless experience.
- Provide personalized service recommendations.
- Provide automatic enrollments.
- Allow 24/7 access for people to access their information.
- Provide notifications about application status.
- Provide connections to ways to get help.
- Support enrollment by using a network of community-based partners and service centers to provide in-person or phone-based assistance for individuals who need help navigating the system.
- Prioritize users who have an immediate crisis. This includes homelessness, domestic violence, food insecurity, or medical emergencies.
- Protect privacy and confidentiality.
- Require cross-system data sharing.
- Provide training for users.
- Ask users to provide feedback.
  - Feedback will be used to evaluate system improvements and for futures planning. This will help make sure the system is taking advantage of new technologies that will make it better.

<u>Additional Details:</u> The following considerations should serve as a starting point for deeper examination of the functional and technical requirements of an integrated system and an analysis of the current Information Technology (IT) system's overlaps and gaps. This is not intended to be an exhaustive list of requirements.

The goal of the Common Application system is to create a unified, accessible platform that allows individuals, families, or caregivers to access all eligible services from any California Health and Human Services (CalHHS) department regardless of the department first contacted. The system will provide a seamless experience, personalized recommendations, and automatic enrollments, with a focus on accessibility and inclusivity for individuals with disabilities, including hearing or visual disabilities.

- Functional requirements
  - Personalized onboarding

- Profile setup:
  - Users create profiles by inputting personal data (e.g., name, date of birth, disability type, current services, preferences).
  - Data fields include both mandatory (e.g., name, age) and optional (e.g., disability type, preferred language, and communication method).
  - Caregivers and family members can set up profiles on behalf of individuals.
- Data integration:
  - The system pulls data from external sources (e.g., medical records, educational plans, social service records) via secure APIs.
  - Users can upload documents manually if needed, with optional OCR to help with document parsing.
  - The system makes sure data is updated in real time across all agencies.
- Proactive eligibility alerts
  - Eligibility monitoring:
    - Continuous monitoring of user data against eligibility criteria across all CalHHS agencies and related programs.
    - The system uses AI to analyze the user's profile and determine eligibility based on disability type, age, income, location, and services the individual is already receiving (in some cases being eligible for one service type may mean that the individual is automatically eligible for another service type).
  - Notifications:
    - Users receive real-time eligibility alerts through their preferred communication method (text message, email, in-app notification).
    - The system supports multi-language notifications based on user preferences.
  - Recommendations:
    - The system provides Al-driven service suggestions based on individual profiles and historical choices.
    - Users can accept or decline recommendations, and the system will learn to refine its suggestions accordingly.

- Automatic enrollment
  - Service enrollment:
    - Eligible users are automatically enrolled in services they qualify for without requiring manual intervention.
    - Users receive a notification confirming their enrollment and instructions on customizing the service (e.g., preferred method of service delivery).
  - Consent and electronic signatures:
    - The system supports electronic signatures for enrolling in services, fully compliant with California digital signature laws.
    - Consent forms are available in accessible formats (e.g., screen reader compatible) and in multiple languages.
- Simplified service access
  - Unified digital portal:
    - All services across CalHHS departments are consolidated into a single, user-friendly portal.
    - The portal supports multiple languages, is ADA compliant, and accessible to users with hearing or visual disabilities.
  - One-click access:
    - Services are accessible with a single click, minimizing the need to fill out repetitive forms.
    - Users can directly request services, schedule appointments, or reach out for support via the portal.
- Ongoing support and updates
  - Virtual assistant & live chat:
    - Users have access to continuous support through a virtual assistant capable of answering FAQs and providing service recommendations.
    - For more complex issues, users can access live chat or call a dedicated hotline, with the option for a video chat with ASL interpreters.
  - Service updates:
    - Regular updates are provided regarding service status, changes in eligibility, deadlines, or upcoming appointments.

- Updates are pushed through users' preferred communication method.
- Feedback loop
  - User feedback collection:
    - After accessing services, users are prompted to provide feedback through short surveys.
    - Feedback helps identify issues, monitor satisfaction, and suggest improvements to service delivery.
  - Continuous improvement:
    - The system incorporates feedback to enhance future experiences and optimize service recommendations.
    - Analytics from user behavior and feedback will also inform future system updates and service adjustments.
- Non-functional requirements
  - Accessibility
    - ADA compliance:
      - The system meets ADA standards, ensuring access for individuals with physical, sensory, and cognitive disabilities.
      - The system supports screen readers, offers alt text for all images, and enables keyboard navigation.
      - The interface is compatible with assistive technology such as text-to-speech software, screen magnifiers, and Braille readers.
    - Multi-language support:
      - The system provides language options, ensuring all pages, forms, and communication methods are available in any language preferred by the user.
      - Text and audio translations are available, and users can select their preferred language for all communications.
  - Data privacy and security
    - HIPAA & state compliance:
      - The system follows HIPAA guidelines and state laws to protect sensitive health and personal data.
      - Personal data is encrypted both in transit and at rest, with role-based access control to make sure only

authorized personnel can access sensitive information.

- Multi-factor authentication:
  - Users can opt for two-factor authentication (2FA) during login for enhanced security.
  - Login options include biometric authentication for ease of access.
- Data minimization and retention:
  - The system only collects the data necessary to provide services and minimizes storage of unnecessary data.
  - Data retention policies will comply with California state laws, ensuring data is purged after predefined time frames unless continued storage is legally required.
- Performance & scalability
  - Real-rime processing:
    - The system must handle real-time data integration and provide immediate feedback on eligibility status or updates to user profiles.
  - Scalability:
    - The system must be scalable to accommodate increasing numbers of users across California, with no reduction in performance as the user base grows.
- Usability
  - User-centered design:
    - The interface is intuitive, with a focus on a simplified user journey to make sure there is ease of use for individuals with varying degrees of technical proficiency.
    - A feedback mechanism makes sure that the user experience continues to improve.
  - Mobile accessibility:
    - The platform will be fully responsive, accessible from mobile devices, tablets, and desktops, allowing users to access services from any device.
- Compliance requirements
  - Legal and regulatory compliance

- The system complies with all relevant federal, state, and local laws, including HIPAA, ADA, and the California Consumer Privacy Act.
- Electronic signatures and document storage comply with California's Uniform Electronic Transactions Act.
- Data privacy
  - Full adherence to privacy regulations, ensuring users are informed about data collection and have control over how their data is shared across CalHHS agencies.

# Topic 5: People With I/DD Being Part of and Being Served by a Strong Workforce

The goal for this topic is that people who want to work supporting people with I/DD have what they need to stay in their jobs. This includes people with I/DD who want to work in this field.

# People Who Provide Services to People with I/DD.

These recommendations focus on making sure that people with I/DD can be supported by a strong workforce.

Master Plan Recommendation: Help People be Successful as Disability Service Providers [page 121]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. The State should work with the community college system to provide training and Career and Technical Education (CTE) programs for those in disability services careers. The training and CTE programs should include an apprenticeship and competency-based education to make sure that students in the program get the skills they need to be successful as disability services providers. These programs would provide easy to access low-cost/no cost training opportunities. The State could begin by identifying a lead person at DDS to work with a community college willing to sponsor this effort or expand existing similar programs.

 This recommendation and the next two recommendations were informed by a report and a presentation by Teresa Anderson, the Executive Director of the California Policy Center for Intellectual and Developmental Disabilities. Work on this recommendation should reference the report: <u>California Policy Center for Intellectual & Developmental Disabilities</u> <u>"Direct Support Professionals Workforce Crisis"</u> (https://www.cpcidd.org/reports/dsp-workforce-crisis/).

Master Plan Recommendation: Make Sure People in Disability Service Careers Have Benefits [page 121]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. The State should create a directory of benefits programs that people in disability-related careers could access if they do not receive benefits through their employer. This would be particularly helpful for people who are self-employed or employed through the SDP. The benefits could include:

- Health care benefits.
- Retirement programs.
- Other savings and insurance programs.

The State could also explore creating new state-sponsored benefit programs where there are any benefits gaps.

 Work on this recommendations should reference the report: <u>California</u> <u>Policy Center for Intellectual & Developmental Disabilities "Direct Support</u> <u>Professionals Workforce Crisis" (https://www.cpcidd.org/reports/dspworkforce-crisis/)</u>.

Master Plan Recommendation: Make Sure People in Disability Service Careers Make Enough Money [page 122]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. The State should update the way it determines how much to pay vendors and DSPs. This is known as the vendor rate model. The goal of an updated vendor rate model is to have a rate that allows competitive pay for DSPs and covers the costs of administering services.

The State should also conduct a study to understand the wages and the required skills and qualifications for other types of jobs that DSPs sometimes apply for. This study should also examine rates needed to make sure there are enough providers in rural communities, to adequately support group services, and for serving individuals with high-support needs.

The State should include an assessment of how vendors use rate increases, including how much money from increased rates goes to paying DSPs.

DDS should use the results of these studies to make sure that the vendor rate model is paying DSPs a competitive wage and provide more flexible ways for providers to obtain rate exceptions when needed. After this update is complete, the State should make a commitment to periodically update the vendor rate model to make sure that it continues paying competitive wages in the future.

 Work on this recommendations should reference the report: <u>California</u> <u>Policy Center for Intellectual & Developmental Disabilities "Direct Support</u> <u>Professionals Workforce Crisis" (https://www.cpcidd.org/reports/dspworkforce-crisis/)</u>.

# **Opportunities for People with I/DD.**

These recommendations focus on making sure that people with I/DD who want to work have the opportunity to work. No additional detail or technical information was developed for any of the recommendations in this sub-topic section.

# Topic 6: Accountability and Transparency in All Systems That Serve People With I/DD

# Keeping People With I/DD Safe.

People with I/DD are more likely to be mistreated, abused, or neglected than people without disabilities. These recommendations focus on keeping people with I/DD safe.

Master Plan Recommendation: Keep People With I/DD Safe From Mistreatment, Abuse, and Neglect [page 126]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. Prevent future instances of mistreatment, abuse, and neglect. Support individuals and families who need help with cases of mistreatment, abuse, and neglect.

- DDS should review and adopt the California State Auditor report and most of the <u>Massachusetts Disabled Persons Protection Commission</u> (<u>https://www.mass.gov/orgs/disabled-persons-protection-commission</u>) recommendations to prevent harm to those served by the system. That means that DDS should:
  - Make sure there is accountability and consequences that are enforced for people who abuse, mistreat and neglect individuals.
  - Create a statewide abuse reporting hotline.
  - Increase transparency in reporting investigations, including creating a registry.
  - Create a "before, during, and after" abuse plan during IEP and IPP meetings with school systems and other partners.
    - This comprehensive plan, serving clients and their family, should include sexual and other abuse education, recognizing signs of abuse, reporting procedures, and a clear outline for managing suspected abuse cases with other agencies. It makes sure there is proactive prevention, support during incidents, and appropriate responses post-abuse, with all parties—including the client, family, and caseworker—aligned.
  - Make sure there are clear processes, technology, and systems for identifying, communicating, and taking care of potential dangers early. Make sure those processes support reporting, investigating, and addressing cases of mistreatment, abuse, and neglect.
  - Make sure people have options and independent support to report problems. Make sure they feel comfortable and protected when they do report problems. Make sure people with complex needs, including people who use alternative communication devices, are supported.
  - Make sure self-advocates who lose their cases against suspected abusers are not retaliated against.

- Strengthen the DDS Office of the Ombudsperson to handle problems better.
  - Create a special unit in the office to support abuse complaints and processes. Hire specialized people to deal with these cases.
  - Define the Ombudsperson's role and provide the necessary resources and authority for effective investigations and enforcement.
  - Adopt successful strategies from other departments' Ombudsperson offices to enhance DDS operations.
  - Create a channel for the Ombudsperson to escalate systemic issues to leadership or external oversight bodies.
  - Notably, there are currently two Offices of the Ombudsperson in the developmental disability service system:
    - The Self-Determination Program (SDP) Ombudsperson program opened on October 12, 2021. WIC Section 4685.9 set out the mandates for the program.<sup>6</sup> Unlike most Ombudsperson statutes, the section does not provide the Office with access authority. To conduct abuse investigations, the Office would need both additional statutory authority and staff.
    - The Office of the Lanterman Ombudsperson opened on December 1, 2022, and was created in budget (not statute).
    - As of spring 2025, there is a bill (SB 471- Office of the Lanterman Ombudsperson) that if passed would support the implementation of components of this recommendation.<sup>7</sup>
- Require training on harm prevention, care for people who experience abuse, and reporting. Include people with disabilities and others with specialized skills in these areas in trainings for dealing with these cases.
- Make sure there is training and resources for individuals and families about examples of mistreatment, abuse, and neglect and how to report it.
- Individuals should be able to use surveillance cameras in their own homes so they feel safe. Individuals should make sure people who enter their homes know there are cameras being used. Rules should be made that talk about how surveillance cameras may be used in other settings. Those rules should talk about how privacy is important, and what rights individuals have about the use of cameras.

