



# Master Plan for Developmental Services

## A Community-Driven Vision

MARCH 2025

# Community Commitments

**What to Expect in the Master Plan for Developmental Services (MPDS).** The MPDS is a community-driven vision. 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. The MPDS provides recommendations for California to provide services for people with I/DD that are:

- Equitable
- Consistent
- Accessible

This plan was developed by a diverse group of stakeholders. A stakeholder is someone who is affected by an issue. The stakeholders who developed the MPDS included:

- People with I/DD
- Their family members
- Other members of the community

The California Health and Human Services Agency (CalHHS) provided staff and other support to stakeholders in developing the MPDS. All the recommendations in the plan were developed with and by community stakeholders. The plan was developed to advise CalHHS, the Department of Developmental Services (DDS), and other state departments on how to achieve a shared vision of improved services and supports for all Californians with I/DD.

This report talks about ways to make the developmental services systems work better. It also provides a vision for a future where people with I/DD have the resources they need to thrive. These resources include the flexible and innovative services and supports that people with I/DD need to be full participants in the community of their choice. The MPDS is designed to inform California's ongoing work to create opportunities for, and to serve, people with I/DD.

**Making This Report Accessible to Everyone by Using Plain Language.** This report is written in plain language. We use plain language so that everyone can understand the recommendations in the MPDS. Plain language is a way of writing that makes information easy to understand. It uses clear words and sentence structures to help readers understand what is in the Plan. This approach is especially helpful for people with I/DD. It helps to make sure everyone can access and understand information that affects their lives.

There is a lot of information in this report about how to make the systems work better. Some of these recommendations are complicated and might use words that are not familiar. There is a glossary at the end of this report with definitions for many of the words used in the report.

**Referring to People With I/DD Using the Language They Choose.** People with I/DD have different ways of describing themselves. People might prefer terms like advocate, self-advocate, disabled person, or individual with lived experience. Some people prefer “person-first” language. Person-first language means saying things like “people with disabilities.” Other people prefer “identity-first” language. Identity-first language means saying things like “disabled people.”

This report usually uses terms like “people with intellectual and/or developmental disabilities” (I/DD) or “people served.” This report will also use the term “self-advocate” to refer to people with I/DD who participated in the MPDS process.

**Self-Advocate Input:** This report uses information and ideas shared by self-advocates. Their personal experiences help us understand how to improve the services they use. The stories, experiences, and ideas of self-advocates and family members of people with I/DD helped shape recommendations to provide equitable, consistent, and accessible services and policies.

In this report there are boxes that highlight quotes from self-advocates. These quotes talk about self-advocate experiences with the system. The quotes also talk about the hopes and dreams that self-advocates have for the MPDS. Self-advocates are experts with real experience. Their ideas were a very important part of the Master Plan process. These voices helped lead and guide the development of the Master Plan.

# Table of Contents

<b>Appreciation From the Agency Secretary .....</b>	<b>5</b>
<b>Why Do We Need a Master Plan for Developmental Services? .....</b>	<b>7</b>
What Is “The System”? .....	10
Equity in the System .....	10
What Is the Master Plan for Developmental Services? .....	12
<b>How Did We Create the Master Plan for Developmental Services?.....</b>	<b>15</b>
Committee and Workgroups .....	15
Public Engagement .....	18
Topics in the Master Plan .....	19
The Master Plan Is Centered in Lived Experience .....	19
<b>What Are the Recommendations in the Master Plan for Developmental Services? .....</b>	<b>21</b>
Systems Serving People With I/DD Are Centered in Equity .....	21
People With I/DD Making Their Own Life Choices .....	27
People With I/DD Living in Inclusive Communities With the Resources They Need to Thrive .....	38
People With I/DD Getting Services They Need and Choose .....	68
People With I/DD Being Part of and Being Served by a Strong Workforce.....	116
Accountability and Transparency in All Systems That Serve People With I/DD .....	125
Inform the Future of the Developmental Services System .....	149
Recommendation Needing Further Consideration.....	162
<b>What Comes Next for the Master Plan for Developmental Services?.....</b>	<b>164</b>
<b>Appendices.....</b>	<b>167</b>
<b>Acknowledgements .....</b>	<b>194</b>

## Appreciation From the Agency Secretary

Dear Committee, Workgroup Members, and Community,

On behalf of the California Health and Human Services Agency, I extend my gratitude for your contributions to the Master Plan for Developmental Services. Your expertise, dedication and collaboration have been essential in understanding and capturing what people in California's developmental disability services community need and want for the future. The process of creating the Master Plan was ambitious, requiring the input of diverse perspectives. Your commitment to inclusivity, thoughtful and thought-provoking conversation, and innovative ideas have enriched the Master Plan.

Whether you participated as a Committee Member, Workgroup Member, or through public forums, provided feedback, participated in one of the more than 45 sessions with community groups, or worked directly with staff to offer assistance and insights, your contributions are invaluable. The recommendations that you developed will improve the quality of services and life outcomes for individuals with I/DD and their families. This work will also help maintain and expand services and supports remain responsive, equitable, accessible, and sustainable for Californians.

I would like to recognize the work of Victor Duron, Chief Deputy Director at the Department of Rehabilitation (DOR), who led the Master Plan effort while balancing his existing responsibilities and briefly serving as acting Director. In addition, thank you to the team of logistics experts, consultants, facilitators, interpreters and translators, note-takers, writers, and others who made possible the dozens of Committee and workgroup meetings, and community listening sessions. The Master Plan itself could not have come together without your efforts.

Significant and transformative efforts are currently underway across Governor Newsom's Administration. This includes the January 1, 2025, full implementation of rate reform in California's developmental services system, to stabilize and expand the service provider network and its essential workforce. Planning is

underway for a modern and unified case management and fiscal system that provides access for individuals, families, and service providers to information, including their own. Employment First policies and a Master Plan for Career Technical Education and new apprenticeship and internship programs present new opportunities for people to achieve their goals and financial success. Collectively, the goal is to make sure that the systems are fair, support the provision of high-quality care, and help people get the services they need. As we move forward, we recognize that the implementation of recommendations in the Master Plan requires continued partnership and collaboration. We remain deeply committed to working with the community and the Legislature to realize the plan developed by and for the community. Together, we will achieve lasting positive improvements for the people of California.

In partnership,

**Kim Johnson**

Secretary, California Health and Human Services Agency

# Why Do We Need a Master Plan for Developmental Services?

All people have the right to make choices about how they live their lives. People with I/DD often face discrimination and stigma. Discrimination happens when people are treated unfairly because of things like their gender, age, race, or ability level. Stigma happens when people believe negative things about someone and treat that person unfairly or do not include them. People with I/DD from certain groups face more discrimination and stigma than people in other groups. This can be true for:

- People who speak a language other than English
- People who are not citizens
- People who are part of racial or ethnic groups that have historically been discriminated against
- People who have certain disabilities

People with I/DD do not always get the same freedom, support, and opportunities as others. This happens for many reasons:

- Sometimes non-disabled people think they know what is best for people with I/DD and tell them what to do.
- Sometimes non-disabled people do not listen to the opinions of people with I/DD.
- Sometimes the systems that provide services to people with I/DD do not explain what supports and opportunities are available.

**“They seem to assume if you’re a consumer, that means you’re not necessarily intelligent enough to make decisions for yourself or anyone else. It’s like—excuse me?”**

Elena

- Sometimes supports and opportunities that people with I/DD want and need are not available to them when they should be.

- Sometimes vendors don't want to provide services and supports to certain people with I/DD because of the disability they have, or for other reasons.

It is not right or fair that many Californians with I/DD do not get to make choices about their own lives. It is not right or fair that they are not always listened to. It is not right or fair that Californians with I/DD do not always get equal treatment.

This Master Plan for Developmental Services (MPDS) is a plan to make things better and more fair for people with I/DD. The Plan has recommendations to make sure 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.

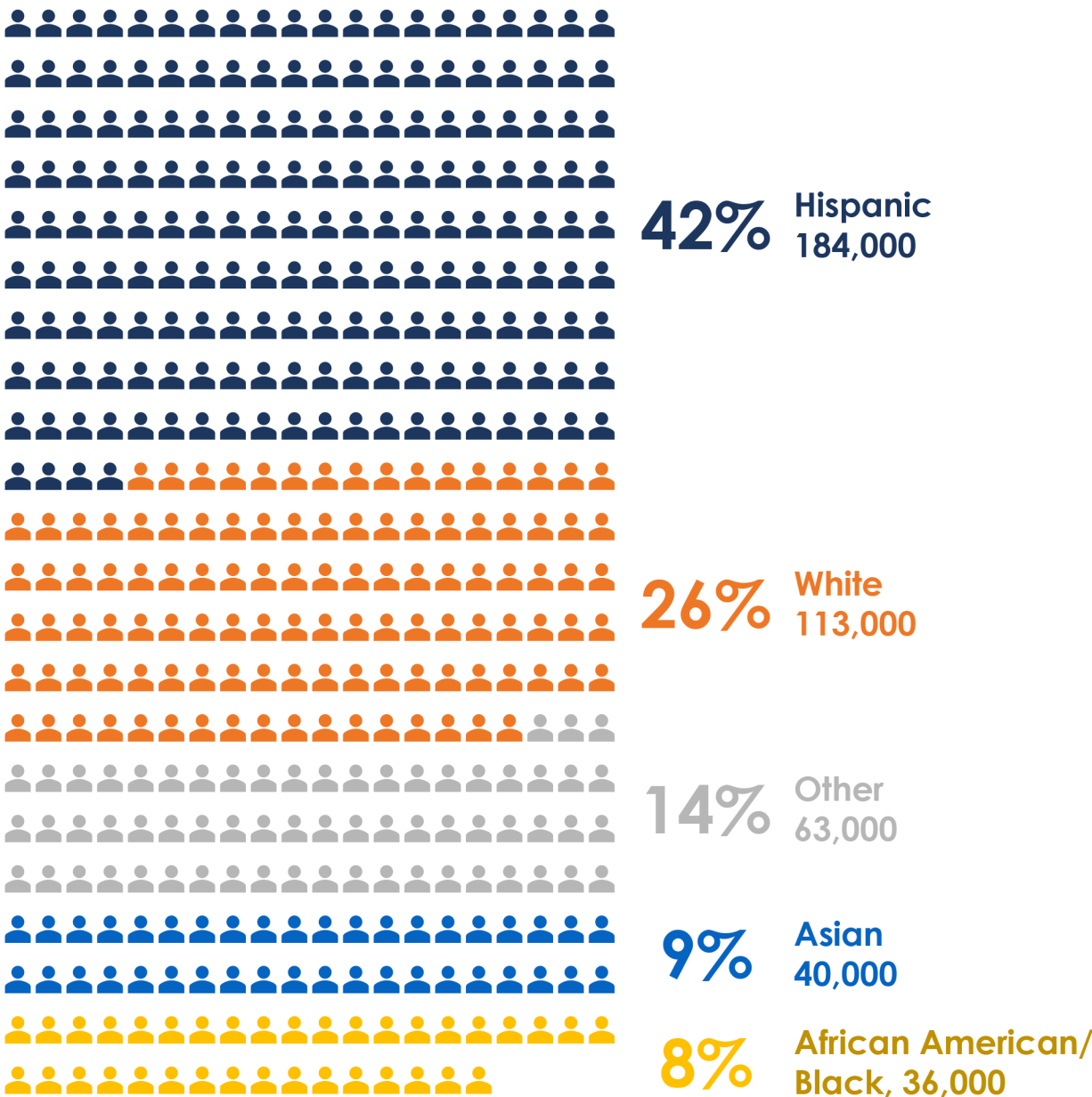
California's law for the developmental services system is called the Lanterman Act.<sup>1</sup> This law was passed in 1969. The Lanterman Act says that people with I/DD and their families have a right to get services and supports they need. This is called an "entitlement." It means that California is responsible for making sure people with I/DD get the services they need to live the lives they want. There are other state and federal laws that support people with I/DD and their families. One of those is the Early Start program. California's Early Start program provides access to developmental services for infants, toddlers, and their families.

In California, the Department of Developmental Services' (DDS) is responsible for making sure people with I/DD receive services and supports. DDS has contracts with regional centers to provide and coordinate services and supports to eligible people with I/DD. There are 21 regional centers in California. Each regional center coordinates services for eligible people with I/DD who live in their area. In 2024, nearly half a million people with I/DD were served by the regional center service system.

---

<sup>1</sup> For more information about the Lanterman Act (<https://www.dds.ca.gov/transparency/laws-regulations/lanterman-act-and-related-laws/>)

Population Served by the Regional Center System in 2024



## What Is “The System”?

People with I/DD and families served by the developmental services system often get services from other systems too. These systems are meant to work together to provide services and supports that people with I/DD and their families need. But the systems don't always work that way. People and families served by the developmental services system may also receive services and supports from other systems like:

- The California Department of Health Care Services (DHCS)
- The California Department of Rehabilitation DOR
- The California Department of Social Services (DDS)
- Schools, colleges, and educational programs

## Equity in the System

Recent reports identified challenges people experience when getting services in the developmental services system. For example, in 2023 a report by the Little Hoover Commission found problems with the ways that people with I/DD and families get developmental services.<sup>2</sup> The report said that people from different racial and ethnic groups did not get services fairly. The report also said that people living in different parts of the state did not get services fairly. The report said that it was important to fix these problems with the system. Fixing problems like these would help to make sure that there is equity in the system.

---

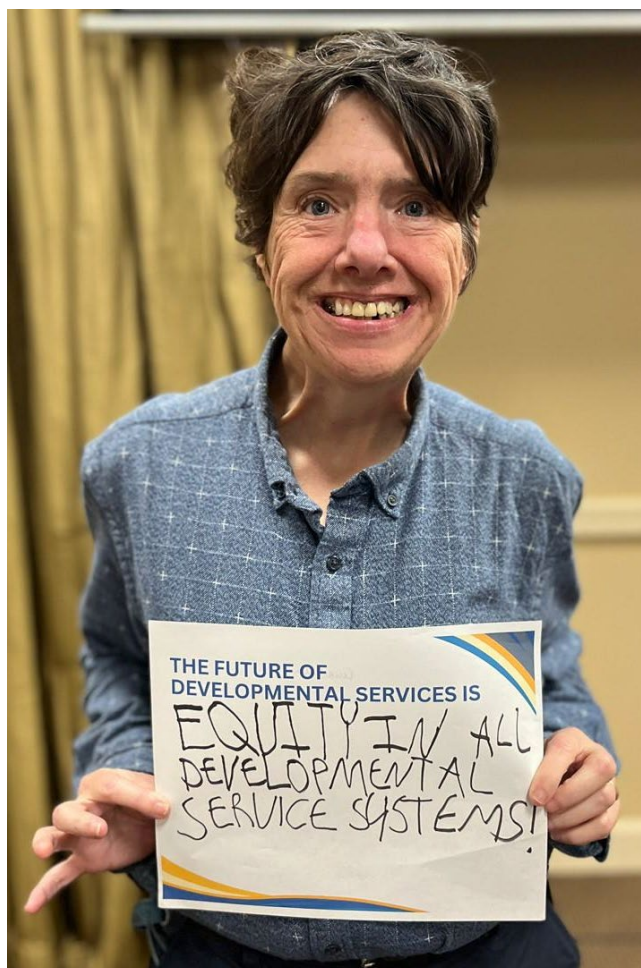
<sup>2</sup> [For more information about the Little Hoover Commission report \(https://lhc.ca.gov/report/system-distress-caring-californians-developmental-disabilities/\)](https://lhc.ca.gov/report/system-distress-caring-californians-developmental-disabilities/)

## What Is Equity?

- Equity means giving each person with I/DD the help they need to lead the lives they want.
- Equity means understanding that people do not start in equal or fair places.
- Equity aims to correct unfairness.

Equity was a guiding principle for the MPDS process because there are people and communities who experience unfair treatment and unequal outcomes in the developmental services system. Early in the MPDS process, the Committee talked about equity to make sure that everyone had a shared understanding of what equity means. Throughout the MPDS process there was outreach to many diverse communities, including communities that are not served by the system and communities that are served by the system. This was to make sure everyone's input would be reflected in the MPDS.

We put equity at the center of the MPDS process to make sure equity was considered in all of the Master Plan recommendations.

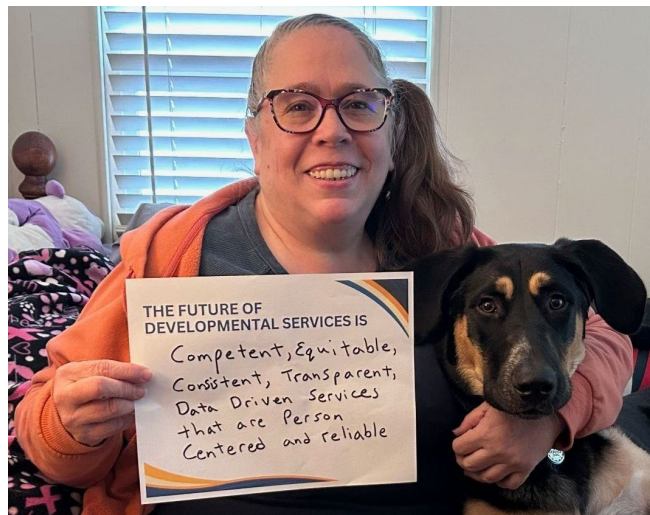


## What Is the Master Plan for Developmental Services?

The MPDS can help inform progress to:

- Better services and supports
- Improved coordination across systems
- People with I/DD getting the life outcomes they want

CalHHS provided staff and other support to stakeholders in developing the Master Plan. But the plan was ultimately developed with and by the community. This includes people with I/DD who are served by the system and their circles of support. “Circles of support” means the people in our lives that help us be successful. This can include parents, siblings, close friends, and other loved ones. The Master Plan was also developed with support from other community members like service providers, policy experts, and other stakeholders. Together, self-advocates and other stakeholders developed this plan and all of the recommendations in it that talk about how to make California better for all people with I/DD.