<sup>&</sup>lt;sup>6</sup> For more information about WIC Section 4685.9

<sup>(</sup>http://leginfo.legislature.ca.gov/faces/codes\_displaySection.xhtml?sectionNum=4685.9&lawCo de=WIC)

<sup>&</sup>lt;u>7 For more information about SB-471 "Office of the Lanterman Ombudsperson</u> (https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\_id=202520260SB471)

- Engage and educate the medical community about abuse and how it can be reported.
- Create partnerships between regional centers and rape crisis centers and train people who work in rape crisis centers about people with disabilities and how to best serve them.
  - Regional centers are not fully equipped to handle sexual abuse cases.
  - Rape crisis centers offer specialized support but often lack the experience needed to work with individuals with I/DD.
  - To bridge this gap and make sure victims of abuse are supported, partnerships between regional centers and rape crisis centers must be established, led by a Regional Center Crisis Manager, and ensuring that rape crisis centers are properly funded and prepared to meet the unique needs of this community.

#### Additional Details:

To prevent harm to individuals served by the system, DDS should:

- Establish proactive risk assessment protocols to identify and address potential dangers early.
- Adopt recommendations from the <u>2022 California State Auditor Report</u> (<u>https://information.auditor.ca.gov/pdfs/reports/2021-107.pdf</u>): The California State Auditor made the following recommendations in the report that should be completed by DDS if not already completed:
  - Provide an initial training to all regional centers about the statutory requirements for vendor monitoring.
  - Develop a policy to provide ongoing vendor monitoring training to all regional centers.
  - Identify best practices among regional centers for tracking their quality reviews to make sure that they are completed as frequently as state law requires.
  - Evaluate its processes for monitoring regional centers' performance of quality and biennial reviews to make sure that its processes are sufficient for identifying regional centers' noncompliance.
  - Require all regional centers to include in their individual program plan document a written acknowledgement that staff discussed the complaint process with the consumer.
  - Review all the written information that regional centers provide to consumers and the regional centers' procedures for providing this complaint process information to consumers.
  - Issue guidance to the regional centers clarifying that state law does not allow extensions in complaint investigations.

- Develop and issue best practices for the regional centers to follow when conducting a complaint investigation.
- To make sure that its staff continue to complete appeal investigations by the statutory deadline, DDS should update its existing appeal investigations policies to reflect its new process.
- Establish independent advocates or peer-support networks to assist with reporting and follow-up. The Disabled Person's Protection Commission (DPPC) has a training curriculum for peer support networks.
  - Peer training by self-advocates for all kinds of audiences self advocates professionals, law enforcement, DA offices, APS social workers and DDS.
  - Peer to Peer training: training by self-advocates to other selfadvocates who have lived experience in abuse to help others. They can help them on the path of healing.
  - Individuals and families need consistent support and resources to assist them with understanding what they can do after something bad happens, what steps to take to report incidents, and to see the process through to a resolution.
- Develop harm prevention approaches and strategies to address systemic problems before harm occurs.
- Require more frequent monitoring and oversight of facilities.
  - While the system currently mandates monitoring visits at service provider facilities, there are limits to the effectiveness of these visits because they are not frequent or detailed enough. More frequent and more detailed visits should be required to keep people safe.

Additionally, to address reporting of abuse, DDS should:

- Engage the medical community.
  - Initiate awareness campaigns focusing on the prevalence of abuse, its warning signs, and the reporting process, with a particular emphasis on the medical field.
  - It's crucial for healthcare professionals to understand that overmedication can often conceal underlying trauma, such as abuse—and that overmedication itself can be a form of abuse.
  - Additionally, incorporate routine sexually transmitted infection (STI) testing (covered by Medi-Cal) into screenings, as most STIs present no symptoms.
- Integrate technology for communication.
  - Invest in software that bridges communication gaps between caregivers and healthcare providers, prompting evaluations based on caregiver input.

- Research shows that barriers to reporting persist, even with wellintentioned training. Wearable technology offers an innovative solution, helping overcome fears of retaliation and emotional difficulties in reporting and can enhance reporting processes and offer key benefits, such as real-time monitoring and alerts that detect unusual physical or emotional states (e.g., bruises, heart rate changes) and alert caregivers, family members, or abuse prevention systems.
  - These wearables can also automatically log incidents, allow individuals to immediately alert others if abuse occurs, and provide voice and communication assistance to empower individuals to report abuse directly.

Additionally, to prioritize critical needs with checklists and timelines, DDS should:

- Create a checklist for prioritizing urgent cases, such as life-threatening medical needs, danger of housing loss, homelessness, or critical safety concerns. These issues must be addressed immediately, not delayed until the next IPP meeting. Implement a triage system to manage and prioritize high-risk cases effectively.
- Establish clear timelines for service approvals, plan renewals, time for appealing, and urgent requests. Make sure timelines are communicated to both clients and service coordinators.
- Introduce penalties for missed deadlines that impact service delivery, holding regional centers accountable, not just people served.

Additionally, to increase transparency in reporting and investigations, DDS should:

- Create a centralized reporting system portal to track incidents, investigations, and outcomes in real-time.
  - Make data about incidents and how they are handled available to the public without sharing personal details. This helps people see what is being done to fix problems and holds regional centers, providers, and others responsible for their actions. Corrective Action Plans should be available to the public.
- Require DDS, regional centers, and providers to report incidents and resolutions consistently.
- Develop easy-to-use systems for reporting concerns, including digital platforms and multilingual hotlines.
- Create a registry to prevent people from re-abusing.
- Discourage use of settlements, confidentiality agreements or Nondisclosure Agreements (NDA).
  - These kinds of agreements can hide incidents and keep them secret.

- It is important to find a way to make sure that incidents are made public, but that the people who are accused of mistreatment, abuse and neglect are not publicly identified until the alleged misconduct has been investigated and punishment has been rendered.
- Work with DHCS (Department of Health Care Services) and DSS (Department of Social Services) to review and improve data to identify problems and come up with resolutions.
  - Data that includes results of licensed facility inspections can be used as a tool for enforcement and to better address root cause issues such as corporate ownership and conflicts of interest.
  - The new Service Provider Directory can be used as starting point to help identify organizations that own and operate these facilities in a more transparent way.
- DDS should build stronger connections with DSS such as working with its <u>Community Care Licensing Division</u> (https://www.cdss.ca.gov/inforesources/community-care-licensing) who also investigate abuse claims. The Community Care Licensing Division also has a <u>complaint hotline</u> (https://www.cdss.ca.gov/inforesources/ccld-complaint-hotline).
  - Increased cooperation can increase transparency about incidents and offenders.
- Provide more data analysis assistance to regional centers.
  - Regional centers could benefit from data experts who specialize in gathering and analyzing data that is both descriptive (i.e., details about services and individuals' experiences) and measurable (using quantifiable metrics to track outcomes and effectiveness).
  - Data consultants (i.e., service data analyst) could help make sure that regional center data is collected systematically and used to enhance service quality, identify gaps, and improve decisionmaking.
- Make sure that monitoring of providers is led by an independent, outside organization.

Additionally, to create and enforce consequences for misconduct, DDS should:

- Develop uniform guidelines for addressing misconduct by providers, vendors, and staff, including timely and proportionate penalties like fines, contract termination, or license revocation.
  - Residential care providers, administrators, and direct service professionals should face similar consequences as medical professionals if they are found guilty of mistreatment, abuse, or neglect.

- If medical professionals can be barred from practice due to misconduct, service providers, who directly impact health, safety, daily care, and social emotional wellbeing should be held to comparable ethical and professional standards.
- Make sure that bad actors who face consequences cannot continue to provide services or work in the developmental disabilities system by moving to a new area. Penalties for incidents of mistreatment, abuse or neglect should be publicized and penalties should apply statewide. Legislative options should be considered so that individuals fired as a result of mistreatment, abuse or neglect incidents are prevented from being rehired to provide services to individuals with I/DD in the future.

Additionally, for public accountability, DDS should:

- Publicize actions taken against bad actors to demonstrate transparency and deter future violations.
- Make sure that settlement agreements do not prevent the public disclosure of factual information about sexual offenses, as required by California Code of Civil Procedure section 1001.
- Make sure that efforts are made by state and local law enforcement agencies to investigate and if appropriate prosecute businesses and individuals who abuse, mistreat, exploit, or neglect people with I/DD.
  - There is an excellent model in Massachusetts on accountability: <u>Massachusetts Disabled Persons Protection Commission</u> (https://www.mass.gov/orgs/disabled-persons-protectioncommission)
  - Law enforcement agencies, including District Attorney (DA) offices and DA victim advocates, need to receive adequate training on how to communicate with individuals with I/DD when interacting with crime victims, witnesses, or the accused.
- Work in many communities and with law enforcement officers to prosecute perpetrators of abuse.
  - Develop a statewide abuse reporting line that goes into the DPPC.

Additionally, DDS should consider the Mandated Report Reform Priorities from the 2024 Report "Shifting from Reporting Families to Supporting Families" from the Mandated Reporting to Community Supporting Task Force (https://www.caltrin.org/wp-content/uploads/2024/08/MRCS-Task-Force-Reportfor-09-04-24.pdf), such as:

- Eliminate the disproportionate surveillance and reporting of Black/African American, Native American/Indigenous people, and Latino families and communities, thereby leading to an environment of anti-racism in support of all children and families.
- Analyze all categories and subcategories of child abuse and neglect under California's Mandated Reporting law to create more precision

about what should and should not be referred to Child Protective Services to make consistent decisions to respond to families' needs appropriately. Make sure that Mandated Reporting laws, policies, practices, education, and training do not incentivize or encourage inappropriate referrals and separation of families.

- Make sure that Mandated Reporters have both access to and training on how families can connect to available resources, services, and supports; that these supports and how they are delivered are culturally aligned; and that families always retain agency in determining whether and how they utilize these supports.
- Establish a long-term, sustainable, and comprehensive investment in Mandated Reporting reform, and its implementation, to guarantee transformative change and honor the commitments we have made to communities, families, parents, and children.

# Hold Regional Centers Accountable.

Regional centers should have clear processes for what needs to happen to support people served. These recommendations focus on making sure that regional centers are doing what they are supposed to do. The recommendations also focus on improving how regional centers do things they are supposed to do.

Master Plan Recommendation: Make Sure Intake and Assessment Processes Are Clear and Equitable [page 129]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should create an intake and assessment process that builds on SB-138 requirements and is family-centered, supportive, accessible, and equitable. DDS should work with a diverse set of stakeholders to:

- Improve transparency, equity and accountability throughout the intake and assessment process.
- Require regional centers to develop intake and assessment processes that are more person-centered. This will make sure that the process is respectful, equitable and sensitive to the culture and background of the individual and family being served.
- Develop and share clear requirements about each step of the intake and assessment process. Those requirements should talk about how many days each step should take. Confusing terms and legal requirements for intake and assessment processes should be clearer. This will make sure everyone can understand how it works.
- Make sure regional centers communicate things simply and clearly in a way that is personalized and culturally sensitive.
- Make sure regional centers provide supports throughout the intake and assessment process for individuals and families who want and need them.

- Make sure mental health and other non-eligible conditions are considered during intake and assessment processes. These conditions must not be used as an excuse to deny services and supports.
- Collect and use more data during intake and assessment processes. This will help to improve transparency, equity, accountability, and performance. That data should include how long each step in the process took, how many people are being turned away, and why they are being turned away. It should also include more information about the kinds of people that are being turned away. For example, information about their race, ethnicity, or language they speak, where they live, and other things about them.
- Make sure people are not automatically being turned away because they don't have the "right" documents they need to prove they are eligible. Develop a screening tool to help identify people that should be automatically eligible for assessments.
- o Identify ways to expand intake and assessment workforce capacity.

Additional Details: To successfully implement this recommendation, DDS should:

- Clarify ambiguous terms and legal requirements, including the following:
  - "Request for assistance":
    - Proposed definition: "Any initial contact or inquiry from an individual, or a person acting on their behalf, on the nature of services or supports available or provided by the regional center, and the individual's eligibility to receive them based on a potential developmental concern or disability."
  - Minimum amount of documentation or "proof" required to obtain an assessment or expediated assessment:
    - The definition must recognize that some people will have a much harder time getting supporting documentation or not have any documentation at all.
    - Develop a workgroup comprised of experts, advocates, regional centers, people served, and families to explore whether an initial screening tool could be used to make sure that people who qualify for services are not turned away or subjected to unnecessary assessment.
    - While standards or screening tools are being developed, groups of individuals should be identified that should automatically proceed past intake, even if they have no supporting documentation. The regional center would be responsible for collecting records and completing more complete assessments as appropriate.
  - What it means for a condition to be "substantially disabling":

- Place guardrails on the ability of regional centers to deny eligibility to an applicant with a qualifying condition who is substantially disabled on the basis that a co-occurring condition is the primary cause of the substantial disability.
  - Option 1: Make clear that if a person who has multiple disabilities has a qualifying condition and is substantially disabled, they cannot be denied on the basis that some other factor is the cause of the substantial disability.
  - Option 2: If any regional center wishes to deny services to an applicant with a qualifying condition who is substantially disabled on the basis that that applicant has a co-occurring condition(s) that is the cause of the substantial disability, the regional center has an obligation to assess whether in the absence of any co-occurring condition(s), the qualifying condition would be substantially disabling.
- Improve transparency, equity & accountability of intake & assessment.
  - Capture key data points in the new case management system so trends can be reliably and consistently tracked: The new case management system should track information at the individual level, so that trends can be analyzed at the individual, regional center, demographic group, and systemwide levels.
    - These data points collected should include the dates on which intakes and assessments are completed; whether the individual qualified for an expedited assessment; and the demographic characteristics of applicants who get turned away at the intake and assessment stages.
    - The new case management system should use a ticketing process to track progress across all the intake and assessment steps.
  - DDS should examine root causes of the challenges encountered by individuals through the intake and assessment process and identify opportunities to remediate that are clinically sound.
  - DDS should establish minimum performance benchmarks related to intake and assessment, such as the average number of days elapsed between a request for assistance and an initial intake, the number of days elapsed between an initial intake and assessment, the percentage of expedited assessments conducted, etc.
  - DDS should track and compare performance at regional center, demographic group, and systemwide levels.
    - Summary data on important trends such as the average number of days elapsed between initial intake and

assessment – for all consumers, broken down by racial and ethnic groups, should be posted on each regional center's website, which may be satisfied by providing a link to the appropriate information on the DDS website.

- Data on intake and assessment should be included in individual-level panel data that is linked with other datasets and made available to researchers in a secure environment that conforms with best practices and protects individual privacy.
- o Improve person-centeredness of intake and assessment procedures.
  - DDS should develop clear, plain language packets that explains the intake process in simple terms. They should use simple visuals, and translated materials, to help all families understand each step of the process. More information should be provided about the "five categories of eligibility." The process of collecting information from families should be standardized and centralized so they do not have to provide the same information over and over to different people during the regional center intake and assessment process.
  - Personalize support:
    - WIC 4511.1 requires implicit bias training for all regional center staff and contractors involved in eligibility determinations. Regional centers should make sure that intake coordinators receive and complete training on empathetic and culturally sensitive communication.
    - Regional centers should make sure that coordinators take a personalized approach by understanding each family's unique needs and provide tailored guidance throughout the intake process.
  - Increase accessibility and cultural sensitivity:
    - Regional centers should make sure bilingual staff and language translation services are available so that families who speak languages other than English can fully understand and participate in the process.
    - Regional centers should increase outreach and education and awareness efforts through community-based organizations and schools.
  - Gather feedback from individuals and families on their experiences with the intake and assessment process:
    - DDS should establish a mechanism for families to provide feedback on their intake experience and use this feedback to continuously improve the process to make sure that it remains responsive to families' needs and concerns.

- The feedback gathered from individuals and families should include, at a minimum:
  - What is most important to, and most challenging for, individuals and families during their first contact with a regional center
  - Which parts of the intake and assessment process feels the most burdensome, and the most effective
  - What questions should be asked during the assessment process
  - How DDS can best educate the community on details of eligibility determination assessments that are required by Early Start and the Lanterman Act
- DDS should develop processes to better document and address "who is left behind" including those who are "high masking" and those with other conditions that an assessment might point to the source of their challenges.
- DDS should expand how to expand intake and assessment workforce capacity including through:
  - Examining rate setting to enhance clinical capacity.
  - Making staffing of psychologists and other qualified contractors more competitive.
  - Supporting training of best practices, e.g., <u>The CA Autism</u> <u>Professional Training and Information Network- CAPTAIN</u> <u>(https://www.captain.ca.gov/index.html)</u>.
  - Expanding the pool of other qualified clinical professionals in the community to support intake and assessment process.

Master Plan Recommendation: Make Sure IPP Processes are Consistent and Equitable [page 130]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should look at and update the new Individual Program Plan to make sure it is more consistent, transparent, and equitable across all regional centers.

DDS tells the department to create one way to make an IPP and provide directions. It also tells all regional centers to use the new IPP by January 1, 2025. This recommendation says:

- IPP processes should be updated to make sure they talk about what services people need, and when those services are available during IPP meetings.
  - It should also talk about when services aren't available, how long it might take to get them, and what other options are available.

- Technology and other processes should be used to make IPP meetings more accessible. This should include using technology and tools so that IPP meetings can happen in person or virtually (e.g., using Zoom).
- Training about the new IPP should be provided to individuals and regional center staff.
- Regional centers should provide clear and consistent communication that is sensitive to different cultures and including translation services.
- Regional centers should provide detailed documentation of IPP meetings, including copies of the individual's IPP, meeting recordings and transcripts to all IPP participants.
- Individuals should have access to advocates to help facilitate IPP processes.
- Anonymous surveys should be sent to self-advocates, their parents, and other people in their circle of supports about the IPP process.
- Fair hearings processes should be reformed so they are equitable and transparent. Fair hearings transcripts and recordings should be available to all participants.
- Self-advocates should have more support during fair hearings. They should have clear and easy to understand information about every step in fair hearings and appeals. This information should talk about what selfadvocates should expect when meeting with judges and other people. It should also talk about words that might be used. This is called a "glossary." Self-advocates should have access to independent facilitators with expertise in the appeals process to support them.
- A technology portal should be developed so individuals can access their IPP documents. The Modernize IT Systems recommendation talks about this.

<u>Additional Details:</u> Many things need to happen to meet the goal of this recommendation. The service coordinators must be able to assess and consider an individual's level of care needs during the IPP process. The IPP should then document the individual's unique level of care needs and match them with the most appropriate services so that they receive the right level of support for their specific needs. The IPP needs to be developed and written in a way so that individuals and families have a clear understanding of the IPP, and understand the rules, regulations, and rights they have that guide service approval decisions. Clear communication is needed throughout this process to help individuals and families understand and be empowered to make service decisions. To support this, DDS should:

 Develop IPP processes that clearly outline what services clients need and when those services are available during IPP meetings. Senate Bill 138 requires DDS to make a standardized IPP template and process available by June 30, 2024.<sup>8</sup> RCs are required to use the standardized IPP template and process made by DDS By January 1, 2025. This must include accountability, oversight, and legal compliance processes to make sure that regional centers comply with SB 138, Lanterman Act, and other rules. The IPP process should:

- Conduct person-centered assessments that link an individual's unique needs to the right services.
- Create clear timelines for completing IPP meetings and summary documents. Provide enough time for self-advocates and families to complete and update IPPs.
- Hold regional centers and service coordinators accountable for meeting timelines and other requirements. Include requirements to make the process transparent and report on compliance.
- Make sure the standardized planning process doesn't replace the personalized, person-centered approach for clients. There needs to be generic resource option standards. Person Centered IPP processes must not replace the person-centered planning (PCP) process. They must be clearly different. Both the IPP and PCP processes and documentation must be fluid. Which means it changes as the individual grows and their life changes. The IPP is a document over which self-advocates have minimal control to create, but the PCP is written by self-advocates or their chosen scribes. These two documents work together to create checks and balances and make sure the story is complete.
- DDS and Regional Centers should use technology that can improve access to individuals and families in the IPP process and make sure the process meets their needs.
  - Individuals and families should have an option for people to have IPP meetings over Zoom or other similar systems. This will help meet people where they are, and make sure the process is equitable.
  - Technology such as DocuSign should be used to make IPPs easy for all individuals and families to sign. Individuals and families that do not have or cannot use technology to sign an IPP should have alternatives. Service coordinators, for example, should provide paper copies whenever requested.
  - Regional Centers should have portals where individuals and families can see their IPP, person-centered plan and what's been approved or denied. The information should follow the individual, it should not depend on the regional center.

<sup>&</sup>lt;sup>8</sup> For more information about Senate Bill 138 (https://legiscan.com/CA/text/SB138/id/2840973#:~:text=SB%20138,%20Committee%20on%20Bu dget%20and%20Fiscal%20Review.%20Human%20services)

- Provide clear communication throughout the IPP process.
  - Simplify language to explain how physical, behavioral, and cognitive care needs influence service offerings.
  - Make sure individuals and families understand service decisions and feel empowered and part of the process.
  - Maintain consistent communication and accountability, regularly revisiting, and adjusting services as care needs change.
  - Educate families about criteria regional centers use to define levels of care. Explain how these levels impact service eligibility in compliance with both state and federal regulations.
- Provide language translation and culturally competent services. IPP processes must be sensitive to different cultures, languages and backgrounds and people being served. Additional supports should be provided if needed during IPP meetings. This will help clients feel comfortable with the process and allow them to communicate effectively with service coordinators.
  - All individuals who do not have natural supports should have access to community-based organizations or other advocates to help them during the IPP process.
  - Extra support should be allowed for self-advocates, like inviting additional family members or allowing more time in IPP meetings, to make sure their needs are fully discussed and understood.
  - Communication support for multi-modal communicators, ASL or an AAC device must be provided when requested or needed.
  - The IPP process needs to include cultural competency. This should include flexibility to work with staff who understand and have lived experience with their culture. It should also accommodate individuals who have different political views about gender, sexual orientation, and other aspects of their identity.
- Offer detailed documentation of IPP meetings to self-advocates and family members. This should include transcripts and audio recordings after IPP meetings or appeals.
  - Regional center should provide recordings and transcripts (whenever requested or as needed) of IPP meetings and fair hearings. This will help make sure that IPPs are not missing information that was discussed during IPP meetings.
  - When there is a new need or change in circumstances, it should be considered and added to the IPP with updated goals within 30 days of the requested or needed change.
- Survey self-advocates and family members should get feedback about the services they received during the planning process. The surveys

should help identify any issues that self-advocates had during the IPP process.

- Provide education for self-advocates and families, and training for service coordinators.
  - Education should include helping people understand their role as employers (where appropriate). It should also help individuals and families ask the right questions, what questions can legally be asked, and other questions that will help them get providers and vendors.
  - Resources may include videos, workshops and other educational materials to help families understand how to help them align an individual's care levels with their choice of services. It should help empower them to make informed decisions and make sure there is accountability through transparency.
  - Provide onboarding and ongoing training for service coordinators and other regional center staff. Training should include ways staff can enhance their service coordination skills and strengthen collaboration with individuals and families they support. It should build confidence and skills of service coordinators to improve their ability to effectively support the individuals on their caseloads.
  - Collect data to assess the effectiveness of regional center staff training. Data should include feedback from staff and families, performance metrics, service delivery outcomes, and staff competency. Data should be used to help identify areas of success and those needing improvement. Data that is collected should be used to assess the impact of consistent, ongoing training, whether training enhances service coordination, supports individualized service coordination, and drives continuous improvement within the system. And more generally, to assess whether the training is achieving its intended goals.
- Reform fair hearing processes.
  - Self-advocates should be able to submit a survey describing their experiences after fair hearing processes.
  - Regional centers should collect and report more detailed information on service denials, appeals and notices of action data.
  - DDS should aggregate and publicly report more detailed information on service denials, appeals and Notices of Actions (NOA) every year.
  - DDS should develop guides about the appeal process. The guides should describe resources available to self-advocates to support their appeal, a glossary of terms that may be used during appeals, what self-advocates should expect when meeting with judges and others during the appeals process.

- Self-advocates should have access to independent facilitators with expertise in the appeals process – if requested – to support their appeals process.
- This information should be used to develop targeted interventions to make sure that all individuals with developmental disabilities receive the services they need.
- Transcripts and Zoom video recordings for Fair hearing on IPPs should be provided. Provide supports to individuals and families for the appeals process following IPP meetings.

Master Plan Recommendation: Make Sure That Rules About Service Approvals Are Clear and Consistent [page 131]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should develop and maintain an updated list of clear, fair, and consistent rules for how regional center services are approved. These are also called "service authorization standards."