The vision for the MPDS is centered in:

- Equity
- The promise of the Lanterman Act's entitlement to services
- The experience and expertise of people with I/DD and their families

The vision applies to all systems that serve people with I/DD and their families. The goals of the Master Plan are:

- People with I/DD and their families experience person-centered service systems they trust. Their basic needs are met so they can live in the community of their choice.

- People with I/DD receive timely, inclusive, and seamless services throughout their life span across all service systems.
- People with I/DD and their families receive services from a high-quality, stable, and person-centered workforce.
- People with I/DD and their families experience consistent, transparent, accountable, and data-driven systems that focus on outcomes.
- People with I/DD receive quality, life-long, person-centered services from systems with adequate resources.

The MPDS talks about how to make these improvements for everyone with I/DD, no matter:

- The type of disability they have
- Their age, gender identity, or sexual orientation
- What language they speak
- Where in California they live
- How much money they have
- What racial or ethnic group they belong to

The MPDS has many recommendations to improve systems. These recommendations would:

- Make sure people with I/DD from all backgrounds feel respected and get person-centered services.
- Make sure people with I/DD live in inclusive communities where they feel they belong and have the resources to thrive.
- Improve accountability in the systems that serve people with I/DD. Being accountable means being responsible for your actions. It is about systems doing what they say they will do and facing the consequences if they do not.

- Make sure people get services they want and choose.
- Make sure there are resources and supports to meet the needs of more people.
- Make sure there are enough highly qualified people working to provide supports and services.
- Improve transparency in the systems. Transparency means making sure people have information to understand how the system works.

Another important part of the MPDS is removing barriers and closing gaps between systems that serve people with I/DD. This means improving coordination between the developmental services system and other systems. This would make sure that systems work together to help people get the services and supports they want and need.

**“We want the systems to work together instead of leaving people to navigate everything themselves.”**

Viri

# How Did We Create the Master Plan for Developmental Services?

## Committee and Workgroups

In early 2024, a MPDS Committee was appointed by the Secretary of CalHHS. The Committee's job was to develop the MPDS. Committee members had diverse backgrounds and lived experiences.<sup>3</sup> The Committee was asked to use their expertise to develop the MPDS together. They got input from diverse communities in California.



The Committee met every month between April 2024 and March 2025. All Committee meetings were open to the public and allowed on-line participation. Committee meetings took place around the state, including:

- Sacramento
- Los Angeles
- San Diego

---

<sup>3</sup> For a complete list of MPDS Committee members, see Appendix A.

- Fresno
- Berkeley

In addition to the MPDS Committee, five workgroups were created to focus on different MPDS goal areas. Each workgroup's job was to develop recommendations for their goal areas. Workgroups included some Committee members and members of the public who applied to be on a workgroup. Almost 900 people from all over the state applied. Of those who applied, 57 people were selected to be workgroup members.<sup>4</sup>

To have a broad representation of workgroup members we selected applicants with the following diversity:

- People with I/DD
- People with diverse expertise
- People from all parts of the state, including rural communities
- People with diverse backgrounds and identities including race and ethnicity, sexual orientation and gender identity, and different types of disability

Each workgroup had about 20 members. Each workgroup was led by two co-chairs. In each workgroup, one of the co-chairs was a self-advocate with I/DD, and the other was a family member of someone with I/DD.

**“Each one of us in our own way, represents thousands of other self-advocates who, for whatever reason, didn’t have the ability or the time or the interest to show up for multiple meetings. In our own way we got to be their voice and represent their needs and interests.”**

Lisa

---

<sup>4</sup> For a complete list of MPDS workgroup members, see Appendix B.

Workgroups met every month between August 2024 and March 2025. Each workgroup focused on developing recommendations in one focus area. The five workgroup focus areas were:

- People with I/DD and families who experienced person-centered service systems they trust
- People with I/DD who received timely, inclusive, and seamless services across all service systems
- People with I/DD and their families who receive services from a high-quality, stable, and person-centered workforce
- People with I/DD and their families experience consistent, transparent, accountable, and data-driven systems that focus on outcomes
- People with I/DD are entitled to life-long services with adequate resources

Recommendations from the workgroups were discussed during Committee meetings. These discussions focused on how to improve workgroup recommendations. During the last Committee meetings, Committee members talked about the final recommendations that should be included in the MPDS.

Some workgroup recommendations are not in this final Master Plan. This is because Committee members could not agree to include them. These recommendations are available in a separate document ("Recommendations That Were Considered and Not Adopted") on the CalHHS MPDS website (<https://www.chhs.ca.gov/home/master-plan-for-developmental-services/>). Committee members who did not agree with the final decisions about the recommendations could make comments about the final decisions. Those comments are also available on the Master Plan website (Stakeholder Committee Comments About Recommendations). There are other important documents on the Master Plan website. One document provides more details and technical information about some of the recommendations (Recommendation Background and Technical Information).

## Public Engagement



Every Committee meeting and every workgroup meeting were open to the public. Members of the public were invited to contribute their ideas. Committee meetings started and ended with comments from the public. Notes were taken on all public comments. The notes were used to make sure that the Committee considered all ideas and experiences in the Master Plan.

CalHHS also had a public engagement campaign during the MPDS process. This included many opportunities to engage with people with I/DD, their families, and other partners in their communities. The goal of the public engagement campaign was to better understand hopes and dreams for an improved developmental services system.<sup>5</sup> During the MPDS process there were public engagement events with 45 different groups. Thousands of people from diverse communities shared their ideas during these meetings. For example, there were events with:

- Diverse cultural community advocacy groups
- Disability civil rights organizations
- Representatives of service provider systems

---

<sup>5</sup> For a complete list of MPDS Community Engagement Opportunities, see Appendix C.

Summaries of public engagement events are available on the CalHHS MPDS website ("Community Engagement Summaries").

## Topics in the Master Plan

Recommendations in the MPDS were organized by topic area. Topics include recommendations from more than one workgroup. The six topics in the MPDS are:

- Systems Serving People with I/DD Are Centered in Equity
- People with I/DD Making Their Own Life Choices
- People with I/DD Getting Services They Need and Choose
- People with I/DD Being Part of and Being Served by a Strong Workforce
- Accountability and Transparency in All Systems That Serve People with I/DD
- Informing the Future of the Developmental Services System

## The Master Plan Is Centered in Lived Experience

People with I/DD and their families shared their real-life stories to help create the Master Plan. This is called "lived experience." It means learning from actual life events, not just from studies or reports. By including these personal experiences, the plan better reflects what people truly need and want.

Self-advocates played a key role in developing the Master Plan. They received the time and support to participate effectively and share their own thoughts and opinions.

**"In any kind of big conversation about people, it's really important to have the people who are being talked about in the room right? And not only just to be there, but to give expertise based on things that we know."**

Elizabeth

To empower self-advocates to participate, a new role, the Support Facilitator, was created. These facilitators helped self-advocates prepare for meetings, understand complex information, and share their own ideas confidently. Facilitators provided one-to-one help, group discussions, and support for self-advocates to participate on their own. Each self-advocate chose the support that worked best for them.

Before recommendations were finalized, self-advocates had their own information sessions. These sessions allowed them to review recommendations from each workgroup before decisions were made.<sup>6</sup>

**“I may be good at one thing, but it does not make me good at everything else. I need supports and real help in many other areas that a lot of people don’t consider...I love the pre meetings, because it gives us the chance to be with other self-advocates.**

Oscar

---

<sup>6</sup> For more detail on how self-advocates were supported during the Master Plan process, see Appendix D.

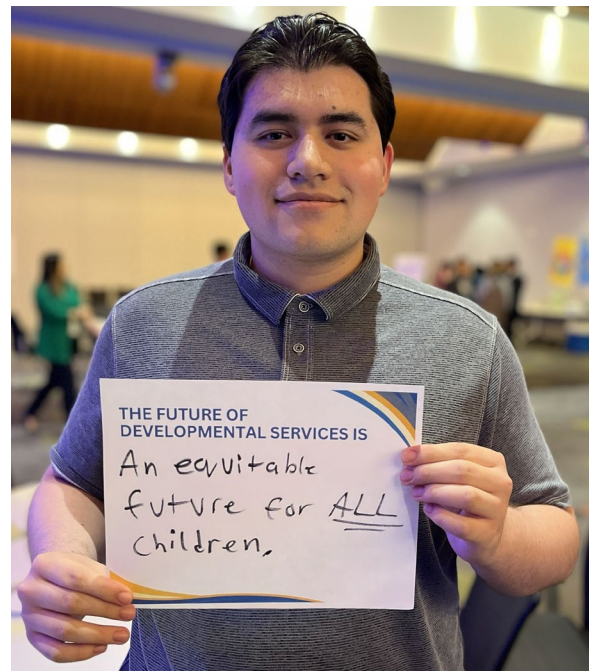
# What Are the Recommendations in the Master Plan for Developmental Services?

There are six topic areas and 167 recommendations in the Master Plan. This report provides a summary of each recommendation. Recommendations are organized by topic area. Each topic area provides information about what problems the recommendations are trying to solve. Some of the recommendations have more details and background than you will see in this section of the report. This additional information is available in a separate document ("Recommendation Background and Technical Information") on the CalHHS MPDS website.

## Systems Serving People With I/DD Are Centered in Equity

There are people with I/DD who experience unfair treatment and worse outcomes than others in the system. Some people with I/DD have an even harder time than others getting the services and supports that they need. This is not fair, and it is not equitable.

Recommendations in this topic area are focused on addressing fairness and equity in the systems that serve people with I/DD. These recommendations will help to make sure that the systems which serve people with I/DD are fair and work the way they should for everyone.



1. **Define Equity.** DDS should work with diverse communities to create a clear, plain language definition of equity. The definition should be updated regularly. This definition should acknowledge that everyone has different needs. This means an equitable system must be person-centered to provide everyone with opportunities to achieve their goals. DDS, regional centers, and stakeholders should use the definition of equity to guide their work and be accountable for achieving equity in the system. To do this, each regional center must work with DDS to create an internal Equity Team, and an equity advisory committee made up of community members. Both the Equity Team and the equity advisory committee should have strong self-advocate representation. Each regional center's Equity Team should participate in an independent statewide community of practice. A "community of practice" is a group of people who are working on a topic. The group meets regularly to discuss the topic and learn together. This community of practice would focus on the topic of equity. Each regional center's Equity Team should report to the DDS equity team regularly. This reporting to DDS would be separate from the Equity Team's relationship with the regional center that they work for.

**"We want clear rules that are fair but they have to be flexible to meet each person's needs. Equity should include clear actions to make sure everyone is treated fairly."**

Kecia
2. **Build Support and Oversight for Equity at DDS and Regional Centers.** DDS staff and leadership should have the resources and expertise they need to support and oversee equity at all regional centers. This means that DDS understands and responds to equity issues for people served by the regional center system. This should include training for DDS and regional center staff on how implicit and structural bias impact individuals and their circles of support. "Implicit bias" means prejudices or stereotypes that a person may believe without even realizing that they believe them. "Structural bias" means inequalities that are part of systems, policies, or practices. Training should also focus on how intersecting identities impact people served by the system. This recommendation means recognizing that people can experience unfair treatment because of multiple parts of their identity, like their race as well as their disability. This is called "intersectionality."

DDS should also incorporate equity requirements into their contracts with regional centers. This recommendation would make sure that DDS uses the definition of equity to analyze system data and outcomes. This would improve how DDS can enforce accountability. It would also support services, like Ombudsperson and client assistance services, to use an equity lens when addressing the needs of people with I/DD and their families. An “ombudsperson” is an independent third party who investigates and resolves complaints. Using an “equity lens” means keeping equity in mind when thinking about a problem or issue. This recommendation would help DDS address the specific needs of people with I/DD and help identify and resolve the causes of issues that are related to equity.

3. **Implement Language Access Plans at Regional Centers.** Regional Centers should adopt language access plans. A “language access plan” is a plan that clearly describes:

- The ways the regional center will communicate with individuals and families
- The languages they will use
- Any other supports that are needed so that individuals and families can easily understand them

The regional center language access plans should expand on plans which other state agencies have developed to serve the needs of individuals and their communities. The plans should be designed to meet the diverse needs of individuals and their circles of supports. The plans should include commitments to:

- Use plain language
- Use preferred language
- Provide digital access
- Provide Augmentative and Alternative Communication (AAC) and other accommodations. “AAC” means communicating using methods other than or in addition to 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.

The plan should also describe how equitable language will be used in all interactions with people with I/DD and their families—for example, during intake, during Individual Program Planning (IPP) meetings, and at fair hearings.

4. **Remove Language Barriers to Services.** DDS should make sure that language is not a barrier when people with I/DD and their families access services. DDS should:

- Make sure that all information about programs and services is available in plain language.
- Translate plain language information into languages spoken by people served by the regional center.
- Create programs and materials in multiple languages. This will make sure that people from diverse cultural communities can get the information they need.
- Develop a process of sharing these language support materials across regional centers.
- Hold regional centers accountable for using these language support materials.
- Make sure all regional center employees meet linguistic competency and cultural humility requirements.
  - “Linguistic competency” means that if employees are expected to use a language other than English, they can speak and understand the language well.
  - “Cultural humility” means that employees understand and respect differences that people from diverse backgrounds might have. It also means they understand there are things they do not know about other cultures, and that they are willing to learn from others.

- Make sure high-quality interpretation services are available at all regional centers. This way people with I/DD and their families will have the support they need during meetings and other interactions.
  - Require companies that provide interpretation services at regional centers to undergo trainings, complete certifications, and adhere to standards. This will help to make sure that the interpretation services they provide are of high quality.
- Establish an office at DDS that receives and responds to complaints about poor quality interpretation or translation supports. This will make sure that issues with interpretation or translation related to IPP meetings, service providers, fair hearings, and other interactions, are fixed.

5. **Make Sure People With I/DD Can Meaningfully Participate in Systems That Serve Them.** DDS and regional centers should provide person-centered supports to people with I/DD, so they can meaningfully participate in the systems that serve them. This includes participating in:

- DDS and regional center advisory boards
- Regional center boards of directors
- Employment opportunities in DDS and regional center leadership positions
- Decision-making in the next steps of the MPDS

Supports should:

- Include support facilitators
- Be provided without reducing or otherwise restricting the other services authorized in a self-advocate's IPP or their Self-Determination Program (SDP) budget

DDS should also provide resources and explain the steps people can take if they believe that they are not being supported to meaningfully participate or

are being tokenized. “Tokenism” is when people with diverse backgrounds are included without their concerns actually being listened to.

6. **Support People With I/DD and Their Intersectional Identities.** DDS and regional centers should develop plans for outreach and meaningful engagement with communities within their service area that experience additional barriers to equity. Some people with I/DD and their circles of support face additional barriers depending on other parts of their identity. This can include their:

- Race
- Sexual orientation and gender identity
- Geographic community
- Immigration status
- Tribal/Native American ancestry
- Disability type. People may experience discrimination within the disability community for their disability. This can be particularly true for people with the highest support needs or for people who have few or no circles of support.

The plans should describe:

- How communities which need better service will be identified
- Partners within communities, like trusted leaders in their community
- How outreach will be provided to those communities. For example, by:
  - Building relationships
  - Inviting the community to provide input
  - Supporting the community in being full partners in decision making within the system

7. **Engage With Tribal Communities to Enhance Services.** The State and the developmental disability system in California acknowledge the unique needs

and governmental status of Tribal communities. In creating the MPDS, the State received invaluable input from individuals receiving and providing developmental disability services in Tribal communities.

- One example of this input was that the State should look at special considerations in the law, such as the Indian Child Welfare Act, and consider if something similar is needed in the developmental disability system.
- Another example was to analyze the ways funding is set aside for Tribal services in other service systems and consider if there should be similar set-aside funding for Tribal communities in the developmental disability system.

After considering this and other Tribal input, the State would then engage in government-to-government Tribal consultation to get input from Tribal leadership and communities. This input would help the State know which changes to the developmental disability system will improve access and outcomes for Native American individuals with I/DD in California.

## People With I/DD Making Their Own Life Choices

People with I/DD often do not feel heard or respected when they share what they want in their own lives. Sometimes people with I/DD are left out of being included in decisions that impact their lives. This can happen when family members or service providers think they know best for a person with I/DD. This can also happen when family members or service providers think they know what a person with I/DD wants without even asking them.

**“We are very knowledgeable in our own lives and how we want to be. We understand each step of our life. So we’re the best experts, and sometimes these agencies don’t give us enough credit where credit needs to be given.”**

Tracey

Sometimes people with I/DD try to make choices and other people do not listen to them. Sometimes people with I/DD lose their right to make choices for themselves. A goal for this topic is that people with I/DD can make their own

choices to live a self-determined life. Another goal for this topic is that people with I/DD get the supports they need to make decisions.

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

Sometimes a court decides that someone else will make choices for a person with I/DD. This is called “conservatorship.” This means that the person with I/DD loses their right to make their own choices.

**“In personal life I get advice from people. People advise me. But I’m the ultimate decision maker. Whether that is good or bad, I’m the one making decisions.”**

Sascha

Conservatorship sometimes happens to people with I/DD who just need support making decisions. Supported decision making (SDM) is a tool that allows individuals to choose supporters who have a legal right to be part of the individual’s decision-making process. This means that people with I/DD can pick people that they trust in their circles of support to support them in making decisions.