These rules should be created by a statewide committee that includes selfadvocates, family members and experts. Experts should have knowledge of DDS policy, regulations, and the Lanterman Act. This means that DDS should:

- Make sure all regional centers use consistent service authorization standards for a core set of services they have to provide. These standards should be clear, equitable, transparent, and flexible to meet the unique needs of all individuals. Authorization standards should be consistent, but there may be certain services that are only available in some communities and not available in others.
- Each regional center should have a diverse, multi-cultural advisory council representative of their local community to advise them about these standards.
- Make sure no one loses a service because a standard was changed or they move to another regional center. These rules must not prevent access to any services that an individual should be able to receive.
- Make sure regional centers provide training for staff on service authorizations standards.
- Review all service authorization standards. Some of these rules are not fair and should be fixed. Others can be fixed when there are statewide standards. Rules that should be fixed now might talk about standards that don't give independent living skills for people who live at home. Other rules that should be fixed now are about regional center that don't pay for transportation for children because they say that parents must do this.
- Require regional centers to have clear, consistent, and transparent processes for Notices of Actions (these are also sometimes called "service denials") and appeals. These should be included in an individual's IPP.

### Additional Details:

- Service authorization standards should be consistently used and applied across all regional centers. They should be person-centered, equitable, transparent, and easily understood by the people served, family members, and service coordinators. This means:
  - Service authorization standards should be person-centered. This means that service authorization policies:
    - Should not create a ceiling for people or put them into a box.
    - Must be flexible so that they do not stand in the way of a person getting the services and supports they need, when they need them, so they can lead the life they want.
  - Service authorization standards should be equitable. This means that:
    - Rules about who can get services or limits on those services should be intentionally designed in ways that consider the whole person, including a person's type or level of disability, where they live, age, race, language, or other parts of their identity.
    - Some variation or other targeted strategies are okay when needed to help people or groups that may have a more difficult time getting the supports they need, when they need them, to lead the lives they want.
  - Service authorization standards should be clear, transparent, and timely.
    - Service authorization standards should use the same clear, plain language to describe who is eligible for different services. This will help people served, families, service coordinators, service providers, and advocates better understand what factors would make it more likely for requests for services and supports to be approved and what factors would make requests less likely to be approved.
    - Standards should require regional centers to look at natural supports, parental responsibility, generic resources, and cost-effectiveness must be clearly defined. Equitable assessment or screening tools should be developed to help determine whether and to what extent a parent, natural support, or generic resources is able to meet the person's IPP goals.
    - Service authorization standards should be consistent regardless of family supports available to the individual. Current law should be reviewed and may need to be changed to support this expectation.

- Service authorization rules and guidance for generic service exhaustion should be clear. They should be written in a way that helps prevent misinterpretation.
- Any "exceptions" process that the standards have should be clear, transparent, and easy to understand. It is not enough for an "exceptions" process to just exist.
- There should be clear timelines for regional centers to identify, approve or deny, and deliver a service. Service authorization standards should include timeliness standards with adequate timeframe for decision-making to prevent delays in services due to the length of decision-making processes. This will help make sure that individuals and families do not wait months or years for services due to Regional Center process delays.
- Regional centers should track and report:
  - When a service need is identified
  - How long it takes to approve or deny a service authorization request including identifying a provider and when the purchase authorization has been entered into the system.
  - How long it takes to deliver a service that has been approved.
- Regional centers should help identify and secure other available resources that are needed for individuals while they wait for their service authorization to be processed.
- All information about how regional centers make service authorization decisions should be made publicly available.
- Service authorization standards should be consistent across all 21 regional centers.
  - This means that regional centers should consider the same fair and equitable factors when deciding whether to say yes or no to a service or amount of a service.
  - Service authorization standards should also be consistent with the text and core values of the Lanterman Act, federal HCBS rules, and other laws that apply to systems that provide services to people with I/DD like the Americans with Disabilities Act and laws that prohibit discrimination in government-funded programs and activities.
  - Service authorization decisions should apply across regional centers. If a self-advocate moves to another regional center, services should continue as agreed upon in their IPP to make sure there is service continuity. If an authorized service is not

available in the new catchment area, the new regional center should help identify other services that meet the selfadvocate's needs. The new regional center will need to conduct a new IPP to discuss any changes to existing services.

- Service authorization standards should be established by a statewide decision-making committee that includes people served, families, regional centers, and impacted members of the community.
  - The committee should reflect the diversity of the State.
  - The formation of the committee should consider the role of the Administration and Legislature.
  - This should not be a one-time event. There should be a commitment to an ongoing process where the impact of new or revised service authorization policies can be reviewed in an ongoing partnership with people served.
  - Service authorized standards should be changed if they are not working in the way people thought they would work, based on data and feedback from the people most impacted by those policies.
  - The committee can consider using equity-based frameworks like the one being used by the Master Plan workgroups.
- Each regional center should have a multi-cultural advisory council with diverse ethnic groups and non-English speaking individuals that represent the diversity of the community. The council would meet regularly with families to understand and advocate for the specific challenges they encounter when accessing services, as well as to monitor regional center implementation of new policies.
- Any service authorization standards that are developed through this process should not cause someone to lose the services they are currently receiving.
- Training on service authorizations standards should be available and required for regional center leadership, service coordinators, providers, and direct support professionals. Training should also be available to people served, their families, and other stakeholders so there is a common understanding of what service authorization standards are and how they should be used.
  - Regional centers should provide education sessions and webinars that clearly describe service authorization standards. Those education sessions should be accessible to everyone and use plain language. The trainings should be consistent statewide. The trainings should also describe details about the people, process, and technology each regional center uses for service authorizations.

- There should also be immediate, short-term fixes to current service authorizations standards, while the longer-term recommendations are happening. This includes a review by DDS of all existing purchase of service policies to make sure that:
  - All information about how regional centers make service authorization decisions are made publicly available.
  - Exceptions processes in existing service authorization standards are clear, transparent, and easy to access.
- A clear and consistent framework for notice of actions ("service denials") and appeals should be put in place to make sure there is transparency in the decision-making process.
  - NOAs must be provided in a timely manner when legally required to be provided. They must be provided in the preferred language of the individual that is easy to understand. They must include a clear description of what an individual's rights are to appeal. They must be provided whenever a service is set to end and the individual does not agree, even if there is an "end date" written into the individual's IPP. And all NOAs should be reported whether they are appealed or not.
  - Lack of support for denied services: A regional center must provide information in the preferred language of the individual on alternative resources or assistance that could help families navigate their options.
  - DDS should collect and report data on denials of services, notices of action, and appeals. This should include service denials that are not appealed, denial reasons and steps taken to provide generic supports for each regional center and make the data public. This data should be included in annual Purchase of Services (POS) community public meetings.
- IPP meetings, service denials, notices action and appeals must be documented in the IPP.
  - Regional centers should provide official records of IPP meetings to individuals and families. This will help create clear documentation of meeting discussions and outcomes. It will also help track which services have been requested, and which services have been authorized. Individuals and families should be given options about what type of documentation would meet their needs.
  - Official records must include a plain language description. It should be provided in multiple languages and modalities. Records should be tailored to the individual's needs.
  - Official records may also include transcripts, audio recordings, and Zoom meeting recordings.

- This recommendation would require the adequate investment of resources to support the additional workload of regional center service coordinators to create the official IPP record, including a plain language description. To implement the recommendation, statute (WIC 4646.6) would need to be amended as it currently allows for only audio recording.
- Improve the experience of inter-regional center transfers for consumers through refreshed and strengthened guidelines.
  - Establish clear guidelines and timelines: Develop standardized guidelines that outline clear steps and specific timelines for the case transfer process. Each regional center should be mandated to adhere to these guidelines to make sure there is consistency.
  - Dedicated transfer coordination team: Designate a specialized team or coordinator responsible for managing case transfers across regional centers. This would help streamline communication, manage cases proactively, and make sure there is accountability.
  - Communication protocols: Implement improved communication protocols between regional centers, which include timely status updates for families, designated points of contact, and enhanced inter-center collaboration to avoid misunderstandings.
  - Staff training and resources: Provide training to staff on efficient transfer procedures, emphasizing cultural competence and understanding the unique needs of underserved families, to make sure there is a more equitable transfer process.
  - Data collection and accountability: Require regional centers to collect and report data on case transfer times and any barriers encountered. This transparency will help identify bottlenecks and provide accountability for improvement.
  - Advocacy and support for families: Develop resources for families to better understand the transfer process, including information in multiple languages and advocacy support, to make sure families can effectively navigate and expedite transfers.
- The data collected should be used for the following purposes:
  - Aggregate and analyze trends
    - Identify patterns in service denials and appeals (e.g., most common reasons for denials, disparities among demographics, or regional inconsistencies).
    - Track whether appeals are successful and where the system is failing individuals.
  - Accountability and transparency
    - Use the data to make sure there is compliance with policies and advocate for fair and consistent decision-making.

- Push for corrective actions where service denials appear unjustified or disproportionately impact certain communities.
- Empower families and self-advocates
  - Provide data-driven insights to families and advocates, helping them better understand their rights and prepare stronger cases when appealing denials.
  - Develop training materials based on real-life trends to guide families through the appeal process.
- Enhance service equity and access
  - Use the data to address disparities in service provision, ensuring equitable access to supports for all communities, especially underrepresented groups like the Latino disability community.
  - Work with regional centers to improve internal training and decision-making processes to reduce unnecessary service denials.
- Develop public reports
  - Advocate for annual public reporting on denial and appeal data by DDS and regional centers.
  - Make the data accessible to community organizations, policymakers, and stakeholders to increase transparency.

Master Plan Recommendation: Make Sure People Served Can Get Compensation Support With Appeals and Complaints [page 132]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should create a fair, transparent system and processes so people can get compensation and supports for appeals and complaints. This kind of compensation is sometimes called "compensatory damages."

The system should recognize disparities and make sure outcomes are equitable. The system and processes should also hold regional centers, and vendors are accountable. This means:

- When people file an appeal or complaint and win, they should be able to receive extra services, or funding for extra services, to make up for what they missed. Making up for what they lost will help build trust in the system.
- Any extra services or funding should be based on a person's individual needs. There should also be some flexibility for how long the individual has to use the extra services.
- People should get more help if they need it so they can appeal bad hearing decisions in court. DDS or the regional center should cover the cost of the individual's attorney if the individual wins their court case.

- People also should be protected from retaliation so they feel safe when making an appeal or complaint.
- DDS should look at other systems that do this well, like special education.
- An equity committee should also support the system. That committee should make sure the system reduces disparities. It should also make sure anyone has a fair chance to try and get compensatory damages.
- Nothing in this recommendation should stop an IPP team from agreeing that a person has not received the services they need. It should also not stop an IPP team from agreeing to voluntarily provide extra services to help them make up for what they lost.

### Additional Details:

- Compensatory services should be awarded upon successful appeal or complaint resolution. The goal is to put the person back in the position, as much as possible, they would have been in if the mistake, rights violation, or wrongful denial of services had not occurred.
- Compensatory services could be awarded in the form of additional services or an increased budget from which services could be purchased. Once compensatory services are awarded, there should not be a timeline that requires the services to be used by a specific date.
- If a hearing decision is wrongly decided and a person needs to appeal the decision in superior court, there should be attorneys available who can help them with their case. This is not happening right now because people cannot afford to hire attorneys. And even if they could, there are few attorneys who take these types of cases. To fix these problems, the regional center, or possibly DDS, should pay for the person's attorneys fees, but only if the person wins their case in superior court. This will help make sure that attorneys will only file appeals for people who have good cases and that more wrongly decided hearings will get changed to make them right.

### Master Plan Recommendation: Improve Vendorization Processes [page 133].

Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should improve the vendorization process and access to service providers and vendors to make them more accessible to everyone.

Vendorization is the process where regional centers contract with providers and others to deliver services. DDS should improve the vendorization process by:

- Streamlining the vendor application process across all regional centers. Once a vendor is approved by one regional center, all other regional centers must accept that vendor.
- Accommodating different requirements for different regions, particularly rural areas and for different populations.
- Reviewing and updating Title 17 vendorization rules.

- Making vendorization standards and processes more transparent.
- Speeding up vendorizations and eliminating "denial by delay" practices.
- o Identifying vendor shortages and coming up with plans to reduce them.
- Making it easier for independent facilitators and non-profit corporations to become vendors. This can be done by removing barriers and having a more flexible process for them for them. A more flexible process to attract vendors must not mean that standards and expectations for vendor quality are lower.
- Making sure there are background checks for vendors and their staff, and that there are ways to remove people and vendors who commit abuse.
- Requiring regional centers to train staff in vendorization processes.
- Requiring regional centers to host information sessions about vendorization processes.