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>7</sup>

**“Free will absolutely does exist, and we all have it, and we have the power to make a decision. But sometimes we get stumped on a certain situation, and we need that support.”**

Oscar

1. **Continue to Invest in Statewide Resources for SDM.** DDS should make sure there is ongoing funding for the SDM Technical Assistance Program (SDM-TAP). SDM-TAP is coordinated through the State Council on Developmental

---

<sup>7</sup> [For more information about the Expert Panel: Review of California Developmental Services Conservatorship Program Report \(https://www.dds.ca.gov/wp-content/uploads/2023/03/ExpertPanelFinalReportMarch2023.pdf\)](https://www.dds.ca.gov/wp-content/uploads/2023/03/ExpertPanelFinalReportMarch2023.pdf)

Disabilities (SCDD). SDM-TAP is a statewide resource and online hub for people seeking information about SDM. SDM-TAP provides education, guidance, assistance, and training to:

- People with I/DD
- Families
- Service providers
- Professionals
- Courts
- Attorneys
- Mediators
- Others in California who wish to use or expand SDM in their professional or personal life

2. **Create System-Wide Values About Alternatives to Conservatorship.** DDS should work with diverse stakeholders, including people with I/DD, to develop system-wide values about alternatives to conservatorship. These values should include:

- Using SDM
- Using conservatorships only as a last resort
- Using conservatorship only for the shortest period of time possible

DDS should create leadership opportunities for people who use SDM to share their experience and best practices. DDS should develop and make mentorship programs available. These mentorship programs would allow experienced users of SDM to provide support to people with I/DD who are new to SDM and families. DDS should develop user-friendly apps and platforms that facilitate SDM processes and communication between people with I/DD and their support networks.

3. **Make Sure People With I/DD and Their Families Can Access Information and Training to Use SDM.** DDS and regional centers should work with diverse stakeholders, including people with I/DD, to develop plain language information and training resources about SDM. These resources should be designed for people with I/DD and their family members. The information and training resources should talk about:

- How people with I/DD can make decisions
- Why conservatorship is not the only option
- Alternatives to conservatorship, including SDM

The information and training resources should:

- Address the needs of diverse communities
- Be available in languages spoken by individuals served by regional centers
- Explain how adults with I/DD can identify a supporter, including a family member, to help them make decisions at IPP meetings

The regional centers should discuss this information during each IPP meeting for transition-aged youth. "Transition-aged youth" means young people who are teenagers through people who are in their mid-twenties. Transitioned-aged youth should be supported in making decisions at each IPP meeting.

4. **Train School Systems and Other Key Stakeholders About SDM and Limiting Conservatorships.** The California Department of Education (CDE) should work with DDS to develop guidance about:

- How people with I/DD can make their own decisions
- Why conservatorship is not the only option
- Alternatives to conservatorship, including SDM

The guidance about SDM should talk about how adults with I/DD can identify a supporter, including a family member, to help them make decisions at Individual Education Program (IEP) meetings. Plain language information

about this guidance should be provided to transition-aged youth with I/DD and their family members at each IEP meeting. Local school districts should support transition-aged youth to make decisions at their IEP meetings.

Training about the guidance should be provided:

- By CDE and local school districts to their staff
- By DDS and regional centers to judges and court staff
- By DDS and regional centers to professionals, including health care professionals
- By DDS and regional centers to their staff
  - Training for regional center staff should also include training about conservatorship court reports which they might be required to complete.

**5. Provide Guidance and Training to Regional Centers to Limit Conservatorships.**

DDS should provide more guidance and training about how regional centers and regional center service coordinators can reduce conservatorships. The guidance, tools, and training should include:

- Clear direction about how to assess a person with I/DD's ability to make their own decisions. This is called "decision making capacity."
- Clear direction about how to report information about decision making capacity to courts.
- Types of services and supports that people with I/DD can use to make decisions. For example:
  - SDM agreements
  - Limited powers of attorneys. This means that someone else can help a person with I/DD make certain decisions.
  - Social security representative payees. This means that someone else can help a person with I/DD to manage their benefit payments.

- Advanced health care directives. This means that a person with I/DD can make a decision about what should happen to them if they have a serious health problem in the future.
- Additional supports to help SDP participants manage their individual budgets and spending plans.
- How to help people with I/DD use these services and supports to make decisions.

These efforts should focus on:

- Transition-aged youth who are often initially conserved between the ages of 18 through 21
- Older adults who sometimes face conservatorship after making their own decisions for many years

The State should also work to change the law so that regional centers are notified about, and required to provide the court with a court report for, all types of conservatorship proceedings for people with I/DD. This includes probate conservatorship and mental health conservatorships.

6. **Make a Plan to Remove all DDS Court-Appointed Conservatorships.** DDS should make a plan to remove all of its court-appointed conservatorships. Right now, DDS is the court-appointed conservator of about 370 people with I/DD. As part of the plan, DDS should:

- Turn down future conservatorship nominations from regional centers and the courts. This may require a change in the law.
- Use the many options available if an adult is in need of SDM. For example:
  - Have the SCDD approve health care decisions on an individual basis
  - Have the regional center physician approve procedures

7. **Measure Progress on Limiting Conservatorships.** DDS should continue to collect data about the numbers of people with I/DD who are conserved. This data should include:

- Demographic data about people with I/DD who are conserved
- The type of conservatorship
- Relevant dates for when conservatorship will be reviewed

A priority should be collecting data on the initial conservatorships of people ages 18 through 21. This is because many people with I/DD are initially conserved at these ages.

DDS should also assess the extent to which SDM reduces the number of conservatorships in California. This data should be used to measure progress and to inform other initiatives to reduce the number of conservatorships.

## **Making Choices in Regional Center Services**

People with I/DD who are served by regional centers can have different experiences. This can happen because regional centers have different ways of doing things. Even at the same regional center, service coordinators can have different ways of doing things. This means that some people served are able to make choices that other people served are not given the opportunity to make. This is not fair. Sometimes IPP does not happen in a person-centered way. This means that the person who the plan is for may not get to choose what is in the plan. Sometimes people do not have access to programs or services which they want and choose. These recommendations focus on making sure that people served

**“I don’t like the fundamental idea of acting in our ‘best interests’... I don’t want that. I want them [the regional center] to act in my interests.”**

Derek

**“When I first entered the Self-Determination Program, I was so used to nobody caring that when they started actually asking me what I wanted, I had to think about it.”**

Tina

by the regional center get to choose what goes into their IPP.

### **1. Use 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.
    - 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.
  - More detail about these rules and expectations can be found in the Recommendation Background and Technical Information Addendum document on the CalHHS MPDS website.
- 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.

**2. Remove Barriers to the SDP. Make the SDP an Option for Everyone Served by Regional Centers.** DDS should break down barriers to participation in the SDP. DDS should also make the SDP more consistent around the state. For this to happen, DDS should:

- Establish streamlined, consistent processes and procedures for the SDP
- Hold regional centers accountable for:
  - Ensuring the five principles of SDP are being met for participants

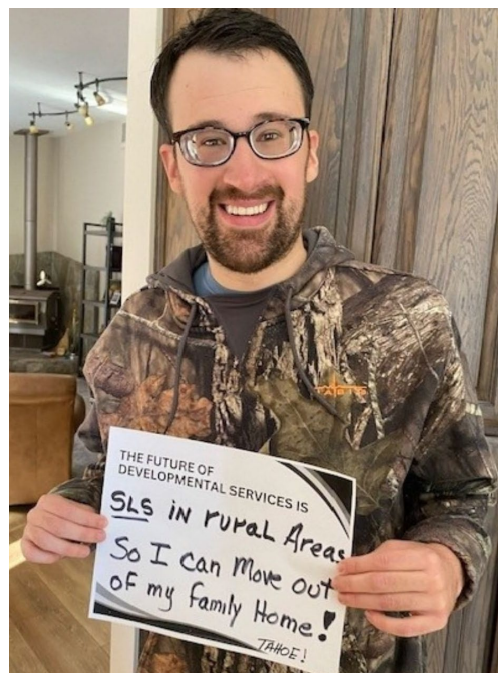
- Making measurable improvements toward achieving equity in enrollment in the SDP (by race, ethnicity, geography, and regional center)
- Make sure that SDP participants have authority over their spending plans by clarifying that:
  - Regional centers only verify federal funding and generic resource requirements
  - Regional centers still have all responsibilities related to:
    - Making sure that people's health and safety are protected
    - Making sure that services in spending plans relate to the goals in IPPs
  - Services used to develop the individual budget are not tied to services listed in the spending plan
  - Purchase of service (POS) standards for traditional regional center service coordination should not be applied to services in the SDP spending plan
- Standardize and simplify spending plans by:
  - Only requiring participants to assign expenses to one of three budget categories
  - Allowing estimation of costs
  - Not requiring names of providers to be listed
- Make sure the Financial Management Service (FMS) is held responsible for any penalties or fines that result from failure to comply with state and federal labor requirements, such as timely pay
- Require budgets and spending plans to roll over until new authorizations have been completed and sent to the FMS. This will make sure that people served can continue to participate in the SDP.

- Reduce delays related to accessing the SDP that are within regional center control by setting explicit timelines for:
  - Sending a consumer their POS twelve-month expenditure report
  - Scheduling budget meetings
  - Reaching out to schedule a renewal budget meeting with a person served
  - Reviewing the spending plan
  - Sending the POS authorization to the FMS
- Make sure every person served by a regional center receives unbiased information at every IPP meeting about the opportunity to participate in the SDP
  - Require regional centers to offer SDP as a standard service model option in every IPP meeting and whenever a person requests it
  - Require regional centers to include information about SDP as a standard option in all collateral and marketing materials
  - Contract with an outside organization to:
    - Develop consistent informational materials about the SDP in plain language. These materials should also be translated into languages spoken by people served by the regional center.
    - Improve the SDP orientation
      - For example, by providing multiple shorter online trainings, available when people need them
    - Train all service coordinators on the SDP
- Have a goal of significantly increasing participation in SDP by:

- Developing a pilot project in multiple regional centers to provide additional supports for enrollment in SDP for communities that are underrepresented. For example:
  - Latinos
  - African Americans
  - Consumers with low or no POSs
- Requiring regional centers to conduct proactive outreach to individuals from these communities and offering comprehensive training on the SDP, intensive supports from independent facilitators and FMSs, and faster onboarding from the regional centers
- Evaluating the pilot project to assess whether more individuals were able to enroll, their satisfaction and outcomes once people enter the SDP, and whether streamlined processes were used

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

People with I/DD face barriers to being included in their communities. This can mean that people with I/DD and their families may experience isolation. “Isolation” means being alone and not being connected to other people. People with I/DD also face stigma and discrimination about what they can do and achieve. It can also be harder for people with I/DD to meet their basic needs like housing, health care, food, and clothing. Challenges like lack of transportation can make it hard for people with I/DD to get where they need to go and to participate in community activities or events. There are more barriers for:



- People who live in rural communities
- People who are immigrants
- People who have a hard time reading, or who cannot read
- People who speak a language other than English

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

People with I/DD want friendships, romantic relationships, marriage, and children, like anyone else. These kinds of relationships are an important part of living a full life and being part of a community. These relationships are also part of a person's circles of support. Natural supports, like friendships with people with and without disabilities, are important parts of a healthy social network. Healthy social networks can give people with I/DD support that they need to be independent. Many people with I/DD experience barriers to building healthy social connections. People with I/DD are more likely to experience loneliness, bullying, or abuse than people without disabilities.

There can be few opportunities for people with I/DD to meet new people in person or in disability-specific online spaces. Some people with I/DD use dating apps to meet people, even though they don't always feel that this is safe.

People with I/DD have a right to privacy, dignity, and romantic relationships. It can be challenging for some people with I/DD to have romantic or sexual relationships.

- Adults with I/DD may struggle to pursue intimate sexual relationships because they do not have privacy in their homes. This can be true for people with I/DD who live in some types of residential living arrangements or in their family home.
- Some people with I/DD have a hard time getting education about sexuality.
  - Students with I/DD have a right to education about sexuality in school, but many schools do not provide this training for students who are educated in non-inclusive settings.

- Many regional centers have long waiting lists for sexuality training services.

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.

1. **Make Sure Students With I/DD Can Access Education About Sexuality.** DDS and the CDE should work with diverse self-advocates to identify best practices and materials for sexuality education for students with I/DD. These materials should:

- Talk about the social rights of people with I/DD
- Talk about safe sexuality. This should include inappropriate touching and abuse protection.
- Be available in plain language
- Be available in the languages spoken by individuals served by regional centers
- Be culturally appropriate for the diverse communities served by regional centers

The CDE should also provide guidance to local school districts about the responsibility to provide sexuality education to people with I/DD covering the same topics as covered in sexual education classes for students without disabilities.

2. **Make Sure People Served by Regional Centers Can Access Education About Sexuality.** Regional centers and community-based partners should also use the best practices and materials for sexuality education which DDS and the CDE develop. They should use these resources to provide information and training about sexuality for people served by the regional centers and their families and/or caregivers.
3. **Make Sure People With I/DD Can Access Social Skills Training.** DDS and regional centers should increase service options for social skills training for adolescents and adults with I/DD. This kind of training would help people with

I/DD to make and keep friendships and romantic relationships. These services should be provided for free to people with I/DD. For example, the services could be purchased by regional centers through their vendored providers or from other community-based services. One example of this kind of skills training would be PEERS.<sup>8</sup>

4. **Support People With I/DD to Grow Their Circles of Support.** Regional centers should make sure that conversations about ways to grow a person's circles of support happen during every IPP meeting. This should include talking to people served about ways that they can:
- Meet new people
  - Continue to grow their circles of support
  - Continue to grow their social networks

Sexuality training and education services should be offered during IPP meetings for adolescents and adults served.

5. **Make Sure People With I/DD Have Opportunities to Meet New People.** DDS should provide guidance about how regional centers can use the social recreation category of services or other services to fund inclusive social gatherings for people served. This could include events like:
- "Speed dating"
  - "Speed friendship"

Regional centers should use the guidance from DDS to work with their vendors and community-based partners to make sure there are more opportunities for people with I/DD to attend inclusive social gatherings.

6. **Relationship Film Contests.** DDS and regional centers should host film contests about relationships for people with I/DD. The films in the contest should be filmed in partnership with people with I/DD. The films could be about:
- Friendship

---

<sup>8</sup> [For more information on PEERS training \(https://www.semel.ucla.edu/peers\)](https://www.semel.ucla.edu/peers)

- Dating
- Parenting
- Inclusive neighborhoods

To make these film contests happen, DDS and regional centers could:

- Work with Film schools
- Work with current vendors who have film studios
- Expand Service Access and Equity grants to be used to produce films

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

Technology is an important tool for many people with I/DD. Many people with I/DD use technology for important parts of their lives. For example, people with I/DD may use technology to:

- Communicate
- Stay safe
- Participate in their communities

People with I/DD are not always able to access the technology that they need. Sometimes it can be hard to get technology services and devices because the process is confusing. Some locations may not support people with I/DD in using the technology that they need. People who live in rural places may have challenges with internet or cell-phone service to support the technology that they need. These recommendations

**“People with speech disabilities are sometimes seen as incapable of speaking for themselves. Nonverbal people can speak, it may be another way. We find some way to communicate in another way.”**

Sascha

**“I grew up in the foothills of Yuba-Sutter, where you get one or two bars on your phone at most, and have to use satellite internet because DSL/wi-fi is not available.”**

Elena

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

1. **Make Sure People With I/DD Can Access and Use Technology.** DDS and regional centers should make sure that people with I/DD can get the technology that they need. DDS and regional centers should make 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>9</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.

2. **Make Sure People With I/DD Can Choose to Access Some Services From Home.** DDS and Regional Centers should also 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 in-person. DDS should make sure that virtual or remote services or 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

---

<sup>9</sup> [For more information on the Middle-Mile Broadband Initiative \(https://middle-mile-broadband-initiative.cdt.ca.gov/\)](https://middle-mile-broadband-initiative.cdt.ca.gov/)

- Learning from home
  - Seeing a doctor or therapist from home
  - Being a part of virtual communities, like social media
3. **Make Sure AAC is Supported in Public Spaces.** The State should make sure that forms of AAC, like technology devices, are allowed and supported at all public places and government facilities. For example:
- Airports
  - Immigration offices
  - Jails
  - Hospitals
4. **Make Sure People With I/DD Can Access Assistive Technology.** DDS, regional centers, and the DHCS should work together to make sure people with I/DD are able to access assistive technology that they need. To make this happen, DDS, regional centers, and DHCS should work together to:
- Make it easy for people to quickly get assistive technology they need
    - This includes working together to make it clear how assistive technology should be provided and paid for
  - Provide insurance and accessible customer service support in case assistive technology needs to be fixed
  - Make sure there are enough vendors to provide assistive technology in a timely manner. This should include equipment (like wheelchairs) and environmental accessibility modifications (like ramps, or wider doors).
  - Research and develop pilot programs for independent living with use of technology
    - For example, expand access to innovative technology, such as “smart homes.” Smart homes use technology to control and

monitor devices remotely. This would help people with I/DD be more independent in their own homes.

- Provide supports and learning opportunities to help people with I/DD, their families, and their staff to improve skills to use technology. For example, skills like:
  - How to use and maintain assistive technology
  - How to use technology that can help people in their daily lives. This could include virtual meeting software, like Zoom.
- Provide access to assistive technology to people regardless of where they live

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

Often, community activities and spaces are not set up in a way that makes it easy for people with I/DD to be included. Sometimes people in the community do not understand how they can help include people with I/DD. Sometimes people with I/DD and their families do not get information about supports that are available to help them access community resources. 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.



1. **Remove Barriers in Communities.** Regional centers should work with community partners, like local governments, to remove barriers that make it hard for people with I/DD to be a part of their community. Regional centers and their community partners should work together to:

- Create more public spaces that use “universal design.” Universal design means creating spaces that as many people as possible can use, no matter their ability level.
- Educate people about the needs of people with I/DD. For example, give information about people with I/DD to local government officials and local businesses to make sure they understand how to support people with I/DD.
- Provide accommodations so that people with I/DD can participate in activities in their communities.

**“Sometimes it feels like you have to fight for the things you need and want. Instead of just having the space made for us to be asked what we want.”**

Tracey

2. **Flexible Ways to Pay for Inclusive Community Services.** DDS and regional centers should make sure there are flexible ways to pay for inclusive community services for people with I/DD and their families. DDS and regional centers should:
  - Provide people with I/DD and their families with information about how regional centers can help pay for inclusive community services. This also includes tools to make payment easy.
  - Make sure people served can be reimbursed to pay for community services. Reimbursed means that a person with I/DD or their family can get paid back for community services they spent their money on.
  - Make sure people served can use Participant Directed Services to access community services. Participant directed services give people served the option to choose how they receive certain services, and who provides those services.

DDS also should provide guidance that says:

- Regional center policies should not limit the number of community services a person can use
- SDP participants can be reimbursed for community services through their FMS

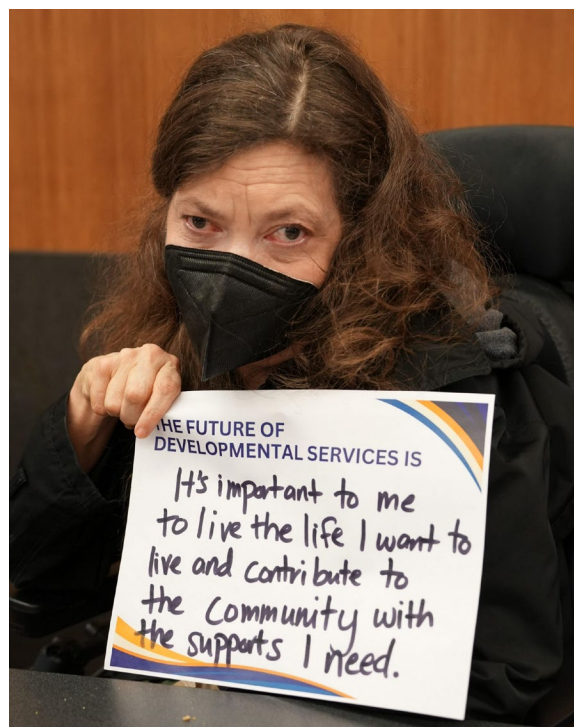
3. **Make Sure People With I/DD Have Support to Participate.** Regional centers should help identify and provide needed supports so that people with I/DD can fully participate in community programs. Regional centers should:

- Help people identify natural supports. For example, a natural support might be a friend who could help a person with I/DD to access or participate in a community activity that they are interested in.
- Work with local government and businesses to provide supports.
- Pay for supports if other options are not available.

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

People with I/DD have opinions about issues in their communities, just like anybody else. Being a part of decision making in communities is called “civic participation.” Civic participation can include things like:

- Voting in elections
- Volunteering to give back to the community
- Serving as a member of a board or commission to give back to the community



Sometimes when people with I/DD try to participate in conversations about their communities, they are left out or not listened to. Sometimes people with I/DD are even told that they should not vote. Sometimes when people with I/DD try to participate in their communities by volunteering, they are not included. 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.

**“I think that it would be great if people with I/DD could run for elected leadership positions within local, county wide, State of California, and federal government positions.”**

Kecia

1. **Learn How to Support Civic Participation for People With I/DD.** Regional centers should put together a diverse stakeholder group which includes people with I/DD. This group should work together to:
  - Define civic participation for people with I/DD
  - Identify opportunities for civic participation for people with I/DD
  - Identify training and support that people with I/DD might need for civic participation
2. **Make Sure People With I/DD Know About Civic Participation.** Regional centers should make sure that civic participation is a topic in all planning meetings. This will make sure that people served get information about civic participation and have opportunities to ask for support with civic participation. This should include meetings about the development of person-centered plans (PCPs), like IPP meetings.
3. **Make Sure People With I/DD Have Opportunities for Civic Participation.** Regional Centers should work with community partners to make sure people with I/DD have opportunities for civic participation. Regional centers should:
  - Develop ways to support the civic participation of people with I/DD, through natural supports or paid supports.

- Make sure there are local volunteer opportunities for people with I/DD.
- Make sure there are opportunities for people with I/DD to participate on local boards and commissions.
- Make sure there are resources available to support people with I/DD who want to take these civic participation opportunities. For example, training and mentoring resources.
  - One example of a training program would be Partners in Policy Making. This program is designed to support people with I/DD in civic participation.<sup>10</sup>
  - Regional centers could also create mentoring programs led by self-advocates with experience in civic participation.
- Educate local policy makers about how people with I/DD can contribute to civic participation.

4. **Make Sure People With I/DD Have the Supports They Need to Vote.** DDS and regional centers should provide support and education about voting rights for people with I/DD. This would increase the number of voters with I/DD.

- DDS should work with diverse self-advocates to review and update plain language about voting rights. This should also include information about when a conserved individual can vote and about voting accommodations. DDS should make sure this updated information is available on all regional center websites.
- Regional centers and community-based organizations should provide families and other caregivers with information about voting rights for people with I/DD.
- Regional centers should work with community-based organizations that have expertise in voting access to provide information on voting to people with I/DD. This should include information about:

---

<sup>10</sup> [For more information about Partners in Policy Making \(https://mn.gov/mnddc/pipm/\)](https://mn.gov/mnddc/pipm/)

- What voting means
- How to vote
- How to understand the issues that are voted on, to be an informed voter
- Regional centers should make sure that voting is a topic at all IPP meetings.
  - It is especially important that these discussions begin at the meeting which occurs closest to the person's 18<sup>th</sup> birthday. This will make sure that people with I/DD have the supports they need when they turn age 18 and are able to vote.

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

All children and young people with I/DD should get a receive a “free, appropriate public education” (FAPE). They should also receive their education in inclusive classrooms with their peers without disabilities. This is the law. But people with I/DD continue to face many barriers in their education.

Education for children and young people with I/DD should:

- Be inclusive
- Be equitable
- Provide individualized supports and services

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

1. **Inclusive and Flexible Education.** The CDE in partnership with Local Education Agencies (LEAs) should make sure that all children and young people with I/DD receive FAPE.

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 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.

More details about this recommendation can be found in the Recommendation Background and Technical Information Addendum on the CalHHS MPDS website.

## **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. There should be many options for transportation. Options are important in rural areas where public transportation is limited. They are also important for people who use mobility devices. These recommendations focus on making sure that people with I/DD are able to access high-quality transportation options.

**“If we need to go to jobs or to other places, we need to know that we are safe in the community out there with transportation services.”**

Sara

1. **Make More Transportation Options Available.** DDS and regional centers should make more transportation options for people with I/DD. This includes identifying efficient ways to pay for these services. To make more transportation options available, DDS and regional centers should:
  - Make sure there are enough transportation options to support independent travel. This would make sure that more people with I/DD can access community services when and where they want. Transportation options to support independent travel should include:

- Ride-share services, like Lyft and Uber
  - Autonomous vehicles, like Waymo
  - Carpools
  - Transportation stipends
- Make sure there are opportunities for people with I/DD to get driver's training that meets their disability-related needs.
  - Provide reimbursement to people with I/DD or their family for vehicle modifications that are needed to provide transportation for people who use mobility devices such as wheelchairs.
  - Support regional center vendors to provide "on-demand" rides by removing barriers like insurance restrictions and liability issues.
  - Encourage transportation vendors to expand service options during evenings and on weekends.
  - Expand transportation reimbursements to increase equitable service access. This includes accounting for long distances in rural community to access services, paying for staff time and mileage then a staff member helps a person access their community, including grocery shopping, picking up prescriptions, or doing errands. Eliminate reductions in the length of services a person receives due to long transportation time.
  - Make sure high-quality mobility training is available to all people with I/DD. There should not be discrimination based on the type of disability. Public transportation mobility training should start while the individual is in school as it increases independence and can change a person's life view. Peer-to-peer mobility training should be among the mobility training options.
2. **Improve Public Transportation Systems.** DDS and Regional Centers should work with partners to develop plans to improve public transit. Partners should include state government, local government, and transit agencies. To

improve public transportation systems, DDS, regional centers, and partners should work together to:

- Identify transportation gaps and solutions.
- Educate transit officials about the transportation needs of people with I/DD.
- Prioritize system improvements for people who experience the most barriers to using public transportation. This includes individuals who use mobility devices and people living in rural areas.

## **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. Some people with I/DD get money every month from the federal government. This is called the Supplemental Security Income (SSI) benefit. California gives people who get SSI additional money. This is called the State Supplemental Payment (SSP). The amount of money that a person gets every month from SSI and SSP is still below the federal poverty level (FPL). This means that even when people get money every month from SSI and SSP, they still do not have enough money to pay for the basic things that they need.

Another problem is that people with I/DD who get married may receive less SSI benefits. Other people with I/DD may lose benefits, like Social Security Disabled Adult Benefits if they get married. This is called “the marriage penalty.”

The federal government increases the amount of money that people get from SSI each year. This is called an annual Cost of Living Adjustment (COLA). A COLA is meant to equal the increased costs of purchasing food or paying for rent. California law does not require the State to provide an annual COLA. This means that the amount of money people get from the SSI benefit may increase every year, but the amount of money people get from the SSP benefit may not increase each year.

These recommendations focus on making sure that people with I/DD have enough money to pay for their basic needs.

1. **Increase the SSP.** The State should increase the amount of money that people get every month from SSP. The increase should be enough to make sure that people who get individual SSI benefits are above the FPL. The State should also increase SSP benefits for all SSI recipients every year to keep up with annual COLA.
2. **Protect Benefits When People With I/DD Get Married.** The State should support changes to federal laws to protect SSI and other social security benefits when people with I/DD want to get married. This includes changing laws to:
  - Make sure that people with I/DD do not receive less money in SSI benefits when they get married.
  - Allow people with I/DD to keep their Disabled Adult Child Social Security benefits when they get married.
  - Increase the limit on the amount of money that people with I/DD who are married can have in their bank account, from \$3,000 to \$4000.
3. **Reduce or End the Marriage Penalty.** California has already taken some steps to reduce the marriage penalty. The CalHHS, working with DDS and the Department of Finance, should analyze the cost and benefits of further reducing the SSI “marriage penalty” or eliminating the SSI marriage penalty. The “marriage penalty could be reduced or ended by further increasing the amount of the SSP. Once the analysis is complete, CalHHS should get input from diverse stakeholders, including self-advocates, about what to do next.
4. **Provide Housing Assistance through the SSP.** The State should give more money through SSP for people with I/DD, including those who live with family members, who pay more than 40% of their income toward housing costs. This would provide assistance to pay for their housing. This would help make sure that people do not become homeless. It would also help to give people a choice on where they want to live.

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

It can be very hard for people with I/DD to find housing in California. This is because:

- Housing costs are very high in California.
- There are not enough apartments and houses for everyone who lives in California.
- Even though there are housing subsidy programs, which are available for people with I/DD, not everyone who needs support can get it. This is because there are limited opportunities to apply for these programs, and the waiting lists can be years long.

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.

1. **Build More Housing.** The State and DDS should create more affordable and accessible housing for people with I/DD across California. To do this, DDS should use existing and new resources and programs. 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.
- Give cities and counties money for making affordable housing available for people with I/DD.

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.
- Set up a low-interest loan program and downpayment 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

More details about this recommendation can be found in the Recommendation Background and Technical Information Addendum on the CalHHS MPDS website.

2. **Provide Clear Housing Information.** DDS should develop plain language, accessible information about how to help people with I/DD get stable housing. DDS should make sure that this information is available to people with I/DD and their families. The information should be made available in different ways so that it is easy to understand for everyone. For example, in writing and in videos. This information should be about:
  - Housing supports that are available
  - The rights that people have when they rent their home
  - Other housing issues
3. **Help People With I/DD Find Affordable Housing.** DDS should make sure people with I/DD and their families can get quick local help to find housing no matter where they live, or which regional center serves them. These services are called Housing Access Services. DDS should:
  - Make sure that regional centers make Housing Access Services available to people with I/DD their families. Especially families that have children and youth with I/DD.

- Update payment rates to Housing Access Service providers so they can afford to serve everyone and provide high-quality support.

4. **Make Sure People With I/DD Can Access Support for Life Changes and Moves.** DDS should develop a statewide plan to help people transition to new housing or services. The plan should include how people with I/DD will get help with:

- Rent
- Deposits
- Utilities
- Furniture for whatever stage of life they are in
- Supports for smooth transitions to more independent living from different living situations, like:
  - Family homes
  - Group homes
  - Foster care
  - Shelters
  - Being unhoused

5. **Make Sure People With I/DD Can Access Affordable Housing and Rent Help.**

The State and DDS should help people with I/DD and their families to easily use existing affordable and accessible housing resources. For example, housing programs, rent subsidies, and other community resources.

DDS should:

- Set up and fund a Rent Subsidy program that provides funding to close the gap that currently exists with other rent subsidy programs.
  - This can include providing rent subsidies while people wait for HUD vouchers.

- DDS and Regional Centers should partner with local housing authorities and managed care organizations to design one seamless process for people to get rent subsidies.
- Make sure people can get a Housing Needs Assessment and Housing Access Services when they have a crisis, are found to be at-risk, or any time they have a need.
- Work with housing authorities and other development agencies to create special rent programs, reserved housing units, or rent help for people with I/DD.

The State should stop unfair housing practices like:

- Rejecting renters based on where their money comes from
- Rejecting renters based on their lack of credit history

6. **Make Sure People With I/DD can Access Legal Help for Housing Issues.** The State should make sure people with I/DD can get quick, local, legal help if they need it. 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.

More details about this recommendation can be found in the Recommendation Background and Technical Information Addendum on the CalHHS MPDS website.

7. **Make Homes Accessible for People With I/DD.** DDS should work with regional centers to create a clear and easy process for people with I/DD to request home modifications related to their disability. People with I/DD should be able to request home modifications no matter what kind of services they receive. DDS should also:

- Make sure people with I/DD can get accessibility updates in their homes whether they rent or own their home.
- Provide funds to remove modifications if a landlord requires it when a person with I/DD moves out of a rental home.
- Collect and use data. This will make sure that DDS can:
  - Understand people's needs
  - Improve the process of requesting home modifications
  - Make sure funding and access for home modifications is fair

8. **Use Incentives to Encourage Renting to People With I/DD.** The State should explore different ways to incentivize companies, people, and organizations to rent housing units to people with I/DD. To “incentivize” means to encourage someone to do something by giving them money when they do it. This could include creating ways for people who rent housing units to people with I/DD to get money, like giving them:

- State tax deductions

- Property tax incentives

The State should also explore ways to provide affordable property insurance to providers who serve and provide housing to individuals with I/DD in residential settings they own or lease. This will help make more housing available to serve people who have high needs.

**9. Make a Plan to Move People With I/DD From Institutions Into the Community.**

DDS should make a plan to support people with I/DD to move from institutional settings into community settings. California has closed large state operated institutions for people with I/DD and supported many individuals to move into the community. Many people still live in private institutional settings like:

- Intermediate Care Facilities
- Nursing homes
- Institutions for Mental Disease (IMDs). An IMD is a setting which is sometimes used for people with significant behavioral health needs.

This plan would help people in institutional settings to move into the community. The plan should:

- Make sure people with I/DD moving into the community get appropriate supports to live self-determined lives
- Use the experience and lessons learned from closing state operated institutions

**10. Make Sure There is Enough Specialized Housing for People With I/DD.** 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 the Home and Community-Based Services (HCBS) final rule
  - More details monitoring and oversight of residential settings to support this recommendation can be found in the Recommendation Background and Technical Information Addendum on the CalHHS MPDS website

**11. Stronger Government and Partner Agency Collaboration on Housing.** The State and DDS should improve how state, federal government, and local agencies work together on housing. This includes how they work together to make sure people with I/DD can access housing and homelessness prevention services.

The State should:

- Establish cross-sector partnerships by requiring formal agreements between DDS, regional centers, and California housing agencies. These partnerships would make sure that there is equitable access to affordable, accessible, and supportive housing resources.

DDS should:

- Create a special housing division to focus on community-based, affordable, and accessible housing issues for people with I/DD. The division should also focus on community involvement of people with I/DD.
- Form a Housing Advisory committee to advise DDS and its partner agencies. This committee should include experts and people with lived experience.

**12. Align With California's Housing First Laws.** The State should align housing programs and services for people with I/DD with California's "Housing First" laws. The State should make sure the principals of Housing First are used as system-wide values. "Housing First" means that everyone is ready for housing, no matter how complicated their needs are. The Housing First principals should replace any "housing readiness" model language that requires a person to meet some standard before being allowed to obtain housing of their choice. The State should make sure that all investments and efforts to develop affordable and accessible housing options for individuals with I/DD fully align with HCBS core principles and requirements.