<u>Additional Details:</u> More service providers need to be vendored. Especially highquality vendors with language and cultural capacity. This is needed to make sure that individuals receive the services and supports they need, when they need them, so they can lead the lives they want. Additional details to support successful implementation of this recommendation include suggestions for how to:

- Streamline the vendor application process across DDS and all regional centers. Make them faster, simpler, and more transparent.
  - Establish clear and consistent timelines for vendorization.
  - If a regional center requires an applicant to submit a revised program design, provide all necessary changes at once, communicate them clearly, and set a specific timeline for the RC's response to the revision.
  - Assign vendor numbers quickly after approval so services can start right away.
  - Once a vendor is approved by one regional center, all other centers should accept them.
  - Allow for new vendors at least monthly.
- Review and update Title 17 vendorization rules.
  - Review current regulations and identify rules that should be updated to support a streamlined vendorization process.
    - Consider how different levels of requirements could be put in place for different types of vendors to simplify processes.
    - Update outdated policies (e.g., that vendor offices need to be in each catchment area).
    - Identify opportunities to get vendors that support other languages and cultural needs.

- Develop draft rule change.
  - Get feedback from self-advocates and families, RC, vendors and other experts and stakeholders.
  - Have public meetings and host public comment process on draft rules.
  - Revise draft rules with stakeholder feedback.
- Adopt new rules and issue new directives to regional centers.
- Put processes in place to measure how well regional centers are complying with new rules.
- Reduce barriers to identify and recruit more high-quality vendors, independent facilitators, and non-profit corporations to become vendors.
  - Provide clearer guidance for any type of license or certification that is required for every different type of vendors.
  - Reduce unnecessary business or other license and certification requirements for vendors if they aren't necessary (e.g., remove business license requirements and instead require Tax IDs that some regional centers have in place for some types of vendors if they are not necessary).
  - Develop processes and criteria for potential vendors to demonstrate competencies to identify more high-quality vendors. Use those criteria to hold vendors accountable for meeting competencies.
  - Explore opportunities to identify businesses that do not need to be vendored at all (e.g., social rec, Financial Management Services [FMS], others). Consider how FMS may be used as bridge funding to expand allowances (i.e., use those funds to cover more services in some circumstances).
  - Explore how effective community resource development plan (CRDP) funds have been used. Identify successful practices and ways that those practices could be shared. Explore whether these funds should be expanded if there is demonstrated success.
    - <u>CPP and CRDP guidelines</u> (https://www.dds.ca.gov/services/cpp/)
- Address vendorization service gaps. DDS and regional centers should document where there are vendor shortages and develop plans to fill gaps.
  - Develop processes like surveys that will help everyone understand where there are shortages.
  - Develop requests for proposal (RFPs) to fill identified gaps.
  - Create incentives to motivate more vendors to provide services.

- Identify and fast-track vendors who serve non-English speaking language and meet other cultural competency needs.
- Create clear requirements and timelines for updating the DDS Service Provider Directory with new vendorizations.
- Make vendorization standards and processes more transparent and accessible for communities that have fewer services available to them.
- Hold regional center information sessions for community outreach to help them better understand the vendorization process.
- Train regional center staff in vendorization and intake processes.
- Eliminate denial by delay by putting in clear timelines and making jobs easier and having consequences for regional centers when they do not meet the timelines and incentives when they do.

Master Plan Recommendation: Use Outcome Measures for Accountability [page 134]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should create clear performance, quality, accountability and outcomes measures at the individual, regional center, and systemwide level.

All measures should:

- Include standards that can help hold vendors, regional centers, and DDS accountable.
- Include accountability through coordination with other departments and agencies.
- Make sure they don't result in unintended consequences that make things worse for people with I/DD, especially those with more intense needs.
- Include measures that prevent abuse, mistreatment, and discrimination against people served and families.
- Meet federal and state legal requirements and human rights principles.
  These requirements should be shared with regional centers and vendors.
- Be measured and tracked in any new statewide IT system that DDS develops.
- Link with other important state datasets for research.
  - An example of outcome measures would be the accountability measures for the public education system in the "Inclusive and Flexible Education" recommendation.

<u>Additional Details:</u> A uniform set of internally consistent and readily quantifiable Quality, Performance and Outcome measures for the I/DD services system should be developed in four phases. The development and use of these measures would help make sure that all stakeholders are working toward a single goal: creating a person-centered developmental disability services system that promotes the inclusion, self-determination, well-being, civil and human rights of individuals with I/DD.

The development, collection and analysis of these Quality, Performance and Outcome measures would progress in five sequential phases:

- Phase 1. The department would comprehensively map, survey, review, and assess all established and currently pending regional center and vendored service provider performance and outcome measures that are used or are being developed for the purpose of performance, quality, or outcome measurement within the system.
- Phase 2. Following the completion of its comprehensive map, survey, review and assessment, the department would convene one or more workgroups consisting of the members specified in WIC Section 4620.5 (b), and academic social scientists with training in program evaluation, causal inference, and data science, self-advocates, and family members. Or consider creating a separate workgroup with self-advocates, family members and other stakeholders to advise on measure development. The workgroup(s) would advise the department and make recommendations to DDS regarding existing and new Quality, Performance and Outcomes Measures that are needed to track performance effectively at the individual, regional center, vendor, and system-wide levels. The workgroup's recommendations may include suggestions for the retention, revision, or elimination of any performance or outcome measures that are currently in use.
- Phase 3. DDS would review the recommendations of the workgroup and submit a proposal for Quality, Performance and Outcomes Measures, along with the anticipated process to systematically gather the required data, to the legislature and to the public for comment. The Quality, Performance and Outcomes Measures should be adopted as soon as practicable thereafter, and DDS would collaborate with stakeholders to disseminate and encourage their use throughout the developmental services system. Adoption of measures should consider the needs of providers to build the infrastructure to report new measures. This process should continue and evolve over time to move the system from process to quality and outcome measures.
- Phase 4. Any IT system(s) that are being developed for use in the developmental disabilities system, or may developed in the future, would incorporate measures for the systematic collection of the Quality, Performance and Outcome Measures adopted by DDS. To make sure Phase 4 is feasible, any IT system development that proceeds before Phases 1-3 are complete should be halted until the completion of Phase 3, to make sure that the Quality, Performance and Outcome Measures adopted by DDS will be fully and timely incorporated into any new IT system and/or modification of an existing IT system.
- Phase 5. Create performance benchmarks at the regional center and vendor level. DDS would tie performance benchmarks to incentives and
#### payments programs, including the Quality Improvement Program, payments associated with regional center Performance Measures and regional center performance contract provisions.

Master Plan Recommendation: Reward Good Outcomes [page 135]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should pay developmental service providers and regional centers for good performance that improves outcomes for individuals and systems.

These incentive payments must be in addition to base rates that are high enough. This means that DDS should:

- Get information about what is working (or not working) with existing incentive program models. For example, existing DDS initiatives like the Quality Incentive Program.<sup>9</sup>
  - Part of this should include developing better definitions of what good and bad performance and outcomes look like.
  - This information should be used to design how payments for good outcomes will be provided.
- Make sure there is funding for regional centers and providers to pay incentives for good performance that goes above and beyond what is required by the job. Performance should be rewarded if it is great in all important areas. But it should not be rewarded if it is great in some areas and bad in others.
- Make sure input from diverse individuals, families and other stakeholders is used to decide what the goals should be and what good performance looks like.
  - Make sure that groups of people who have a harder time accessing services are able to provide ongoing input about outcome standards and incentive program goals. DDS should work with each regional center, SCDD, and others to help identify diverse groups. These groups include:
    - People with complex needs.
    - People with multiple disabilities.
    - People who live in rural areas.
    - People from communities that have historically faced discrimination.
    - People who speak a language other than English.
- This will help make sure the goals and standards for good performance are equitable. This will also help make sure that the goals and standards do not have unintended negative impacts on quality of life or service

<sup>&</sup>lt;sup>9</sup> For more information about the Quality Incentive Program (https://www.dds.ca.gov/rc/vendorprovider/quality-incentive-program/)

delivery. Make sure diverse groups also help define bad performance and bad outcomes that will be used to result in consequences and corrective actions, when appropriate.

- Make sure regional centers and service providers know what performance standards they are expected to meet to receive incentives. This should include accountability and outcome measure goals.
  - Make sure that when regional centers and providers go above and beyond the standards and goals, they are rewarded.
  - Make sure that if they do not meet the basic performance standards, they will face corrective actions.
- Make sure that efforts for accountability do not result in bad outcomes for people served. That also means making sure money does not leave the developmental services system. Develop incentives that benefit DPSs to make sure providers take good care of certain populations that may have a harder time accessing services.
- Create incentives for vendors so that their employees can be directly rewarded.
- Think about ways to provide non-financial incentives for regional center employees that align with the goals of the individuals served.
- Investigate providers and regional centers when performance is consistently poor or when there is reported mistreatment taking place. Update regional center contracts to pay for the right high-quality outcomes.
- Make sure all the data that is needed to identify high-quality outcomes can be collected and used for payment, research, and accountability. An example of using incentives to encourage an outcome would be the "Use Incentives to Encourage Renting to People with I/DD" recommendation.

<u>Additional Details:</u> The establishment of payment and incentive structures that support sustainability, service availability, and systemic, organizational, and individual outcomes would be developed in six phases as follows:

- 1. Establish sustainable formulas and a funding commitment that support meeting expected standards and contributing to overall outcomes, including adjustments to base funding levels as cost inputs change.
- 2. Through a comprehensive and transparent stakeholder process supplemented by an analysis of federal and policymaker expectations, clearly define anticipated systemic outcomes. Established incentives should be based on outcomes that are able to be calculated and tracked over time with high-quality data that is able to be independently audited.
- 3. Determine the role of each entity (e.g., DDS, regional center, service provider) in achieving the expected outcomes and develop coordinated measures to establish the relative success of each in carrying out its

mandates. The developed measures must include the capacity to evaluate a variety of performance levels ranging from compliance with basic requirements to high-level performance.

- 4. Align incentive payments with high-quality performance to support innovation and strong individual outcomes that align with the priorities established in step #2. Make incentive payments when regional centers and providers meet high quality standards. Have consequences when they do not meet high quality standards. Consequences should not result in resources leaving the I/DD system and should not negatively impact individuals served by the system.
- 5. Evaluate whether the needs of certain populations (e.g., geographic, linguistic, support needs intensity) require the establishment of differential funding or incentive structures to support their service access and achievement of outcomes at parity with others served, and if yes, develop funding models that better support them.
  - Note: bilingual stipends for direct support professionals are part of a new initiative launching next fiscal year called "direct support professional university" which provides additional pay for individuals that pursue bilingual proficiency for as long as they remain working in the I/DD system.
- 6. Create incentives that align with, and support, goals of individuals served by regional centers. For example, employment incentive structures should be developed that track progress at each milestone toward career goals. They should require documentation of measurable changes such as skill gains (education, language proficiency, or training program), job satisfaction, opportunities for advancement (more hours, increased wages, promotion) in addition to retention. Employees should also be incentivized to learn about other systems, departments, and areas of government so they can best assist clients who may have complex needs or interact with multiple systems. While the implementation phases above logically flow in sequence, there may be opportunities to address certain steps concurrently, such as the commitment to sustainable funding formulas in tandem with the establishment of comprehensive outcome expectations and measures.

Master Plan Recommendation: Use Contracts for Accountability [page 137]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should review and update contracts they have with regional centers to make sure they provide high-quality services and outcomes for everyone they serve.

This recommendation says that:

• The Legislature should review and recommend if there are ways DDS contracts with regional centers can be improved. The recommendations

should talk about whether DDS needs more power to make sure regional centers do a good job.

- Individuals, families, regional centers, and other stakeholders should be able to provide their ideas when DDS updates regional center contracts. DDS should also get stakeholder input when they update regional center performance contracts. Regional center performance contracts talk about financial incentives and goals regional centers must meet.
- DDS should create a process and standards to make sure regional centers are providing high quality services and outcomes. DDS should pay regional centers for meeting standards and have consequences when they don't.
- DDS should make sure that penalties for regional centers do not lead to fewer services being available. DDS should also make sure there are no unintended consequences for people served by the system.
- DDS should more regularly check to make sure regional centers are doing what they are supposed to do. These are called audits.
- DDS should make sure regional centers have requirements in their vendor contracts that talk about how vendors must deliver high-quality services and outcomes.