**13. Make Sure Housing Laws and Technology Are Fair.** The State should make sure that housing laws and housing programs are fair for people with I/DD. To do this, the State should:

- Support laws that:
  - Protect fair housing rights for people with I/DD
  - Remove barriers to housing for people with I/DD
  - Prevent discrimination against people with I/DD
  - Protect people with I/DD
- Fix laws that need to be updated or changed to better protect people with I/DD
- Make sure that any new technology used for housing programs does not accidentally:
  - Discriminate against people with I/DD
  - Leave out people with I/DD
  - Create unfair outcomes for people with I/DD trying to live in their community and access housing
- Make sure that people with I/DD who are trying to access housing programs, services, or resources can:

- Get help
- Report problems
- Overcome barriers

## **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. This can be because justice system services are not designed to accommodate the needs of people with I/DD. These recommendations focus on making sure that the justice system works for people with I/DD.

1. **Provide Diversion Services Consistently.** DDS and regional centers should work together to develop guidance on how people with I/DD get diversion services. Diversion services are an alternative for people who would otherwise be incarcerated for committing a non-violent crime. Being “incarcerated” means going to jail or to prison.

All people with I/DD who meet the legal criteria for diversion services should have that option available to them. Diversion services, like all Lanterman Act services, are based on a person's individualized support needs. They are also based on a judge saying that the diversion plan will not pose an unreasonable risk to public safety.

The guidance that DDS and regional centers develop should talk about:

- Parts of the diversion process
- How to make sure that diversion is available to all eligible people with I/DD
- The regional center's role
  - The regional center's role should not be:
    - To give an opinion about whether diversion is appropriate

- To make recommendations for or against diversion

DDS could also help strengthen diversion programs by streamlining rate increase requests when needed for a person's diversion plan, such as for emergency housing or crisis intervention services.

2. **Transition Planning for Individuals Committed to Porterville Developmental Center (PDC).** DDS and the Regional Centers should work together to develop guidance about comprehensive transition plans for people at PDC. Sometimes people with I/DD do not get diversion services and need to go to trial. If the person does not understand why they are being charged or how to assist in their defense, they can be found "incompetent to stand trial." When this happens, they do not go to jail and are not found guilty. Instead, they may be ordered by a court to go to PDC, a large institution run by DDS. At PDC they are supposed to receive treatment that will help them understand why they were charged with a crime and how trials work. But there are some people that will never be able to understand why they were charged with a crime. Some people in this situation are locked up at PDC for many years, sometimes for longer than the time they would have served in jail if they went to trial and were found guilty. But not everyone at PDC needs to be there.

Transition plans for people at PDC should:

- Identify what kind of services the person needs to live in their community again
  - Identify best practices for supporting people while they are at PDC and after their release
  - Include a description of the issues or barriers preventing community placement for the person
  - Include what actions are being taken to resolve the barriers to placement
3. **Make Sure Regional Center Services Are Provided Even if a Person Is Incarcerated.** DDS and regional centers should make sure that all

incarcerated people who are eligible for regional center services continue to get necessary support while they are incarcerated.

- The person should get supports from the regional centers to prepare them for release.
- The person should get support from the regional center as they come back into the community after release.
- Regional centers should not be allowed to “deactivate” a person's case solely for being incarcerated. Deactivate means to close a person's case and stop supporting them.
- Regional centers should continue to serve and monitor individuals who are incarcerated to prevent bad outcomes, like the person getting sent back to jail.
- DDS and regional centers should work together on how to identify and serve incarcerated people who are eligible for regional center services.
- DDS, regional centers, jails, youth corrections and state prisons should work together to develop a plan to support people with I/DD who are incarcerated. The plan should include requirements and best practices for supporting people during incarceration and after their release.
- DDS should provide guidance clarifying the roles and responsibilities of the regional centers in serving individuals who are incarcerated. This guidance should talk about how to partner with other systems, such as DHCS, to make sure people exiting incarceration have other important services, like health care.

## **Emergency Preparedness**

People with I/DD should have plans and supports to stay safe during emergencies, just like other people in their communities. Emergencies can include:

- An emergency a member of their household might experience. For example, a sudden health problem or a power outage in their home.
- A larger-scale emergency such as a natural disaster. Large-scale emergencies can impact entire communities. An example of this type of emergency would be the wildfires that recently occurred in Southern California.

1. **Make Sure People With I/DD Are Safe During Emergencies.** Regional centers should help people have a plan for what to do during an individual family emergency, as well as a disaster that is impacting entire communities. This emergency plan should be discussed and updated at each individual's IPP meetings. The emergency plan should include information and options on who to call for help and how to evacuate from a dangerous situation. DDS and many regional centers also have dedicated staff who are responsible for emergency preparedness and response. Families and individuals should know who these staff are and how to reach them in an emergency.

Regional centers should also have a plan for how they will respond to a large disaster that impacts:

- Their staff
- Their ability to provide services
- Their ability to keep their offices open

This plan should include:

- Agreements with neighboring regional centers, so they can help impacted individuals, regardless of the service area they live in.
  - This should include neighboring regional centers providing a place that people can call, text, or email to get information and help.
  - This is especially important if the local regional center is impacted by the disaster and cannot provide the help directly.

- A coordination plan with state entities like DDS, the California Office of Emergency Services, and the State Functional Assessment Service Teams.
- A plan for coordinating with first responders, like firefighters and paramedics, so they know where people with I/DD are and what they need.

## **People With I/DD Getting Services They Need and Choose**

It can be hard for many people with I/DD to get the services and supports they need. Services can be harder to get for people in some groups than others.

- People who live in rural areas are often far away from places that provide services. It can be hard for them to travel to get services. It can also be hard for service providers to travel to their homes to provide services.
- It can also be harder for people with different ability levels to get services. People with I/DD who have specific needs, like being blind or using AAC, can have a harder time finding service providers who can meet their needs.
- People with I/DD who do not speak English may have a harder time getting services. Sometimes information about services is not available in different languages the way that it should be. Sometimes it can be hard to find service providers that speak different languages.

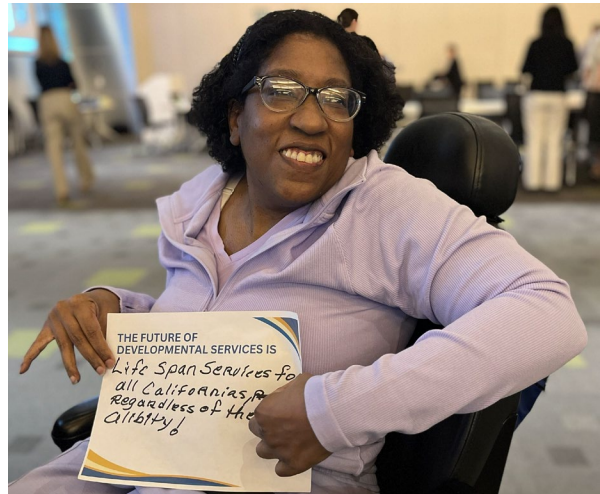
Some people with I/DD who are eligible do not get any services at all. Challenges with accessing services can be difficult because of barriers in the system. Barriers in the system happen when:

- Information about services and supports is not accessible to people with I/DD
- People with I/DD live far away from the places where services and supports are available

- There are not enough providers for everyone to receive a service that they choose
- There is not enough money to pay for everyone to receive a service that they choose

These barriers may be caused by unfair rules, discrimination, or unfair treatment. There can also be barriers because there are not enough resources for everyone to get what they need.

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**

The DDS's regional center system provides important services and supports to people with I/DD and their families. There are 21 regional centers in California, and they do not all do things in the same way. People I/DD who receive regional center services can have very different experiences with the system. Sometimes people with I/DD and their families have a hard time getting the information that they need from regional centers. Sometimes people with I/DD and their families cannot get services that they need and choose, even if they are eligible. People with I/DD and families from different groups can have an especially hard time getting what they need from regional centers.

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.

1. **Make Communication Better.** DDS and regional centers should work to improve the way regional centers and providers communicate with individuals and families. To do this:

- DDS should establish customer service standards that guide Regional Centers and providers in how to better support individuals and families. These standards should include:

**“Most of the information relating to the regional center, I had to find out on my own, and Mom was there to help me out...don’t leave the consumer to figure things out on their own if the coordinators are there to help with the services they provide... I keep learning things I could have gotten.”**

Eric

- Requirements that communication should be in plain language and in the language preferred by the person served and their family.
- Requirements to return phone calls or emails in a timely manner.
- Requirements not to use complex “phone trees.” A “phone tree” is an automated telephone system that directs callers according to options selected in response to recorded questions. Phone trees can be confusing and frustrating. People served should be able to get a live person when they call. This person should help them get to the right place to have their questions answered.
- Requirements to have options for people with I/DD and their families to communicate without technology, if that is their preference. Regional Centers and providers should only use technology to communicate when it is helpful.

2. **Conduct Focused Outreach to Under-Represented Communities.** DDS and regional centers should develop outreach plans to under-represented communities. Many people with I/DD and their families live far from a regional center. They would benefit from focused outreach from regional centers. DDS should:

- Require regional centers to develop and implement outreach plans. Outreach plans should focus on geographic areas that are far from regional center offices.
- Require regional centers to send staff to communities where it is more challenging to access and maintain services. For example:
  - Rural communities
  - Tribal communities
  - Communities of migrant workers
  - Communities that do not speak English
- Outreach should include information about Medi-Cal and other available services. This can help make sure that all eligible individuals are aware of and can access the services they need.
- Require regional centers to measure outreach efforts and outcomes.
- Include outreach expectations and accountability in regional center contracts.

3. **Make Sure People With I/DD Can Access Services and Supports.** DDS and regional centers should make sure that every person served has access to any service and support they are eligible for. This should be true no matter where a person with I/DD or their family live. Every regional center should:

- Offer the same core set of services.
- Make sure those services are available in all areas, including those with fewer resources.
- Work with people served to find acceptable solutions in cases where a service is approved but there are no available vendors. The responsibility and lack of services should not be the burden of the individual served.
- Expand the use of high-quality online services for eligible participants statewide.

- Make sure people with I/DD and families can access services within a reasonable driving distance and have reliable and timely transportation options to access those services.
- Create ways for vendors to pay enough to make sure that they are able to send clinicians and other providers to serve people with I/DD who live in remote areas.

4. **Make Sure Definitions of Services Are Clear and Consistent.** 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 the 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.

5. **Give People With I/DD More Flexibility in Services and Providers.** DDS should modernize the developmental services system to make sure people with I/DD have more flexibility in how they receive services.

6. **Make Sure Day Programs Are Person-Centered.** 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.
7. **Improve Support Services That People With I/DD Receive at Home.** 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.

More detail to support this recommendation is available in the Recommendation Background and Technical Information document on the CalHHS MPDS website.

**8. Seamless Services Between Child Welfare, Probation, and Regional Centers.**

DDS and regional centers should continue their work with counties to establish statewide best practices for serving children with I/DD in the child welfare or probation systems, including youth served in both systems. The best practices should include:

- Providing child welfare and probation systems with tools to screen for developmental disabilities in children who are not yet being served by regional centers
- Expediting referrals for regional center assessments

Case management systems should include data on disability related needs of the children they serve that can also be shared with regional centers. They should also include a process for seamless transfer of cases between regional centers when a child in the child welfare and probation systems moves to a different regional center catchment area. Regional centers and the child welfare system should collaborate to create a transition plan with families and youth when they transition out of the child welfare or juvenile legal systems. This is particularly important for young adults with I/DD who are going to age out of these systems. The plan should include describing the services that will be needed, and which organization will provide the services, like:

- Housing
- Health care and behavioral health
- Employment services

## **Health Care and Wellness**

Health care and wellness services can include many different types of services. For example:

- Medical services

- Behavioral health services. These are services to support people who have mental health or substance use needs.
- Dental services

Many people with I/DD have complicated health needs. This can mean that they need to get health care services from different systems. People with I/DD should get the health care services that they need to be as healthy as possible, just like anybody else. But people with I/DD sometimes have a hard time getting the health care services that they need. There are many reasons for this barrier.

- In some places, there are not enough health care providers. This can mean that people have to wait a long time to get the services they need.
- Sometimes health care providers, like doctors, do not fully understand that people with I/DD can have health problems that do not have anything to do with their disability. They might believe that people with I/DD should only get disability-specific health care services. For example:
  - If a person with I/DD also has a mental health condition, like depression, their doctor might think that the person with I/DD does not need behavioral health services like counseling. The doctor might think that the person with I/DD only really needs disability services.
- Sometimes health care providers do not have the training to appropriately serve people with I/DD.
- Some providers may not have resources they need to provide disability related accommodations to be able to serve people who need accommodations or additional supports.
- Sometimes the systems that provide health care services to people with I/DD do not work together to coordinate services in the way that they should.

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.

1. **Address All Parts of Health for People With I/DD.** The State should develop equitable medical and behavioral health care where all parts of an individual's health are addressed. This means that their health needs should not be overlooked because they have a disability. This will lead to healthier individuals with disabilities living a better quality of life.
2. **Recognize That People With I/DD Have Health Needs That Are Not Related to Their Disability.** The State should make sure that health care and behavioral health systems recognize that individuals with I/DD can have a full range of human experiences. This means that they can have physical health, mental health and substance use conditions, in addition to their disability. People with I/DD who have health conditions are entitled to receive necessary services and supports to meet all their needs.
3. **Make Sure People With I/DD Do Not Face Discrimination From Health Care and Behavioral Health Systems.** The State and DHCS should make sure that health care systems do not discriminate against people with I/DD. This includes health care and behavioral health services that DHCS funds and oversees. People 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 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.
  - The State should create a responsible organization where people can report when they experience discrimination and barriers to health care services.
    - 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.

Background and more details about this recommendation can be found at the CalHHS MPDS website in the “Recommendation Background and Technical Information Addendum.”

4. **Make Sure Health Care Providers Understand How to Support People With I/DD.** CalHHS should work with the University of California and State University Systems to make sure that health care providers learn about disability and about serving people with I/DD. This would give health care providers the knowledge and skills they need to meet the needs of people with I/DD. This would mean providing information to health care professionals. This information should be included in requirements for training programs, like medical school. This information should also be included in continuing education requirements. The State should:
- Incorporate requirements for training on person-centered principles and practices into health care workforce development.
  - Make sure systems and professionals are aware of their legal obligation to serve all individuals regardless of disability status. They should provide necessary accommodations to ensure equitable services for individuals with I/DD.

- Establish awareness building and education efforts about disability for the general community.
- Include self-advocates and family members in development and delivery of trainings.
- Provide financial incentives to providers to complete disability and I/DD specific trainings.
- Collect data on current education/training of physicians, therapists, psychiatrists and other health care and behavioral health professionals on topics related to I/DD populations and needs. Use the data to promote and improve training.
- Training should reflect demographic, cultural, geographic, and other diverse characteristics of California's population.
- Training and awareness building efforts should also cover a variety of other areas that serve or impact people with I/DD including, but not limited to:
  - Law enforcement and correctional systems
  - Child welfare systems
  - Dentists

5. **Make Sure There Are Enough Health Care Providers to Support People With I/DD.** DHCS and DDS should provide resources and funding to make sure there are enough providers for people to choose from across the State. This includes providers in 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.

6. **Make Sure Health Care Service Systems Coordinate to Support People With I/DD.** 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 ECM and Community Supports services from DHCS.<sup>11</sup>

More details about this recommendation can be found in the Recommendation Background and Technical Information Addendum on the CalHHS MPDS website.

---

<sup>11</sup> [For more information about ECM and Community Supports \(https://www.dhcs.ca.gov/CalAIM/ECM/Pages/Home.aspx\)](https://www.dhcs.ca.gov/CalAIM/ECM/Pages/Home.aspx)

7. **Make Sure People With I/DD Can Get Telehealth Services.** DDS and DHCS should partner with health care providers to continue to expand telehealth options, to make sure that people with I/DD can access specialized telehealth services. “Telehealth services” mean health care services that a person can receive remotely or virtually, instead of going into a health care office. Health care providers should include managed care organizations and community-based organizations. This will help people with I/DD to get remote and virtual supports from doctors and other professionals that are specialized in supporting people with I/DD. This could allow individuals to connect quickly with a doctor at any hour of the day, 365 days a year, for any medical concern or for disability-specific advice. This also helps people with I/DD and families who live in rural areas. They might not be able to access the same health care resources as people who live in more urban areas. With telehealth, they can access services from experts without having to leave their own homes and communities.

## **Health Care and Wellness: Behavioral Health Services**

Many people with I/DD cannot get the behavioral health care services they need and choose. There are many causes for this. For example:

- There are not enough behavioral health care providers with the skills and knowledge to serve individuals with I/DD. It is also difficult to find providers who speak languages other than English and who can support people in a culturally responsive way.
- There is a lack of coordination between many regional centers, county behavioral health agencies, and managed care plans.
- There are fewer resources in rural areas. In many areas throughout the State, there are long waiting lists to receive behavioral health services.
- People with I/DD and co-occurring significant behavioral health disabilities may be placed in restrictive settings such as Institutions for Mental Disease (IMDs).
  - IMDs are locked residential treatment facilities with at least 16 residents. These placements may be used because there are not

enough supports for people to live in their own home or family home, or enough smaller facilities that meet their needs.

- Sometimes, regional center staff may not be aware of less-restrictive service options for people with significant co-occurring behavioral health disabilities.

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.

**1. Develop a System of Care for People With I/DD and Behavioral Health Needs.**

As a part of the larger work to coordinate care between health care systems, DHCS should develop a System of Care plan for providing services to people with I/DD. A “System of Care” means that different service systems work together to provide all of the different services that a group of people need. The plan for people with I/DD should be based on the principles of trauma informed care and the fact that individuals with I/DD can also have mental health conditions. The plan must include:

- Memorandums of understanding (MOU) in all 58 counties. An MOU is an agreement in writing. The MOU agreement should include different organizations that provide behavioral health services to people with I/DD, including:
  - Regional centers
  - County behavioral health departments
  - Managed health care plans
  - County offices of education
- The MOU work should be led by a team of leaders from the different organizations.
- The MOU should include information about:

- Processes for screening, assessment, and entry to behavioral health services
- Processes for universal service planning
- Processes for aligning and coordination of services
- Processes for information and data sharing
- Processes for financial management and cost sharing
- Processes for resolving disagreements between organizations

**2. Make Sure There Are Enough Behavioral Health Providers for People**

**With I/DD.** CalHHS and its departments, including DHCS, should build on the workforce efforts undertaken by California's Department of Health Care Access and Information (HCAI). For example, DHCS and HCAI should:

- Expand HCAI's Health Care Work Force Pilot Projects and Workforce Initiatives to include efforts to increase the number of professionals with training to serve individuals with I/DD and co-occurring behavioral health needs
- Build on current workforce initiatives to allow staff with an Associate of Arts (AA), Bachelor of Arts (BA), or Bachelor of Science (BS) degree and unlicensed staff with a master's degree to deliver, with appropriate supervision, "manualized," structured, evidence-based services
- Expand the availability of HCAI internships at regional centers, University Centers for Excellence in I/DD and other programs serving individuals with I/DD and behavioral health needs
  - A focus of these internships could be in rural communities and other underserved communities
- Expand the pre-service training and in-service continuing education for behavioral health providers to include knowledge and skills to meet the needs of individuals with I/DD

- Work with community colleges, state colleges and universities to develop career pathways for individuals to serve individuals with I/DD and behavioral health needs
  - Consider loan repayment, scholarships, or student loan grants

3. **Change Behavioral Health Billing Practices.** DHCS should change billing practices and rules to allow new behavioral health service delivery models to be billed across all funding sources. This will make sure that behavioral health services can be paid for and will be provided.

For example, allow billing for:

- Services provided by providers who would not usually be allowed to provide services, as long as they have appropriate supervision
  - For example, staff who have an associate's degree, a bachelor's degree, or a master's degree, but who do not have a license
- Group therapy services
- Behavioral health intervention services provided on the same day as a health care visit at Federally Qualified Health Centers
  - Current rules do not allow providers to get paid for some services if they are provided on the same day as other services
- Behavioral health services which are provided based on the symptoms a person is experiencing, even if they do not have a mental health diagnosis
- Behavioral health services which are provided to parents or other primary caregivers of people with I/DD
  - For example, allowing the mental health provided who is treating a child with I/DD who has behavioral health needs to also provide and bill for services provided to a primary caregiver parent who is experiencing anxiety or depression related to the child's care. This would allow a similar approach to treating both the newborn and

a mother who experiences post-partum depression by the child's health care provider.

4. **Make Sure People With I/DD and Behavioral Health Needs Get Enhanced Care Management (ECM) and Enhanced Service Coordination.** 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 IMDs as a criterion for complex needs and lower caseload ratios.
5. **Expand Services for People With I/DD With Complicated Needs.** DDS and DHCS should work together to make sure there are enough services for people with I/DD who have complex needs. For example, people who have I/DD and high behavioral health needs. To make this happen, DHCS and DDS should explore different models for providing care to people with I/DD with complex needs. These models should include:
  - Supports models in crisis homes. This includes models that provide therapeutic, trauma informed care models for people with I/DD who have substance use issues.

- Trauma-informed care is an approach to providing services which recognizes that people experience trauma, and that trauma impacts their lives and experiences.
  - Models that are different from traditional Applied Behavioral Analysis (ABA).
    - ABA is a service that works to understand a person with I/DD's behavior and help them to change their behavior. ABA does not work for everyone, and some people with I/DD require different approaches.
  - Crisis management techniques rooted in the belief that the use of physical restraints is unnecessary and unproductive. For example, Ukeru.<sup>12</sup>
  - Individualized residential homes for youth.
  - Long-term wraparound services for families and single child residential homes.
    - These are services that provide high-need children and families with many different services and supports to meet their needs, over a long period of time.
  - Short term single person residential homes for people with I/DD with supports to transitions back to family home or community living.
  - Homes for people with I/DD and Alzheimer's, to provide them with needed services and supports.
    - Alzheimer's disease is a common cause of dementia. Dementia causes problems with memory and thinking.
6. **Address Complex Needs for People With I/DD.** DDS and regional centers should use develop an improved approach to meet the complex needs of people with I/DD. This approach should:

---

<sup>12</sup> [For more information about Ukeru \(https://www.ukerusystems.com/\)](https://www.ukerusystems.com/)

- Use strategies and assessment tools
- Recognize the higher rates of abuse, neglect, and trauma that people with I/DD may experience
- Include training for regional center and other staff
- Guide assessments for community services
  - This will make sure that people with I/DD who have complex needs can get support in their current living arrangement
  - This will help to make sure people with I/DD and complex needs can stay living in community-based residential settings instead of more restrictive settings
    - More restrictive settings would include IMDs, Canyon Springs Community Facility, and state operated facilities

7. **Support Families and Caregivers to Support People With I/DD and Complex Needs.** DDS should clarify, and expand as needed, the kinds of training, services, and supports that are available to individuals, family members, and other care givers. Regional centers should provide training and services and support to families and caregivers of people with I/DD and complex needs. This will help families and caregivers to better support the needs of at-risk individuals with complex needs. Support should include:

- Individualized, person-centered strategies to de-escalate behavioral challenges
- Environmental modifications
- Timely access to additional supports and services

8. **Make Sure Parents and Caregivers of People With I/DD Can Get Behavioral Health Support.** DHCS, DDS, and regional centers should coordinate to make sure that parents and other family member caregivers of people with I/DD can access behavioral health services. These services should not be limited to peer support services. This will make sure that family caregivers of people

with I/DD can get the services and supports that they need to continue providing care to their loved one.

9. **Develop Person-Centered Crisis Care Plans.** DDS should identify best practice recommendations for person-centered crisis care plans. Regional centers should develop person-centered crisis care plans for people with I/DD and their families and/or caregivers. These crisis care plans should include ways to use specific crisis services which are available through regional centers and system partners during a crisis. This Crisis Care Plan should be included in the person's IPP.
10. **Expand START Teams.** DDS should continue to expand the availability of Systemic, Therapeutic, Assessment, Resources and Treatment (START) teams to all regional centers. START teams provide person-centered, trauma-informed services, and crisis support for people with I/DD over the age of six. START teams provide services 24 hours a day to people with I/DD. Expanding START services to all regional centers will make sure that prevention and early intervention services are available to all people served by regional centers in California.<sup>13</sup>

## Dental Services

People with I/DD may have significant dental needs due to their disability. They may also experience difficulty timely accessing dental care. Some regional centers have Dental Coordinators, who can help address access challenges. 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.

1. **Increasing Access to Dental Care Providers.** DDS and regional centers should identify strategies to increase access to dental coordinators. This could include regional models which coordinate services beyond specific regional center catchment areas.

DDS and other State partners should work with the dental care industry to identify and implement strategies to increase the number of dental care

---

<sup>13</sup> [For more information about START \(https://www.dds.ca.gov/services/crisis-safety-net-services/start-program/\)](https://www.dds.ca.gov/services/crisis-safety-net-services/start-program/)

providers for people with I/DD. This should include working with schools of dentistry to prepare dental students to treat people with I/DD. Dental students could also provide basic dental services to people with I/DD as part of their training.

The State should also consider higher or supplemental rates for dental care providers in rural and underserved communities. Untreated dental issues often result in more expensive treatments in the future, so offering higher rates may save the State money and increase availability of providers.

2. **Increasing Options for Dental Care Services.** DDS should work with insurers, DHCS and the Medi-Cal system, and dental care providers to increase access to the types of services that people with I/DD often need. This includes services like:
  - In-home dental care
  - Desensitization services for individuals who are easily overstimulated
  - Anesthesia for individuals with greater behavioral needs or involuntary movements

DDS should begin by providing education and awareness about why these services are medically necessary for many people with I/DD. DDS should also work with insurers and Medi-Cal to identify the barriers to accessing these services and possible solutions. For example:

- Providing exemptions or expedited approval processes to obtain services like anesthesia and in-home services for individuals with I/DD
- Providing incentives to expand providers that accept Medi-Cal Dental

## Transition Supports

These recommendations are about transition supports. These are supports and services that people with I/DD get when they are going through a big change in their life. Life transitions include:

- When a child leaves Early Start services and starts to go to school
- When a young person leaves school and starts planning what they want to do after school
- When a person becomes a parent
- When an older adult wants to make changes in their life and the services they receive



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

1. **Make Sure People With I/DD Have Transition Supports.** 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 support that they need. These transition supports should include:

- The option of a 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 community-based organizations, navigators, and service coordinators.
  - Include information about 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 long-term 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.

More details about this recommendation can be found in the Recommendation Background and Technical Information Addendum on the CalHHS MPDS website.

2. **Coordinate Supports for Transitions From Early Start.** CalHHS, DDS, regional centers, the CDE, and local school districts should work together to provide effective transition supports. This collaborative work should include:
  - Developing plain language information about the types of programs available to children. This includes the qualifications of providers. It must be translated into languages spoken by families served by the regional centers and school districts.
  - Developing common processes and planning tools for Early Start transitions. All school districts and regional centers should also be required to use these processes and tools.
  - Requiring regional centers and school districts to develop or update local MOUs about the transition process. This should include information about each agencies' responsibilities and how they will resolve any disputes.
  - Developing strategies to increase inclusive preschool and transitional kindergarten options for 3–5-year-olds served by the regional centers. This should include providing the needed supports and accommodations so children can be successfully included.
3. **Support Transitions From Early Start.** Regional centers should provide families of young children transitioning from Early Start services to school services with the transition supports they need and choose.
  - Transition supports should start at least six months before the referral to school services and continue until the child and their family receive the services they need and choose.
  - Transition supports should be provided to every Early Start family.
  - Transition supports should include:

- Information about the transition, person-centered planning, and navigation supports.
  - Navigators who have received training and are knowledgeable about:
    - The needs and strengths of young children with disabilities and their families.
    - Services available. For example, services from regional centers, school districts, other state programs (such as Medi-Cal and California Children's Services), and local resources.
  - Navigators who know how to support families, before, during, and after planning meetings. They must be able to attend planning meetings with families.
4. **Train Staff on Early Start Transitions.** DDS and regional centers should provide training and support on Early Start transitions. This will make sure that service coordinators and other navigators are knowledgeable about the needs and strengths of young children and available services. Navigators must know how to support families or caregivers before, during and after planning meetings. They must be available to attend planning meetings. DDS and regional centers should provide training and information so service coordinators are better equipped to support families in these meetings.
5. **Improve Transitions From Early Start.** DDS should support successful transitions from Early Start to school services. This includes:
- Monitoring eligibility decisions. This includes identifying and correcting disparities about who is eligible for regional center services.
  - Developing guidance about regional centers paying for services not available through schools and other departments. This guidance will be used by all regional centers.
    - This will include information about the types of services and supports young children served by regional centers can receive. This includes children who are:

- Eligible for school services
  - Ineligible for school services
  - Provisionally eligible
  - On waiting lists for school or HeadStart services
  - Developing guidance about Early Start Service Coordinators responsibilities to attend IPP meetings. This includes:
    - Monitoring and analyzing Lanterman Act and provisional eligibility decisions to determine if there are disparities in who is eligible.
    - If there are disparities, DDS will develop a plan to address the disparities.
  - Developing guidance about Early Start service coordinator's responsibility to attend school district planning meetings with families.
    - This should include the regional center's responsibility to provide training and information, so they are equipped to support families in these meetings.
  - Developing guidance to make sure that provisional eligibility decisions are completed before a child is referred for school services.
  - Analyzing data to determine if there are disparities in who is eligible under the provisional eligibility criteria.
    - This includes working with diverse stakeholders to develop strategies to address identified disparities.
6. **Support Transitions From High School.** 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.
7. **Support High School Students to Make Decisions.** DDS, the CDE, and regional centers should work together to help transition-aged students make their own

decisions. This should include staff training about how to help individuals with I/DD make decisions. They should also include developing uniform plain language information about alternatives to conservatorship. This information should be provided to staff, the people served, and their families.

8. **Improve Transitions From High School.** CalHHS, DDS, DOR, and the CDED should work together to improve planning for transitions from high school. They should develop a way for each person with I/DD who is leaving high school to develop a post-secondary pathway plan. A post-secondary pathway is the educational, training, or career path an individual chooses. The collaborative transition planning should include uniform guidance and tools to develop this plan that all departments will use. It should recognize that transition planning is an ongoing process and not a one-time event. These efforts should be coordinated with the California Master Plan for Career Education.
9. **Support Transitions From High School to Work.** DDS and regional centers should support successful post-secondary transitions by increasing ways to get work experience. This should also include planning for competitive integrated employment (CIE). This should include:
  - Piloting reduced service coordinator caseloads for transition-aged youth
  - Expanding the Coordinated Career Pathways program to help more students get CIE
  - Providing information and guidance about how regional centers can provide work experience while individuals are in high school
  - Developing guidance to eliminate waiting lists for post-secondary services
  - Increasing the number of employees with I/DD at all levels of DDS and regional center organizations
10. **Increase Opportunities After High School.** DDS, the CDE, and DOR should work together to support post-secondary transitions. This should include:
  - Removing barriers for employment services supports.

- DDS and DOR should enter into an MOU to make sure that employment services are provided and continue no matter which department the consumer initially contacted.
- DDS and DOR should increase the number of benefits counselors so that each person with I/DD can access this service.
- Working with the State and local college leadership to expand college options.
  - DDS and DOR should work with the Community College Chancellor's office, and State Universities and University of California systems and trade schools to increase the number of students with I/DD who attend college.
  - This may include expanding college options and expanding the supports available for students with I/DD at college.
- The CDE should provide guidance and resources to increase the number of students with I/DD who obtain a high school diploma. This will make sure they have access to the same career education supports as students without disabilities. For example:
  - Career exploration.
  - Volunteer opportunities.
  - Opportunities for paid and unpaid CIE.
- The CDE should provide guidance to local school districts about the rights of students with I/DD to complete needed classes for post-secondary education.
  - This should include best practices for providing accommodations and supports so students with I/DD can complete classes.

**11. Give Young Adults With I/DD the Choice to Leave School at Age 18.** The State should amend the Lanterman Act so that people with I/DD who are age 18 or older can still receive services from their regional centers, even when they choose to leave the school system without formally graduating. These

individuals should not be required to remain in public school transition programs until the age of 22 in order to receive services. Instead, they should have the option to leave the school system with access to developmental services between the ages of 18 and 22. The law used to offer this choice before State budget cuts in 2009.

While many students with I/DD may be happy to stay in their school for a transition program until age 22, this is not true for everyone. Some people find school stressful or disrespectful. Young adults with I/DD should be able to exit school at age 18 just like young adults without disabilities can. If they do, they should still be able to get the services they need from their regional center to lead the kind of life they want.

**12. Make Sure Parents With I/DD Have Supports They Need.** DDS and regional centers should make sure that people with I/DD who are parents or becoming parents get the supports they need and choose. These supports include:

- Plain language information and training available in many formats. Topics should include:
  - Pregnancy complications
  - Pre- and post-natal care
  - Well baby care
  - Developmental milestones
  - Dealing with emergencies
  - Dealing with stress
  - Discipline
  - Hygiene
- Person-centered planning
- Navigation supports

- Help interacting with courts, and the child welfare system
- Help getting housing, government benefits, and other services

**13. Expand Services for Parents With I/DD.** DDS and regional centers should support successful transitions for parents with I/DD by developing additional flexible service options. This should include:

- New kinds of flexible living arrangements such as co-housing.
- Expanding the Coordinated Family Supports (CFS) program and not capping the number of direct service hours that are available.
- Identifying more providers who can support parents with I/DD.
- Purchasing adaptive equipment needed by parents with I/DD. For example, a modified crib that can be used by a parent who uses a mobility device.

**14. Support Parents With I/DD With Information About Services and Supports.**

CalHHS and its departments, including DDS and the DSS should develop plain language information about:

- Services and supports that people with I/DD who are parents can get from different state and local agencies
- Child welfare system processes and court processes
- Domestic violence and victimization and how to get help

The information should be developed in consultation with individuals with I/DD who are parents and other stakeholders.