<u>Additional Details:</u> The successful implementation of this recommendation would be supported by suggestions to:

- Strengthen oversight of the developmental disabilities system. The Legislature should initiate an evaluation of the I/DD system and consider how it can strengthen the ability of the Department of Developmental Services to provide oversight of the regional centers.
  - The evaluation should assess what is and is not working across the 21 regional centers.
  - The evaluation should consider how regional center performance contracts can be updated to support improvement in oversight of regional centers by DDS.
  - The evaluation should also consider whether additional authority is needed to drive systemic change or make sure there is a level of consistency in experiences for individuals and their families when seeking services.
  - The evaluation should describe what additional authorities the director of the Department of Developmental Services may need to have similar oversight authority as the directors of sister departments, such as the Department of Social Services or the Department of Health Care Services.
  - This recommendation is similar to recommendations made in a report by the Little Hoover Commission in 2023

#### (https://lhc.ca.gov/wpcontent/uploads/Reports/273/Report273.pdf).

- Review and revise regional center performance contract requirements (see footnote).<sup>10</sup> DDS should develop a process for supporting a comprehensive review of regional center performance contract requirements that include robust stakeholder engagement. Contracts should use clear, plain language and provide information in multiple languages while being presented in an accessible way. The process to review and revise contracts should include:
  - Review recommendations from the evaluation supported by the legislature to strengthen oversight of the I/DD system.
  - Make annual contract changes:
    - Review performance objectives with input from a public stakeholder group and sister departments and agencies, including steps to monitor regional center compliance with contract requirements.
    - Update regional center performance measures (RCPM).
      - This should consider how measures can be "rightsized" to prioritize regional center behaviors and performance for DDS and Master Plan priorities.
      - Align RCPM measures with Quality Incentive Program (QIP) measures to help make sure the entire system is aligned with DDS and Master Plan priorities.
    - Update and reinforce compliance requirements with the Lanterman Act and other requirements identified in the Master Plan for Developmental Services.
      - This may include special contract language for regional centers that have been identified through annual compliance reviews that need to improve their compliance with the Lanterman Act and with board governance requirements and best practices.
    - Update federal requirements as those requirements change or where regional centers are falling short of compliance including:

<sup>&</sup>lt;sup>10</sup> For regional center performance contracts

<sup>(</sup>https://www.dds.ca.gov/rc/dashboard/performance-contracts/).) Performance contracts are in Article VIII of the base contract (WIC 4629 (c)(1)). Performance contract measures follow statutory requirements related to things like achieving life quality outcomes, measuring progress in reducing disparities, and developing supports to meet identified needs of individuals. Performance contracts are developed through a public process. Each regional center must also do an annual public meeting to present its performance data and take public input.

- Home and Community Based Services (HCBS 1915 (c) I/DD Waiver]
- State Plan Amendment [1915(i)]
- Add or revise requirements identified in the Master Plan for Developmental Services, including but not limited to:
  - Equity, access, and timeliness
  - Intake and assessments
  - Individual Program Planning (IPP)
  - Person Centered Planning (PCP)
  - Mistreatment, abuse, and neglect identification and whistleblowing protections
  - Service coordinator roles and caseloads (including those that align with:
    - <u>The Lanterman 2024 Publication; Role and</u> <u>Responsibilities of a Service Coordinator</u> <u>(https://www.dds.ca.gov/wp-</u> <u>content/uploads/2024/02/Lanterman 2024 Pub.pdf)</u>
  - Self-advocate and family experience
  - Coordination with other regional centers and health and social service systems
  - Service authorizations
  - Outreach and referral pathways
  - Service navigation (including generic services)
  - Vendorization
  - Data exchange
  - Life transitions
  - Competitive, integrated employment
  - Emergency response
  - Enrollment in Medi-Cal, waiver and other health and social service programs
  - Governance
- Develop flow-down requirements that RCs must put in place for providers and vendors they contract with.
  - This may include, but is not limited to, requirements for contracted vendors to meet service level expectations, data exchange requirements, access and timeliness standards, corrective action plans needed for vendors that aren't

meeting expectations, and other expectations described in the Master Plan and by DDS.

- Implement a performance evaluation system tied to contract terms. The system should include common performance measures and protocols across all regional centers.
  - DDS should engage with self-advocates, family members, regional centers, and other stakeholders in the development of the evaluation.
  - The system should include evaluations of the regional center, the regional center board, and the regional center's service providers. Measures should include those related to:
    - Percent of eligible participants served
    - Participant satisfaction
    - Service impact on individual's goals over time
    - Community integration
    - Employment
    - Equity in service access
    - Timeliness of services
    - Case management responsiveness
    - Individual and family choice
    - Human and civil rights
    - Health, and safety
    - Potentially others
  - Accountability should have a strong focus on the people served.
  - Evaluations should be publicly reported in machine-readable formats.
- Review regional center biennial audit process, and consider how often audits occur, how audit outcomes are made public and what follow-up actions are taken.
  - Information about the different audits, who conducts them, and their intent should be made public to better inform individuals and families expectations and help them interpret audit outcomes to help hold regional centers accountable.
  - Because there are multiple state entities conducting audits on different timelines, there should be a systemwide effort to harmonize and standardize the audit system to make the best use of resources.

- Review and revise enforcement mechanisms describing performance expectations and consequences related to poor performance.
  - Consequences may include:
    - Issuing a letter of noncompliance
    - Amending contract provisions
    - Establishing a corrective action plan
    - Placing a regional center on probation
    - Termination or non-renewal of a regional center's contract

### Make Sure the DDS System is Transparent

People served by the system need clear information about what to expect. This helps people with I/DD and their families have choice and control in their lives. This also helps them know when things are not happening how they should, so they can reach out for help. These recommendations focus on making the DDS system, including regional centers, more transparent.

Master Plan Recommendation: Improve the Information Technology System [page 146]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should develop and maintain a single statewide information technology ("IT") system for the California Developmental Disability Services.

- DDS and all regional centers should use a single IT system to track service access, delivery, payment, and case management.
- DDS should work with stakeholders to create a plan and a charter ("rules of the road") to guide development of the system. The plan should talk about the goals of the IT system and how it will be put in place. The Plan should talk about how the IT System will get more data for analysis, reporting and research. Researchers and other people from the community should be involved in the plan and how the IT System is used.
- DDS should regularly present updates about the development of the IT system to the Legislature.
- The system should improve data exchange between regional centers, DDS and other health and social service departments. Regional Centers should be required to sign the CalHHS Data Exchange Framework Data Sharing Agreement.<sup>11</sup> There should be clear data exchange privacy and security rules.
- The system should have a portal that individuals and families can use to access all of their information. The portal should allow people to track requests and communicate with the regional center and providers.

<sup>&</sup>lt;sup>11</sup> For more information about the CalHHS Data Exchange Framework Data Sharing Agreement (https://www.cdii.ca.gov/committees-and-advisory-groups/data-exchange-framework/)

- DDS and regional centers should develop and provide training for regional centers, staff, individuals, families, and other stakeholders about how to use the system. Self-advocates should help create these training programs.
- The system should include a plan for how data will be available for analysis, reporting and research.
- DDS should make sure there is support for individuals and families so they can get internet service and devices. Those supports should be used to help people access and use the new IT system.
- DDS should make sure regional centers who have fewer resources and less reliable high-speed internet have more support to meet these recommendations. DDS should also make sure that these regional centers do not face unintended consequences by using a new IT system.

# <u>Additional Details:</u> The successful implementation of this recommendation would be supported by suggestions to:

- Design a new flexible case management and financing system that aligns with best practices, including the following:
  - Includes four dashboards:
    - Individual dashboard: Allows individuals with I/DD to access the data that is collected about them. Make sure that individuals are provided with the assistance they need to access their information. For example, there should be a way to give permission for an Independent Facilitator to help the individual.
    - Provider dashboard: Allows providers to see how well they are doing with outcome measures and provider incentive measures.
    - Regional center dashboard: Allows regional centers to track how well they, and the providers that they have vendored, are performing on each of the Quality, Performance and Outcome measures.
    - DDS dashboard: Allows DDS to track outcomes for different groups (and different regional centers) across the state.
  - Create an integrated IT system for the entire state: All regional centers should utilize a single, integrated system to track purchase of service, case management and service delivery to people with intellectual and developmental disabilities.
    - The system should integrate all data elements (accessible through separate dashboards) into a unified system.
    - The system should have capabilities to link to and share data with other state department and agency systems.

Particularly, integration and linkages with DHCS systems for billing and administrative claiming of Medicaid funding.

- Includes collection of all key data elements that are necessary to promote meaningful accountability, including but not limited to the following:
  - Person-centered data on individuals served.
  - Quality, Performance, and Outcome Measures (to support ongoing analysis at the individual, regional center, DDS and systemwide levels).
  - Finance and case management data on DDS, regional centers, and state-operated facilities.
- Protects data security, accuracy, and individual privacy.
  - Utilizes a user interface with built-in, state-of-the-art data quality controls.
  - Is stored in a secure research environment, in a manner that addresses concerns about individual privacy, security, and data sharing.
  - Creates a firewall between individuals who may access individual-level data for research purposes, and individuals making decisions about individuals' services.
  - Includes periodic Qualified Observation visits (audits) to make sure that the data collected is accurate and reflects the lived experience of individuals served and their families.
  - Supports the secure exchange of data with providers, Medi-Cal managed care plans, counties behavioral health providers, and other entities (e.g., In-Home Supportive Services) that provide support to regional center consumers. For Early Start consumers and those exiting the school system, it should enable data-sharing with school systems for care transitions.
- Uses a simple and intuitive interface.
  - Minimizes redundant data entry by auto-populating demographics on all required forms, applications, and assessments.
  - Allows corrections to populate all systems at once to avoid inconsistencies.
  - Uses a streamlined, intuitive interface that is easy for diverse stakeholders to navigate.
- Is flexible and adaptive (can be easily upgraded or reconfigured over time).

- The system that is initially built may, over time, fail to keep pace with changing needs.
- It should be designed in a way that allows for incremental changes or improvements in key regards (user interface, scope of data collected, data formatting, etc.).
- Makes sure that data collected can be interlinked at the Individual Level with other datasets.
- Data is collected in a format that supports the analysis of trends across groups and over time.
- The data can be easily linked, in a secure fashion, with data from other state systems or programs e.g., other California Health & Human Services Agency departments, the Labor and Workforce Development Agency, and the California Department of Education.
- Supports infrastructure for providers. Accommodate the needs of providers including ability to collect provider data for performance measures and other reporting requirements.
- Improve data exchange across regional systems and between DDS and other health and social service systems.
  - The new case management system should be designed to support real-time data exchange. This includes sharing data across and between regional centers, and with all vendors and providers that service all self-advocates. It should also include sharing data with other health and social service systems, including health care, education, housing, employment, and other systems. Data exchange should be in "real-time" to support care and service coordination.
  - Regional centers should be required to sign the <u>CalHHS Data</u> <u>Exchange Framework Data Sharing Agreement (DSA)</u> (<u>https://dxf.chhs.ca.gov/</u>). This will require regional centers, health care providers, managed care plans and other organizations that have signed the DSA to share information with regional centers.
  - Develop clear data exchange privacy policies. This includes developing clear and plain language documents that selfadvocates, family members and authorized representatives can sign to give consent to share (or not share) sensitive disabilityrelated information with other organizations in alignment with section 4514 of the Lanterman Act (https://leginfo.legislature.ca.gov/faces/codes\_displaySection.xht ml?lawCode=WIC&sectionNum=4514) and other state and federal rules related to privacy protections.

- Improve data exchange between DDS, EDD, and other agencies. Improve matching of individual-level data across systems to track trends and promote accountability.
- Make sure that the individual portal embedded in the System is accessible, comprehensive & person-centered.
  - The individual-level portal would allow people served to access their own data. The portal should meet the following criteria:
    - HIPAA-compliant.
    - Accessible via both a web browser and a mobile app (so it is accessible from any smart device).
    - Allow users to request to update their personal details (address, phone numbers, etc.) and demographics (race, ethnicity, sexual orientation, gender identity, preferred language, etc.).
    - Enable users to view, download, or print key documents such as their IFSP, IPP, and Annual Cost Statement.
    - Display details about authorized services, including authorization numbers, vendor names and contact information, service amounts, and start/end dates.
    - Allow users to access the contact information of their Service Coordinator and Manager and include an option to directly call or message them through the portal.
    - Display scheduled meetings with the Service Coordinator, so users stay informed and prepared.
    - Support secure messaging between the individual and their Service Coordinator, as well as notifications about regional center events or important update.
    - Store information that can inform IPPs, ISPs, person centered plans, etc.
    - Allow individuals to upload photos (photo library) & other documents.
    - Uses a simple, intuitive interface that is easy for the individuals served and their family to navigate.
    - Includes a link to a web page with an updated inventory of online communities, platforms, or hubs.
      - The inventory should include information about what online resources exist and how individuals with I/DD and their family members can access them.