**15. Support Parents With I/DD to Keep Their Families Together.** CalHHS and its departments, including DDS and DSS, should develop effective best practices and models for supporting parents with I/DD. These practices and models:

- Will support the principle that many people with I/DD are able to care for their own children

- Will include strategies to reduce the removal of children from their parents' home and care

CHHS and its departments will work with regional centers and county child welfare agencies to develop agreements about how they will implement these best practices. These agreements should include:

- Identifying effective best practices and models for providing coordinated services to people with I/DD who receive services from regional centers and child welfare agencies
  - These practices and models should meet the needs of parents from diverse disability, racial and cultural backgrounds
- Requiring child welfare agencies and regional centers to develop MOUs identifying how they will implement the identified effective best practices and models to reduce the removal of children from the parental home
- Developing training modules about the needs of parents with I/DD and best practice strategies and services to meet those needs
  - The training should address the stigma and discrimination that parents with I/DD face about their ability to successfully parent a child
  - The training should address the disproportionate focus on removing the child from the parent's care
  - The training should be available for regional center staff, child welfare staff, health care professionals, and attorneys involved in the child welfare system

**16. Make Sure Older Adults Get Transition Supports.** DDS and regional centers should make sure that older adults get the transition supports they need and choose, when they need them. Regional centers should proactively provide information and discuss transition supports with people served no later than age 55. This should happen sooner if requested or when needed by the person served. For example, for individuals with Down Syndrome who are at risk of developing dementia. These supports include:

- Information
- Person-centered planning
  - This should include the individual's preferred future as an older adult and any additional support needs. It should also discuss end of life planning including health care advanced directions, powers of attorneys, wills, burial instructions. It should consider the family as a whole, additional care-giving resources and access to shared generic services.
- Navigation supports
  - All navigators must receive training and be knowledgeable about:
    - The needs and strengths of older adults
    - The needs of aging parents or caregivers that the older adult lives with
    - Services, including those available from regional centers, community based older adult services, and other state programs (such as Medi-Cal, IHSS, Aging and Disability Resource Centers, and local resources)
- Access to support groups led by peers with I/DD
- Access to support groups for aging caregivers so they can connect with their peers

**17. Improve Supports for Older Adults.** DDS and regional centers should develop new and more flexible ways to support older adults. For people with I/DD who live with an aging parent or other aging family member, the support should address the needs of the family unit. These supports should include:

- Guidance about paying for supports to attend older adult programs in their community.
- Flexible ways for older adults to get services during the day and where they live such as the ability to attend vendored programs on a part-time basis. Expand the definition of supportive living services to include

living in their family homes, so older adults can continue to live in their aging care-giver's home.

- Training on modules for direct support professionals (DPSs), service coordinators and other professionals about the needs of older adults with I/DD and their aging caregivers.
- Considering how smart home technology can be used to support people with I/DD living in their own home.
- Continue and expand the Coordinated Family Supports program to meet the needs of older adults and their aging parents. For example:
  - Expand CFS to help people who live independently who may need help coordinating their services.
  - Remove the cap on direct service hours so people living with an aging caregiver can continue to live in their family home.
- Developing new ways to help older adults maintain benefits such as IHSS, Medi-Cal and SSI when they need help managing their benefits.
- Developing new ways for SDP participants to get additional help to manage their Spending Plan and Budgets so they can stay in the SDP.

#### **18. Help Plan for the Future for People With I/DD Who Live With an Aging**

**Caregiver.** DDS and regional centers should help people with I/DD and their families plan for long-term housing and residential care needs. This 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.

More details about planning tools to support this recommendation can be found in the Recommendation Background and Technical Information Addendum on the CalHHS MPDS website.

#### **19. Improve Transitions for Older Adults.** CalHHS and its departments including DDS, and the Department of Aging should collaborate to support older adult transitions. They should:

- Develop plain language information about the types of programs available to older adults.
  - This should include services available through regional centers and local senior services community-based living options. Particularly services for individuals who may no longer be able to live with an aging parent or caregiver.
  - The information should be developed with diverse stakeholders. It should be translated into the preferred languages of persons served by regional center.
- Increase the number of Alzheimer's Disease Centers. Make sure these centers have knowledge of I/DD and adequate funding to be able to provide assessments. Identify strategies to train Alzheimer's Disease Center staff, regional center staff, and staff at the Aging and Disability Resource Centers and community service providers about the needs of people with I/DD and dementia.

20. **Make Sure End of Life Planning Is Available.** DDS and Regional centers should proactively make sure end of life planning is available for older adults and individuals with I/DD who have serious health conditions. The regional center should make sure they get the supports they need and choose at the end of their lives. This includes:

- Developing uniform plain language end of life information that regional centers proactively share with all adults.
- Developing end of life resources.
  - This should include information and forms for an Advanced Health Care Directive including identification of a substitute decision-maker who can help make decisions when the person cannot do so and Powers of Attorney.
  - It should also include estate planning information such as a simple will. This will help individuals make their own decisions about who can get their property.

- Developing flexible models for increasing the types/amount of support that people can receive.
- Developing training modules for staff and other professionals. This information should include:
  - A road map to help people with I/DD and their families or other caregivers understand the end-of-life process.
  - Information on available services and supports, including hospice, and the decisions they need to make including burial and memorial service preferences.
- Developing best practices for intensive care planning, for people with serious health conditions. Intensive care planning can include hospice and other services. Intensive care planning should involve the individual's circle of support. These best practices should be considered during the development of a PCP.
- Developing flexible models for increasing the types and amount of support that people at the end of their life can receive. This should include:
  - Additional services and supports for individuals who are hospitalized.
  - Support for interacting with health care providers and benefits programs.
  - Increasing support so individuals can continue to live in their own home at the end of their life.
  - Expansion of the CFS program to be available to individuals at the end of their life. This should include an elimination of the cap on direct services hours.

## 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.

### 1. Clarify the Definition of Generic Services.

DDS should clarify the definition of generic services. This will make sure that people with I/DD and their families understand what services are available to them. This will help them to access services and supports that they need and choose.

The definition should:

- Be easy to understand by people with I/DD and their families.
- Be used by all regional centers.
- Respect the individual's choice about how they use generic services.
- Say what a generic service is and when the service is available.
- Say what is and is not a generic service.
  - For example, cash benefits such as Social Security benefits, SSI, and Cal Fresh are not generic services.
- Say when generic services are available. This will make sure that services are provided on time.
  - Individuals must receive the service within 30 days or sooner if it is an emergency or immediate need putting the individual's health and safety at risk.



- The definition should make it clear that if a person is on a waiting list, the service is not available to them.
- Explain that generic service agencies must use their own eligibility, assessment, or planning processes when making decisions about services.
- Explain that regional centers may provide services that are different from generic services which are provided.
  - This means that IPP teams may decide that other services are still needed, in addition to generic services.
  - For example, a school IEP team may decide to provide a communication device for a person with I/DD to use at school. The regional center can then decide to provide a communication device at home to meet the person's in-home communication needs.
- Explain that the IPP should include:
  - The generic services that a person is referred to.
  - The way the regional center will support the person in accessing these services.
  - The steps the regional center will take to make sure the person gets the service they need and choose, if the generic service is not available.

2. **Make Sure Regional Centers Can Provide Generic Services That Have Waitlists.** 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.

More details about this recommendation can be found in the Recommendation Background and Technical Information Addendum on the CalHHS MPDS website.

3. **Make it Easier for People to Get Generic Services.** 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. They 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.
  - 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 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.

More details about this recommendation can be found in the Recommendation Background and Technical Information Addendum on the CalHHS MPDS website.

## **Help Getting Services**

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

1. **Strengthen Community Networks.** DDS and regional centers should work to strengthen community networks that connect people with I/DD to services. DDS should learn from a successful outreach strategy currently used by the DHCS to connect people with services.

- DHCS uses community health workers—who are also called Promotores in Latino communities—to educate and refer people to services in communities that have been historically marginalized and disconnected from the health system
- These individuals speak a variety of languages and serve diverse communities with diverse needs across the State

DDS should use this strategy to connect people with I/DD and families to regional center services. It is critical to partner with organizations who are trusted and trustworthy to connect individuals and families with needed support. This is especially true for immigrant communities who face real and perceived risks of interacting with government-related services. Trusted community organizations and individuals could include:

- Faith-based organizations, like religious leaders at churches, temples, or mosques
- Medical providers, like pediatricians
- School staff, like school administrators and teachers
- Social workers
- Staff at senior centers

When these communities understand disabilities and the services available to, they can serve as essential referral networks to connect people with I/DD to services. DDS should fund and hold regional centers accountable for outreach to trusted communities and leaders. Regional centers should:

- Educate these leaders and organizations. This education will help them to model acceptance, respect, and celebration of neurodiversity. This should include providing education about:
  - Neurodiversity
  - Ableism
  - I/DD issues and services

- Share accurate and consistent information and materials, in multiple languages, with these trusted community members and organizations about regional center services, so they can learn about and connect families and individuals with services, as early in life as possible.

2. **Make Sure Regional Centers Offer Peer Mentoring.** DDS should work with regional centers to make sure every regional center is providing effective peer mentoring opportunities. Peer mentoring is a process where two people of similar lived experiences work together to help each other. Peer mentoring offers a level of acceptance, understanding, and validation not found in many other relationships. Turning to peers for advice and support is an important way for people served by regional centers to:

- Understand the service system
- Learn to advocate for themselves
- Gain leadership, social, and other skills
- Discover opportunities and networks in the broader community
- Connect with others who “get it” and can relate to their specific challenges

There is wide variation across regional centers in the availability of and support for peer mentoring. All regional centers should have thriving peer mentoring communities in which people served feel a sense of belonging and connection, no matter how complex their needs may be. DDS should work to:

- Develop an understanding of what “peer mentoring” looks like at each regional center today
  - Have regional centers submit descriptions and share a statewide inventory of the 21 programs or opportunities on DDS’s website
- Identify regional centers that have strong peer mentoring programs or opportunities and share these best practices across regional centers

- Develop a common framework to guide regional centers in the elements of effective peer mentoring to include in program development
  - Have regional centers collaborate with people served to design a peer mentoring plan that includes elements from the framework and responds to the needs of that people served community
    - For example, people served may want to choose from group and one-on-one mentoring opportunities. They may want to choose from different platforms for communicating with their peer mentor: online, in-person, or through an app.
  - Develop and implement training for individuals who will serve as peer mentors
  - Implement peer mentoring programs at regional centers with ongoing feedback from people served and collaboration to improve peer mentoring programs
  - Post peer mentoring information and resources on every regional center website where it is easy to find and understand; and have DDS's website serve as a central source of this information.
3. **Make Sure Information About Generic Services Is Accessible.** CalHHS should work with its departments and stakeholders to expand or create accessible, user-friendly plain language information, and tools about generic services. This includes how to access these services and how to get help. The tools should help people gather the information they need. The materials should be in languages spoken by people served by the regional center. The information, tools and any forms should be short. They will be accessible on mobile devices. They will be in formats used by people with disabilities, including videos. The user-friendly plain information should:
- Be designed with the end-user in mind. The end-users are individuals and their families.
    - The design should consider people's experiences accessing generic services and data about equitable use of generic services

- The information should address common barriers to accessing services, for example, eligibility criteria
  - The materials should be developed with the California Office of Data and Innovation
  - Be easy to access through state and local agencies, regional centers, and community-based organizations.
    - The information must be located on DDS's website and updated as needed to make sure it is accurate
    - Regional centers, generic service agencies, and community-based organizations' websites should provide links to this information
  - Include links to other user-friendly information such as BenefitsCal.com which helps people apply for cash benefits such as CalFresh, cash aid such as CalWORKs and Medi-Cal. It also provides information about accessing mental health services.
  - Be supported by regional center strategies to proactively outreach to communities that underutilize generic services.
    - Data about who uses generic services should be used to focus outreach to groups that under-utilize generic services
    - Outreach should include other non-traditional means, such as providing information to video relay services
4. **Give People With I/DD and Their Families Tools So They Are Referred to the Right Generic Services and Can Keep the Benefits They Have.** CalHHS should work with its departments and stakeholders to develop tools to help people get the generic services they need. This should include services that are available across agencies, departments, and systems. The initial priority should be developing tools for the most frequently used generic services.

The tools should:

- Include eligibility screening tools for generic services that will be used before making a referral
- Be based on the rules for generic services developed by DDS and other departments that provide generic services
  - This means the tools should include eligibility requirements and steps to be taken before eligibility can be decided.
  - For example, to receive some generic services, a person needs to be Medi-Cal eligible. If they are not Medi-Cal eligible, they should not be referred to the generic agency unless they get Medi-Cal eligible.
- Be available to all generic services agencies, navigators, and community-based organizations
- Be used by all regional centers each year to help people who work keep their benefits
- Include tools to help people keep their SSI and SSDI benefits
  - For example, the tools should include uniform processes to report job-related income and employer subsidies and special conditions that reduce countable income. This will help make sure that people who work avoid large Social Security benefit terminations and overpayments.

5. **Make a Single On-Line Application for Services.** 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 emergency.
- 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 ensure the system is taking advantage of new technologies that will make it better.

More details about this recommendation can be found in the Recommendation Background and Technical Information Addendum on the CalHHS MPDS website.

6. **Make Sure Navigators Are Available.** DDS should increase the number of navigators available to help people with I/DD access the generic services they need and choose. People served should have choices about who provides navigation supports. Navigation services should include services provided by people with I/DD. Navigators should be culturally diverse and have cultural humility. When expanding its navigation program, DDS should work with diverse stakeholders, including self-advocates, to develop:

- Common services that navigators provide. For example:
  - Information and training about generic services. This includes eligibility requirements, how to access services, how to get help.
  - Help with generic services applications and annual review forms.
  - Help talking to generic service agencies. This can be about an application, assessment, notices from the agency, or to fix a problem.
  - Collaboration with other navigators and agencies to make sure the person gets the right help at the right time.
- Common skills and knowledge for navigators. For example:
  - Communication skills.
  - Interpersonal and relationship-building skills.
  - Navigation and advocacy skills.
  - Community education and training skills.
  - Outreach skills.
  - Knowledge of the regional center system. Knowledge of the generic service system(s).
  - The needs of the community they will serve.
- Common reporting used by all navigators that is reported to DDS at least once a year. For example:

- Demographic data about each person who was helped.
- The kind of service(s) provided to each person.
- The outcomes. For example, the generic services the person received. Or the skills the person learned.

7. **Increase Funding for Navigators.** CalHHS and DDS should work to increase federal funding for navigation services. Federal funds should be used to increase the number of navigators.

- CalHHS should learn from work done by departments to develop programs like Community Health Worker and Promoters. These are other programs that help people get the services that they need in other services systems. Learnings from the development of these programs should inform the navigator services eligible for federal funds.
- The navigation model proposed for federal funding must be developed in consultation with stakeholders.

8. **Develop Local Resource Guides.** Regional centers and DDS should work with local partners to develop and expand local resource guides. The guides should provide information about resources that are available to people with I/DD.

- The guides should include information about regional center services. This information should include consistent information on who is eligible for regional center services and the services available.
- The guides should be available online. They should also be accessible to people who do not have easy access to the internet. It is important to keep resource materials up to date.
- AI could be used to keep materials up to date. AI could use available information on websites and other sources to update contact information and the services provided by the listed agencies.

Regional centers and DDS should also:

- Work to improve the quality of information provided by 211
- Provide training to front-line staff to use systems like 211

9. **Provide Funding for Resource Centers.** DDS should provide state-wide funding for Resource Centers to help people with I/DD and their families or other caregivers access state and local community resources and services.

- The intention should be to develop a system to better integrate available resources, including peer-support resources.
- These Resource Centers could be an expansion of current models such as Family Resource Centers, Aging and Disability Resource Centers or Independent Living Centers.
- Another model would be to provide funding to other community-based organizations to establish Resource Centers. Resource Center staff must include individuals with I/DD.
- The services must be provided in languages spoken by people and families served by regional centers.

10. **Develop Shared Service Models.** DDS should work with people with I/DD, families, and other community partners to develop innovative service models where people can share resources and services with others. These models:

- Can be called “co-op models”
- Can be more resource effective
- Can include sharing staff or hours of support
- Can make it easier for people to get assistance from providers who are not their parents or relatives
- Can be explored to develop supports for people with I/DD who live with their aging parent or caregiver who also needs services and supports

- Should reflect United States Department of Labor overtime compensation requirements

DDS and Regional Centers should develop policies and oversight to prevent this model to be used to develop unlicensed group homes or similar models that are not based on person's choice. DDS and Regional Centers should also develop ways to measure quality and outcomes of this service.

**11. Life Tracker System.** The State should develop a "Life Tracker System" that supports individuals from birth through end of life. This system should provide people served with access to information about their services across all systems of support. This includes:

- Regional centers
- Health care, including behavioral health
- Schools
- DOR
- Other service systems

In developing the Life Tracker system, the State should keep in mind:

- Individuals should have a choice to participate in Life Tracker system or not.
- Individuals should have a choice on what information about them should be shared in Life Tracker.
- Life Tracker should have a portal so people with I/DD can see important information themselves. This portal can be similar to "MyChart." "MyChart" is a patient portal tool in the electronic health record system. Using the portal people with I/DD should be able to communicate with their RC and providers by sending secure messages.
- Life Tracker should be able to alert systems of support to prevent late responses, lags in supports, and remove barriers to services.

- Each system of support should have access to the Life Tracker system based on their role in a person's life. This will help them track, deliver, monitor services, and to coordinate with other systems, if the person chooses that.
- The Life Tracker system should provide resources to individuals and families and support them in planning for and going through life transitions. This can include information about services and resources, support with paperwork, and more.

## **People With I/DD Being Part of and Being Served by a Strong Workforce**

There are not enough people working to provide services to people with I/DD. These kinds of jobs are called the “disability field.” There are not enough people working in these jobs because the disability field is often viewed as a temporary job with low pay and challenging work situations. People don't get paid enough and don't get enough benefits to want to stay in the field. They are forced to find other jobs, even when they don't want to change careers. There are not enough opportunities for training and promotions. Another reason that there are not enough people working in the disability field is that many people do not know about careers connected to disability. There is not enough information for how to get a career in disability services.

Some jobs in the field can be very different depending on where someone works. For example, service coordinators at regional centers. Service coordinator roles and caseload sizes are very different at different regional centers. Their responsibilities can shift and change over time. This can make it hard for service coordinators to support people with I/DD and their families well.

There are also many people with I/DD who would like to work in the disability field but who have a hard time finding a job. People with I/DD are not encouraged and supported to seek jobs in the disability field.