- The list should be used by DDS to help identify gaps in services, so that resources or organizations can be identified to help fill those gaps.
- Enable accessible online groups for self-advocates and their families and others to share ideas and encourage community building about topics important to them. They should be designed input from the community and community-based organizations to take advantage of the relevant expertise and experiences in the community.
- Embed training and learning modules within all four dashboards
  - All four of the dashboards included in the FCMS at the individual, vendor, regional center, and DDS levels – should include training and learning resources, including videos and training modules.
    - These trainings should be available to a variety of stakeholders, including staff that support individuals (with credentials including DSP 1, 2 & 3) and regional center service coordinators.
    - This training should be in plain language that everyone understands.
  - DDS should consider ways in which AI might be integrated into training modules (or dashboards) to help educate individuals and families about available resources (or respond to questions via chat).
- Draft a Project Charter to Guide the Development of a Flexible Case Management System (FCMS) and a Uniform Fiscal System (UFS)
  - The Project Charter should incorporate participation and input from all critical stakeholders, including consumers, families, regional centers, service providers, and academic researchers.
  - It should include, at a minimum:
    - An impact statement, including how it will improve data quality, privacy, confidentiality, and integration of all data sources at an individual level, and enable data-driven decision-making and performance measurement
    - Guiding principles and goals
    - Project scope
    - How, and in what format, data will be made available to each key group of stakeholders (individuals served and their families, vendors, regional centers, and researchers)
- Make sure that stakeholder input informs the initial design and ongoing maintenance of the FCMS and a UFS.

- Initial development phase: Before the initial system is designed and built, DDS should gather input from stakeholders regarding consumer impact and consumer-functionality, which should inform the vendor procurement process. Stakeholder input should be gathered through:
  - Community engagement meetings and webinars with Community Based Organizations (CBOs) and grassroots organizations
  - Meetings with researchers knowledgeable about the developmental services delivery system who have training in quantitative social science disciplines (e.g., statistics, econometrics, and data science) and/or qualitative research methods
    - Leveraging and building upon the work DDS has done with regional centers and other system users to get inputs on the design and functionality of the system.
- After the initial system launch:
  - As soon as the system is launched, DDS should establish an IT Advisory Committee as a standing committee that meets (at least) once per quarter.
  - The IT Advisory Committee should:
    - Be briefed regularly by DDS, and the contractor, on the progress of the design, and creation, of the FCMS and UFS.
    - Include researchers that are familiar with the developmental services delivery system and have training and experience in quantitative social science research to make sure that the FCMS and UFS are built to align with the goals and principles in the project.
    - Advise DDS on how to address any problems that arise.
    - Suggest areas in which the system could be improved.
    - Monitor performance and advise DDS of any needed changes.
- Establish a data warehouse and governance structure to support research on system performance.
  - Identify a secure research environment in which comprehensive data on the Developmental Services System—including data on individuals, families, DSPs, providers, regional centers, etc.—can be securely stored and linked to other datasets at the individual level.
  - Develop a governance structure so that researchers can access the data in the form of individual-level panel datasets and use

social scientific methods to examine root cases and conduct rigorous program evaluation.

Note: These recommendations should be integrated into the workgroup recommendations for Performance Measures since those recommendations will further refine data requirements and IT system planning and business goals and requirements.

Master Plan Recommendation: Make the Service Access and Equity Grant Program More Transparent [page 147]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should strengthen the Service Access and Equity Grant Program. DDS should:

- Develop a clear definition of equity. That definition should be used to help decide what types of projects, organizations, and communities should be funded by the grant program. That definition should also be used to create flexibility in grant processes to meet the needs of the community.
- Include more people in the grant review and selection process. It should include people with lived experience from the community and people with research, program evaluation, and data analysis experience.
- Provide more support to community-based organizations to help them write grants and access funding.
- Hold grantees accountable for using funds the way they are supposed to. Make sure grantees provide reports on how they served the community, what successes they had, and what barriers they faced.
- Be more transparent about the results of each grant and how grant funds are used.
- Give stakeholders a chance to provide feedback on whether the services that were paid for by a grant met their needs. This feedback should include surveys from people who receive services that were paid for by an equity grant.
- Develop equity and other measures to identify successful grant programs that should be prioritized.
- Find out which grants worked well. Make successful grant programs available statewide. Add them to regional center POS policies.
- Evaluate the equity grant program using equity and other measures. Get help from researchers to evaluate the program.

## Additional Details: The successful implementation of this recommendation would be supported by suggestions to:

- Develop a clear definition of equity that can be used to refine the equity grant program and help identify and decide:
  - What types of projects should be funded.
  - What kinds of organizations should be funded.

- What kind of communities the grants should target.
- Use the definition to create metrics and goals to measure whether progress is being made to address equity. It should be used to hold DDS, regional centers, vendors, and other systems accountable to meeting equity measure targets and goals.
- Create performance measures that identify successful programs that can be duplicated and expanded. Report measures during implementation to make sure the project is helping people in the way that it was written in the application.
- Secure funding to help spread successfully grant activities, practices and programs so they can help eliminate disparities.
- Develop innovate approaches to the grant review process. The approach should take into consideration the organization's background, track record and capacity to do the grant and achieve good results. The grant application should include letters of support from organizations that have partnered with them in the past. The application review process should explore including reviewers with direct experience in the community that could participate in the review process.
- Provide transparency regarding the use of funds and the results of each grant.
- Develop data points to measure and track the delivery of services to underserved communities so organizations receiving grants are held accountable.
- Re-evaluate the equity grant program once some of the foundational problems—such as no consistent definition of equity and no consistent measures of success—are fixed.
- Create satisfaction surveys to send to those who have signed up with community-based organizations who have been granted funds.

### Topic 7: Inform the Future of the Developmental Services System

The goal for this topic is that the developmental services system will continue to improve over time.

### Funding for I/DD Services in California

Master Plan Recommendation: Use Waivers to Make Seamless Service Systems [page 153]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS and DHCS should work together to develop a way to use Medicaid waivers and state plan options. The goal would be to create a seamless and easy access to services and supports.

DHCS and DDS will work with individuals with I/DD, family members, and community partners to look at Waivers and state plan options and see if the way

Medicaid programs exist today makes it harder for people and families get the services they need. DHCS and DDS should check if there are services that people cannot get because of the waiver or state plan option they are enrolled in.

- DDS and DHCS should work together with people with I/DD, family members, and community partners to develop and implement a Medicaid program that helps individuals get all the services they need throughout their life. This Medicaid program should help people access services without having to choose between various Waivers or having to move from one Waiver to another.
- Regional centers shall improve the way they support individuals and families in understanding available options for HCBS waivers and programs and making best choices for themselves. Regional centers should be the one source of information to know where to enroll and to connect to supports.
- DDS and DHCS should provide regional centers and service coordinators with resources, training, and information they need to support individuals and families well in understanding their choices of Medicaid programs. This includes Service Coordinators working with smaller number of individuals and families so that they can support them better, having low caseloads.

# <u>Additional Details:</u> Work to implement this recommendation should include consideration that:

- $\circ$  Today DDS is funded and provides services under two Medicaid Waivers:
  - HCBS Waiver for Californians with Developmental Disabilities, and
  - Self Determination Program for People with Developmental Disabilities
- DDS also has a third Medicaid option called 1915(i) that serves people who are Medicaid eligible but do not qualify for the HCBS or the Self Determination Waivers. All three programs provide similar services.
- Some people who need specific supports have to enroll into other Medicaid Waivers or programs. For example, a person who needs nursing services may need to enroll in the Home and Community Based Alternative Waivers operated by the Department of Health Care Services (DHCS).
- An individual can only be enrolled in one Waiver program. It can be difficult to understand all the options. People have to work with multiple agencies to get to the multiple Medicaid programs.

## **Changes in Federal Funding**

The MPDS process started in March of 2024. In January 2025, there was a different Federal Administration. This Administration has different priorities than the Administration before. It is hard to know if any changes will impact California's developmental disability systems. For example, there might be changes to Medicaid program funding. There might also be changes to how Medicaid funding can be used. Any changes or cuts made to Medicaid funding will require difficult decisions to be made about how to use available funds. It is important that the State is prepared to make these decisions to protect the services that people with I/DD rely on. These recommendations focus on things that California can do to address these kinds of policy changes in the future.

Master Plan Recommendation: Prepare for Cuts to Medicaid [page 155]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. If the federal government makes cuts to the Medicaid program and funding, DDS should follow certain principles and approaches.

- Preserve all aspects of the Lanterman Act entitlement. Keep eligibility standards where they are. Everyone should continue to have access to necessary supports.
- Keep the commitment to inclusive, person-centered services in the community. Prioritize supports that keep people in their own homes, their communities, and at their jobs. Continue to limit or reduce the need for more costly and restrictive licensed settings.
- Explore services that are person-centered and support independence, self-determination, and quality of life. This can include skills building and creative use of technology to reduce the need for in-person supports, where appropriate (e.g., through enabling technology, remote monitoring, and remote mental health supports).
- Explore and improve access to early start services and services supporting life transitions (from school to work, from day programs to work, with aging caregivers, family grief, to senior services).
- Recognize housing as a disability-related need (e.g., Housing First).
- Preserve participant-directed and self-directed services.
- Keep access to respite services, including therapeutic respite for people with complex needs.
- Prioritize HCBS compliance across all settings to maximize quality of life and independence of choice, regardless of federal and state climates that impact people's lives.
- Strengthen natural supports, including community-based organizations, family resource centers and "Circle of Friend" systems.
  - "Circle of Friends" is an approach to including young people with disabilities who are having a difficult time in school.
- Make it easier for people to access generic services.
  - Strengthen generic services and the capacity for regional centers to provide technical assistance to generic services systems and providers on serving people with I/DD. This can include strengthening ability of regional centers and services

#### coordinators to work with and coordinate with schools to make sure children receive services they need.

- Give people informed choices on sharing their demographic or legal status information to protect privacy.
- Prioritize Get Out the Vote, People First, and civic engagement efforts that create and increase platforms for self-advocates and families to be heard.
- Create and strengthen advisory committees that prioritize self-advocates and families to make sure that systems are working as well as they can with expert feedback from people with lived and living experience.
  Provide supports for participation.

## Gap Analyses

When people cannot access services they need, it is sometimes called a "gap" in services. A "gap analysis" is a way to understand the ways the system is and isn't working, so that it is easier to fix or change it. It is also a way to see if services are accessible, high quality, and if they are delivered equitably in a person-centered way. Understanding these things can help to make sure people can have good service outcomes. It is important that findings from gap analyses are used to make things better.

The Master Plan committee and workgroups have worked with the information they can get, but gap analyses of the system are needed to support the transformation of service systems that impact the lives of people with I/DD. These recommendations focus on different gap analyses that the State should do to understand gaps in services and to fix those gaps. Following any gap analysis, CalHHS and its departments should develop recommendations to address any gaps.

Master Plan Recommendation: Gap Analysis on Services for People With I/DD [page 156]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. The State should conduct a gap analysis of the ways people with developmental disabilities are served in systems across California throughout their lives.

As part of the gap analysis, the State should review the Lanterman Act to:

- List all services that people I/DD should get.
- Find out who pays for each service and which agency is in charge of it.
- Make sure people with I/DD can actually get all the services they need and have a right to.
- No matter what the gap analysis finds, the State should not move all services people with I/DD into managed care system.

# <u>Additional Details:</u> The recommendation was originally for the gap analysis to be specifically of Medicaid, to make sure that Medi-Cal and the systems that tie into

Medi-Cal (like IHSS) are being looked at to make sure they make changes to better serve people with developmental disabilities. It is also important to look at other systems people use in the state that are not Medi-Cal or the regional center (like the foster care system, schools, and the justice system), to make sure we know all the ways people with developmental disabilities need to be supported in those systems and all the different funding types that might help us get there.

If people need support in learning how to work with people with developmental disabilities, regional centers should play an important role (this is sometimes called technical assistance), but there needs to be a big conversation across systems about the needs people have and where they currently are and aren't being met. This information will help make sure technical assistance can happen and work well. It can also help us better support people from different cultures, who speak different languages, and more. We are trying to make sure that everybody who works in different state systems works together to support people with developmental disabilities, because this is important to help California thrive.

### Data

There are barriers to accessing services and gaps in the system that are hard to understand. One reason for this is that the data collected is not complete or of high quality. Data can be used to understand patterns in how individuals receive (or don't receive) services. Access to high-quality data is important to understand what is happening within a system and what might need to be improved.

Master Plan Recommendation: Collect Data on Hiring and Keeping Regional Center Staff [page 160]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. The State should conduct a study of the regional center service coordinator role at all regional centers. This study should collect data on:

- Vacancy, meaning open positions.
- Pay (including benefits).
- Retention rates, meaning how long service coordinators stay in their jobs.

This study should include existing data that is already collected to compare wage ranges across the regional centers. The study should look at how wage ranges align with retention and performance outcomes for service coordinators. The results of this study should be shared with regional center Boards and the public. The results should be used to create recommendations and requirements for regional centers to support better recruitment, compensation, and retention of service coordinators.

<u>Additional Details:</u> This recommendation and the next recommendation were informed by a focus group with service coordinators which took place in November of 2024. The main points which came up in the focus group are summarized here and should be considered in the design of the recommended study:

- Recruitment and retention challenges.
  - Pay discrepancies
    - Service coordinators face significant salary variation. Entrylevel pay for service coordinators can be as low as \$22/hour, despite regional centers receiving uniform funding. This creates inequity and leads to high turnover of service coordinators.
  - Administrative burden
    - Service coordinators mentioned that excessive paperwork, frequent system changes, and frequent changes to case management processes discourage them. The need for waivers and exceptions processes also adds to their workload, which contributes to burnout.
- Role and job expectation misalignment.
  - o Discrepancies between job expectations and reality
    - Service coordinators shared that they expected their jobs to be about client interaction and advocacy. They also shared that they find their roles to be filled with bureaucratic tasks. They expressed that their job title and description do not fully represent their responsibilities.
  - Overextended roles
    - Service coordinators shared that they fill roles beyond coordination, including crisis intervention, legal advocacy, and case management.
- Workload impact on service delivery.
  - Heavy paperwork and bureaucracy
    - Service coordinators shared that their work is more administrative than service oriented. Part of this is that IPP paperwork takes a long time, which makes it hard to focus on the needs of people served.
  - Limited time with clients
    - Service coordinators shared that, due to their large caseloads, they often do not have the time to provide thorough, personalized support. They also shared that this impacts their relationships with people served and family satisfaction.
  - Enhanced and specialized caseloads
    - Service coordinators shared that one strategy to address high caseloads is more utilization and hiring for enhanced caseloads (smaller caseloads focused on individuals with

low service utilization) and specialized caseloads (caseloads focused on specific populations with specific needs).

- Staffing and caseload issues.
  - Outdated caseload formula
    - The existing service coordinator caseload formula has not been updated since the 1990s. This leads to inflated caseloads and inadequate staffing. Some service coordinators carry 90+ cases, with additional load from covering vacancies.
  - Caseload data manipulation
    - Regional centers reportedly use deceptive data (e.g., mean vs. median caseloads) to request waivers, masking true caseload numbers.
  - Consequences of large caseloads
    - Large caseloads reduce service coordinators' ability to provide timely, personalized support to people served, especially in complex cases or for people served in the SDP.
- Need for specialized training.
  - Job-specific training
    - Service coordinators shared that the training which they currently receive is inadequate, which leads to high attrition. They said they need training in topics like:
      - The California developmental disability system
      - Policy processes
      - Crisis intervention
      - Support services
  - On-the-job learning
    - Many service coordinators noted that most of their job requirements are learned over time. This is due to the complexity of tasks which aren't captured in any standard training or formal educational programs.
- Desired incentives and benefits.
  - Flexible and supportive work environment
    - Service coordinators advocated for a more flexible work environment to improve work-life balance and retention and to make them more available to people served. Suggestions included:
      - Flexible schedules

- Telework options
- A 4-day workweek (which could include a 4 day/ 10hour work schedule)
- Recognition and growth opportunities
  - Service coordinators suggested ideas including:
    - Formal recognition programs
    - Loan forgiveness for tenure
    - Tuition reimbursement
    - Monetary retention bonuses for long-term service.
- Health care and pension
  - Service coordinators shared that desirable benefits like dependent healthcare and CalPERS retirement benefits are not offered consistently across regional centers.
  - They suggested that providing these benefits would improve retention.
- Proposed changes to improve service quality.
  - Smaller caseloads
    - Service coordinators shared that smaller caseloads would enable them to focus on supporting individuals and families and providing thorough follow-ups.
  - Redefining service coordinator responsibilities
    - Service coordinators suggested that assigning specialized staff for certain tasks (e.g., legal support, benefits planning, crisis intervention) and refining the service coordinator role could help them focus their work on meaningful interactions with people served.
  - Flexible service delivery options
    - Service coordinators shared that remote meetings and streamlined processes, including authorizations for services and exceptions, would reduce time and administrative burdens, allowing them to focus on the needs of people served.

Master Plan Recommendation: Collect Data on the Service Coordinator Caseload Sizes [page 160]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. The State should conduct an independent study of regional center caseload sizes and staffing ratios. This should include ratios for all specialized caseload types. This study should be used to update and modernize requirements for:

- Caseload sizes.
- Caseload types.
- Staffing ratios for roles like service coordinators and client advocates assigned to regional centers.

The results of this study should be used to update:

- Statute on the service coordinator caseload formula.
- Funding formulas for regional centers to support the new caseload and staffing levels.
- Consequences for failing to meet caseload requirements.

This recommendation and the previous recommendation were informed by a focus group with service coordinators, which was conducted in November of 2024. Please see the prior recommendation for more information. The main points, which came up in the focus group, are summarized above and should be considered in the design of the recommended study.

Master Plan Recommendation: Increase Access to Data [page 161]. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text. The entire recommendation is provided for context. DDS should increase access to high-quality data for individuals, the public and researchers. DDS should:

- Create a work group with individuals from the community, researchers and other people that have experience with data. The workgroup should talk about how data must be collected and used to support accountability, oversight, and research.
- Create an action plan that describes these steps:
  - How different types of data should be collected, combined, and used from service providers, regional centers, and health, education, and other systems.
  - How individuals, the public, and researchers should access the data.
  - How data will be protected and can be accessed by different types or organizations where appropriate and necessary.
  - How privacy will be protected. That means there are also ways that the wishes of individual to keep their data private can be respected.
- Develop a guide describing how data will be collected and made available for individuals and families, the public, and for research.
- o Collect, manage, and keep data safe for research and analysis.

# <u>Additional Details:</u> The successful implementation of this recommendation would be supported by a suggestion to establish a small working group to undertake a

fact-finding mission about the scope and quality of existing data and the need for new data.

- An output of the working group would be to create a roadmap for compiling, cleaning, and linking existing data and supplementing it with newly collected data.
  - The roadmap would also include the design of processes and a governance structure (set of rules and decision makers) that would make these data available, in different formats, to several groups of stakeholders.
- The working group would consult and collaborate with other entities (or agencies) as needed, and would consider data privacy and security, and community concerns about data sharing.
  - For example, the governance structure would create a firewall between researchers accessing individual-level data and the individuals who make decisions about those individuals' services. The governance structure would consider the role of CalHHS in obtaining approval from an Institutional Review Board (IRB) to allow researchers to access these data.
- The working group would carry out its work in five, partly overlapping stages:
  - Stage 1: Identification of data requirements
    - Based on stakeholder input, the workgroup would identify data\* fields required to support accountability at four levels:
      - Individual/family level
      - Vendor level
      - **Regional center level**
      - State level
        - \* "Data" is not limited to objective, readily quantifiable outcomes like employment status or education. It can also include subjective, qualitative, or self-reported data that may, or may not, be easily converted to a numerical scale.
    - Determine how to make these data available:
      - For data elements that already exist, from where and how they can be extracted.
      - For data elements that do not exist, which entity/agency can collect and store them.

- Determine which data elements (content and format) will ultimately be made accessible to:
  - Persons served (who will access their own data through an individual portal).
  - The public (who will access basic data on DDS and RC websites).
  - Researchers (who will access individual panel datasets trough a secure research portal).
- Stage 2: Development of a "Data Action Plan"
  - Based on fact-finding, the working group would determine:
    - Which agencies and other entities would collect and compile and store old data and new data, respectively (including timelines).
    - Which agencies and other entities would collect, compile, clean, interlink and store all data (including timelines).
  - In collaboration with designated agencies and other entities, plan how data would be made accessible to:
    - People served
    - The public
    - Researchers in secure environment
  - The working group would work with stakeholders to make sure the action plan and recommendations are written in plain language. At times, additional information would be necessary to emphasize or elaborate on the details in order to impact policy.
- Stage 3: Collection and compilation of data. The Data Action Plan would designate agencies and other entities to collect:
  - Existing data
    - Most of the historical data is stored in CalHHS Data Center.
    - Some data, such as Department of Education data and National Core Indicators data, may be extracted from other systems.
  - New data
    - Some new data collection efforts (such as PAVE) are already underway.
    - Some new data collection initiatives would be phased in over time.

- Data privacy and security
  - Privacy and security policies related to existing and new data would be reviewed and updated as needed to safeguard the privacy of individually identifiable data.
  - Stakeholders would be consulted to consider how data should be protected and who should be granted access to it and for what purposes.
- Stage 4: Linkage, cleaning, and storage of data. Per the Data Action Plan, designated entities would link, clean, and store data in different formats for different groups:
  - Persons served would access their own data (potentially including data from other state systems).
  - The public would access basic data on resources and outcomes.
  - Researchers would access individual-level panel data, including historical data.
- Stage 5: Data made accessible to key groups (in different formats). Per the Data Action Plan, designated entities would make data accessible in different formats to different groups:
  - Persons served would access their own data through an individual portal.
  - The public would access basic data on DDS and regional center websites.
  - Researchers would access individual panel datasets through a secure research portal.

### **Recommendation Needing Further Consideration**

There was a lot of discussion about this recommendation. There were diverse opinions about how the recommendation should be finalized. There were two final versions of this recommendation. Each of these versions received a close vote but did not reach consensus. Details for this recommendation that are not included in the Master Plan are shown below in **bold** text.

These are the two versions of the recommendation, which are provided here for context:

• DDS should look at best practices at regional centers that are currently using vendored service coordination. DDS should also look at models in other states that allow choice of service coordination. The study should include input from very diverse perspectives on this issue. Based on this information, DDS should develop a report on the study findings. The report should explain the pros and cons of service coordination provided outside the regional center. The results of

this study should be shared with the DDS Master Plan Committee. The Committee could then make recommendations to DDS to create a pilot program. This pilot program could create an option for people served by the regional center to choose a service coordinator outside of the regional center. The Lanterman Act already allows for certain individuals from outside of regional centers to serve in the role of service coordinator, with regional center approval.

• DDS should look at best practices at regional centers that currently use vendored service coordination. Based on this information, DDS should develop a pilot program to create an option for people served by the regional center to choose a service coordinator from outside of the regional center. The Lanterman Act already allows for certain individuals from outside of regional centers to serve in the role of service coordinator, with regional center approval. Based on the results of reviewing current vendored service coordination and this pilot program, DDS should determine next steps.

<u>Additional Details:</u> Section 4647 (c), (d), and (e) is the part of the Lanterman Act that currently allows for certain individuals from outside of regional centers to serve in the role of service coordinator with regional center approval.

Creating an option for any person served by a regional center to obtain service coordination from a qualified external organization or individual would require amending the Lanterman Act. This amendment could provide a standard option for any regional center client, without requiring regional center approval.

Parameters would need to be developed that outline the qualifications of the external organization or individual serving in the service coordination role.

The proposed external service coordination role could:

- Include all services that meet state and federal requirements for "targeted case management," which is the way service coordination is paid for by Medi-Cal in California. Specifically, service coordination by the external organization or individual would include:
  - Assessment
  - Person-centered plan development
  - Linkage to services/resources and consultation
  - Assistance in accessing services
  - Periodic review (quarterly, annual, etc.)
  - Crisis assistance planning
- Also include assistance to expand the client's and family's circle of support and natural supports
- Be compensated

These draft recommendations should be considered in ongoing work to implement the MPDS but are not being included as a final recommendation.

For more details about what comes next for the Master Plan for Developmental Services, please see the <u>Master Plan for Developmental Services Report</u> (<u>https://www.chhs.ca.gov/wp-</u> content/uploads/2025/03/MPDS\_ACommunityDrivenVision.pdf).