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. Recommendations in this topic area include:

- Ways to get more people working in the disability field
- Ways to make it easier for people in the disability field to stay in their jobs
- Ways to make it easier for people in the field to do their jobs well

## **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. Some of the recommendations are about making sure that people who already work in the field have what they need to do their jobs well. Some of the recommendations focus on making sure that people who work in the field have what they need to stay in their jobs. Some of the recommendations focus on making sure that more people will work in the field. This will help to make sure there are enough people working in the field to support people with I/DD.

1. **Build Trust With Regional Center Service Coordinators.** DDS should work with regional centers to hold service coordinators accountable to certain expectations about how they do their jobs. These expectations will help people served feel like they can trust their service coordinators. To support trust, DDS should make sure that service coordinators receive training to support people with I/DD and families:

- With cultural humility and awareness.
- In a trauma informed way.
- With an inclusive and person-centered approach.

Service coordinators should also be expected to:

- Try to understand what people served communicate about their needs and goals.
  - This includes asking questions when they do not understand.
- Support people served when they communicate with staff at regional centers and service providers.

- Service coordinators should not make assumptions about what is in the person's "best interest."
- Tell people served about all possible options and service providers related to what they want and need.
- Refer people served to assessments, when necessary, instead of judging their abilities and needs.
- Support people served by asking if they want advice, instead of giving people advice they did not ask for.
- Let people served decide which services might be a good fit. Service coordinators should not make judgments or discourage what people served want.
- Value the perspectives of people served over others' biases. Promote the self-advocacy of people served over social approval.
  - For example, service coordinators should not discourage people served from communicating their triggers and authentic goals, even if the service coordinator judges them to be "too negative."
- Support people served to express their feelings. This includes validating beliefs about flaws in the system.
- Assume that when people served seek information, they are not necessarily implying an action should be taken.
  - This means that service coordinators must obtain explicit consent from a person served before moving forward.
- Keep a log of all actions taken for the person served and share it with them.
- Respect when people served decide to switch coordinators for any reason. This includes not tolerating any form of regional center retaliation in response to these or other decisions.

- Participate in interviews so people served can choose the service coordinator that is right for them. This should happen outside of IPP meetings.
- Fully disclose ahead of time all decisions that will be made about a person served without their consent. This should include decisions to withhold information to prevent a person's anxiety.
- Learn and respect how people served think and communicate.
- Assist and encourage people served in making complaints, even against the service coordinator themselves.

Asking for help is one of the most vulnerable things anyone can do. Asking for help is what people served by the regional center do every time they reach out to a service coordinator. If people served do not trust their service coordinators, they may not feel safe to share information. This trust in the relationship between service coordinators and the people served is vital for service coordinators to do their job.

2. **Support Staff at Regional Centers.** DDS and regional centers should create a support staff position at regional centers. This staff could be assigned to support multiple service coordinators with processing paperwork. The goals for this position would be to:

- Allow service coordinators to focus on building relationships with people and families that they serve
- Allow service coordinators to spend more time providing services
- Provide another opportunity for people interested in disability-related careers

The first step should be to get information about best practices used by regional centers that have similar support staff positions. This could show what is already working well at regional centers. DDS and regional centers should work together to decide which tasks that service coordinators are responsible for could happen in different, more efficient ways. For example, by:

- Using technology to complete certain tasks instead of assigning those tasks to a regional center staff
- Removing tasks that are not actually necessary
- Streamlining tasks that can be made simpler or quicker

This information should then be used to inform the job description for the regional center support staff position.

3. **Give Students Information About Disability Service Careers.** DDS should collaborate with the CDE to launch a curriculum for middle and high school students, including students with disabilities. This curriculum should teach students about:

- Disability history.
- The abilities and contributions of people with disabilities.
- Disability services careers. This should also include information and career guidance for students who are interested in disability-related careers.

4. **Spread Awareness About Disability Related Careers.** The State should sponsor an awareness campaign to increase interest in disability-related careers. It should:

- Feature major employers
- Highlight people with I/DD in successful careers
- Reduce stigma about disability

This campaign should reach culturally diverse and underserved communities and youth in middle and high school.

5. **Help People Start Disability Service Careers.** The State should create a partnership with community colleges, and employers to establish a paid internship program. This program would help people start their careers in disability services. This should be in addition to the Paid Internship Program, known as the PIP. This new internship program should be available to anyone

interested in a career in disability services. This internship program could begin as a pilot through a partnership with a community college and their local regional center.

6. **Help Connect People to Jobs.** DDS and Regional Centers should create regional plans for using existing employment tools. Tools should be used to:
  - Promote disability services careers
  - Match people looking for disability services careers with organizations and individuals that are looking to hire

This should include expanding and enhancing state-sponsored online tools, like the DSPCollaborative and CalJobs. It should also include more partnerships with private industry resources like Indeed and LinkedIn.

7. **Help People Be Successful as Disability Service Providers.** 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 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.
8. **Make Sure People in Disability Service Careers Have Benefits.** 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.

9. **Make Sure People in Disability Service Careers Make Enough Money.** 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.

## 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. Some of these recommendations focus on making sure that people with I/DD can find a job. Some of these recommendations focus on making sure that people with I/DD who are working have the supports that they need to be successful.

1. **Make Sure People With I/DD Get High Quality Employment Services.** DOR and regional centers should work together on how they provide employment services. This will make sure that people get excellent service



from both programs. They can do this by having designated DOR liaisons for each regional center who can work together with the service coordinator on helping people achieve their employment goals. They should also work together to help young people who are still in school so they can:

- Learn about employment options
- Start thinking about their future employment goals
- Include employment goals in their IEP

This should include working with parents, teachers, and special education staff on having high expectations and believing in the goals of young people with I/DD.

2. **Support People With I/DD in Leadership Positions.** DDS, DOR, and CalHHS should work together to create an annual State Leadership Academy. This program would support employment for people with I/DD disabilities in well paid leadership positions. These positions should be at:

- Regional centers
- State departments
- The State Legislature

This leadership academy should prepare its participants for how to be leaders in public service. It should include ongoing mentorship and an internship placement with the State, legislature, or a regional center upon completion of the program.

3. **Make Sure People With I/DD Get Benefits.** The State should create guidance for employers on how to offer flexible benefits for employees with I/DD who also get public benefits. This should be provided to regional centers and their vendors. DDS, work incentive planning experts, and individuals with lived experience can inform the best practices to be shared with employers. Best practices should be used to provide people with good compensation benefits without negatively impacting their eligibility for other public benefits. Best practices should include:

- Benefits planning
- Financial planning
- Use of CalABLE and other similar programs. For example, a CalABLE account allows people with I/DD to receive money (like pay from their employer) without that money being counted in a way that might cause their benefits to be lowered.

4. **Support People With I/DD to Start Businesses.** DOR and regional centers should work together to create a program that helps consumers successfully start and run their own business. This program should provide step-by-step training on:

- Requirements to start a business
- Managing money
- Finding customers
- Understanding labor laws
- Doing important things like paying taxes and managing benefits

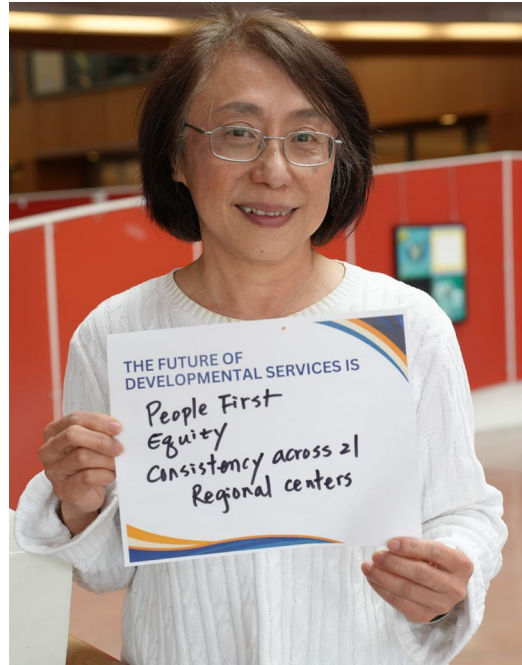
DDS and Regional Centers should partner with other programs that already provide services for people interested in starting their own business. For example, Job Centers and employment service vendors.

The program should also include finding people a mentor who is experienced at running a business. The mentor would provide frequent check-ins, advice, and help to answer questions.

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

Information should be available to help individuals understand what services and supports are available and what the rules are for getting different services and supports. This is called “transparency.” Transparency means that people can get the information that they need to understand what is happening and why. Many people with I/DD do not get clear information about the system. People with I/DD need clear information to:

- Understand their rights
- Understand how to get help they need to stay safe
- Get the services and supports they choose to lead the lives they want



There also is not enough information available for the system to track how well regional centers and providers are doing to meet the needs of people served. This is because the information collected is more focused on compliance, and not enough on person-centeredness or outcomes. It is also because information technology (IT) systems used by regional centers and DDS are too old to collect all the data needed to track and pay for good, equitable outcomes. It is important that information is available about what is happening across the system and if the system is working well. Having this type of information will help make sure everyone is responsible for doing the things they are supposed to do. This is called “accountability.”

**“There need to be consequences that are for the regional center, not just the clients. There’s plenty of consequences for us, but there’s no accountability for them. You need accountability, or nothing will change.”**

Tina

The goal for this topic is that systems will have more transparency and accountability.

Recommendations in this topic area include:

- Ways to make sure people with I/DD are safe in the systems that serve them
- Ways to create statewide standards that are also flexible to meet individual needs and circumstances in different communities
- Ways to make information easier for people to access, understand and use
- Ways to use information to help everyone navigate the systems while keeping information private and secure
- Ways to make sure everyone is accountable for achieving equitable and person-centered outcomes

## Keeping People With I/DD Safe

People with I/DD are more likely to be mistreated, abused, or neglected than people without disabilities. Sometimes people with I/DD experience mistreatment and are not sure what to do. People with I/DD should be safe in the systems that serve them. If a person with I/DD is ever mistreated, they should have a way to report what happened to them and make sure it does not happen again. These recommendations focus on keeping people with I/DD safe.

1. **Keep People With I/DD Safe From Mistreatment, Abuse, and Neglect.** 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 Massachusetts Disabled Persons Protection Commission 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.
- 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.
- 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.
- 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.

**2. Protect Children and Young People With I/DD in the Child Welfare System.**

DDS and the DSS should work together to develop a joint framework for preventing and responding to abuse of children with I/DD. Regional centers and county child welfare agencies should use this framework to strengthen their ability to jointly serve children who may be experiencing abuse or neglect in either system. This framework should include strategies for:

- Rapid responses
- Good communication
- Using technology solutions
- Consideration of the child's disability related needs when addressing possible abuse and neglect
- Education of regional center, child welfare staff and local community partners such as the educational system, on the issues that families in the I/DD community face
  - This includes understanding that poverty does not necessarily mean neglect
  - It also includes understanding the behavioral challenges some children and youth with autism and other disabilities face and the

need for additional services and supports in the family home to address these challenges when deciding if there is an issue of abuse

## **Hold Regional Centers Accountable**

Regional centers should be accountable for the ways that they support people with I/DD. Sometimes services with the same name can mean different things at different regional centers. Sometimes rules for what services and supports people can get are not the same at every regional center. This is because there are not consistent statewide standards about what services individuals can get and how they can get them. 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.

1. **Make Sure Intake and Assessment Processes Are Clear and Equitable.** DDS should create an intake and assessment process that build 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.
- Identify ways to expand intake and assessment workforce capacity.

2. **Make Sure IPP Processes are Consistent and Equitable.** 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. DDS should look at and update the new IPP to make sure it is more consistent, transparent, and equitable across all regional centers. This means:

- 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 self-advocates 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.

3. **Make Sure That Rules About Service Approvals Are Clear and Consistent.** 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 self-advocates, 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.

4. **Make Sure People Served Can Get Compensation Support With Appeals and Complaints.** 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.

5. **Improve Vendorization Processes.** 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.
- 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.

6. **Use Outcome Measures for Accountability.** 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.

7. **Reward Good Outcomes.** 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>14</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

---

<sup>14</sup> [For more information about the Quality Incentive Program \(https://www.dds.ca.gov/rc/vendor-provider/quality-incentive-program/\)](https://www.dds.ca.gov/rc/vendor-provider/quality-incentive-program/)

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 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.
8. **Use Contracts for Accountability.** 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 means 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.

9. **Strengthen Consumer Advisory Committees (CAC).** DDS and regional centers should strengthen the role of CAC to make sure people served have a strong role in system oversight. The CAC should play a central role in driving improvements at the regional center level and statewide level of developmental services. The Lanterman Act should be amended to reflect these expectations. DDS should work with regional centers to strengthen the role of CACs in the following ways:

- Every regional center should be required to have a CAC.
  - The Lanterman Act currently states that regional centers “may” have a CAC. This option should be changed to a requirement.
- The regional center CAC should meet monthly.
- All people served should be invited to attend CAC meetings.
- The officers of CAC should be elected by people served at an annual election meeting.
- The role of the CAC should be:

- To share experiences of people served.
- To make recommendations about:
  - Person-centered services and service coordination.
  - How to eliminate systemic discrimination and ableism;
- To present recommendations for improving developmental services and service coordination at each meeting of the regional center board of directors.
- To identify and plan activities that people served by the regional center want. These activities could include trainings and information opportunities.
- The regional center should support the CAC by:
  - Providing an individual to support the CAC in its preparation and presentation of recommendations. The CAC should have options for facilitators to choose from.
  - Providing sufficient resources and expertise to help the CAC grow and maintain its efforts.
  - Providing support for the CAC to share ideas and complaints. The regional center should provide a safe and welcoming space for the CAC to share input.
- A report on the recommendations should be compiled by each regional center and sent to the DDS CAC. The report should also be posted on each regional center's website under "Transparency."
- The DDS CAC should:
  - Be comprised of the chairs of each regional center's CAC, or the chair's designee in their absence.
  - Meet quarterly to advise DDS on addressing systemic changes to:
    - Improve service coordination and delivery.

- Eliminate systemic discrimination and ableism.
- Each member of the DDS CAC should be supported by the individual who supports that individual on the regional center CAC.
- A report of the DDS CAC's recommendations should be compiled by DDS and posted on the DDS website under "Transparency."
- The DDS CAC should make recommendations for updates and changes to the Bill of Rights in the Lanterman Act and/or by departmental policy.

**10. Support Regional Center Governing Boards for Oversight of Regional Center and Executive Director Performance.** DDS should work with regional centers to make sure regional center governing boards are supported. This will allow governing boards to provide effective and independent oversight of regional center and executive director performance. To strengthen governing boards, DDS should improve processes for:

- Recruiting and nominating members of the governing board.
  - The process for board appointments needs to be transparent. This includes nomination and voting processes. These processes should be accessible and easy to understand for anyone who wishes to participate.
  - The process should be clear and easy to find in materials related to the regional centers' boards. For example, on their websites.
    - Information about the process should clearly encourage self-advocates, family members, and community members to participate.
    - Information about the governing board and the application process should be available to every person served by the regional center and/or their family.
  - The board nominating committee should solicit interest and nominations from the broader community through outreach.

- The community should be asked for help in board member nomination, recruitment, and selection.
- The committee should interview board member candidates. Then the committee should make recommendations to the governing board for election.
- The nominating process should also establish rules for an individual to be nominated “from the floor.”
  - This means that a person could be nominated as a candidate for the board during a board meeting. This would require one board member to nominate the individual at the meeting and have a second board member also express support for this nomination.
- The Chair and Vice Chair of the regional CAC should be given the option of sitting on the governing board or selecting someone to sit on the board for them.
  - This should include supports for helping people find someone to sit on the board for them.
- Regional center Executive Directors, staff, and vendors should be prohibited from voting, or influencing the votes, in the election of board members.
- Providing effective board training and support.
  - DDS should provide board member training for all regional center governing boards. DDS should collaborate with the State’s designated “protection and advocacy agency” and the State Council on Developmental Disabilities.
    - The training should be developed with community input, including individuals served and family members.
    - DDS should provide and require consistent board member trainings.

- In addition to the universal board member trainings from DDS, regional centers should have flexibility to provide trainings that are specific to their local needs.
  - This should include training for outreach and recruiting diverse representation from their unique community.
  - The training should include the importance of engaging and representing the voice of the community.
  - Training and information should be provided to members of the community who want to better understand the responsibilities of the board and how a board is managed.
  - This will help encourage community members to seek positions on the board. Board training should be provided annually.
- DDS should ensure appropriate and adequate support for consumer and family board members by surveying members about their ability to meaningfully participate and understand the subjects and votes at board meetings and using the survey feedback to make improvements to the training and to ensure additional supports are provided.
- Improve facilitation for consumers and family members who sit on regional center boards by using independent supporters, making the board members less reliant on staff.
- Protecting board members and their families.
  - DDS should review policies to protect board members from retaliation. DDS should also review grievance procedures for board members who have concerns, complaints, or questions. Based on this review, DDS should make improvements as needed.
  - Governing board members should serve six-year terms and be required to step off the board for five years before being eligible to run for the board again. This would create more opportunities for community members to serve on the board.

- Other supports and protections.
  - DDS should establish guidelines for governing boards on regional center Executive Director compensation.
  - DDS should support boards in their review of large contracts by developing an objective rating system or set of criteria to consider in their decision-making.
  - Make sure regional centers are accountable to their contract with DDS and the State of California and not to outside organizations or trade associations.
  - Require boards to be notified of complaints with sufficient evidence against a service provider before the board takes up a vote to approve, renew, or deny that provider's contract. These complaints would include mistreatment, abuse, or negligent injury or death.

**11. Make Sure Regional Center Governing Board Meetings Are Transparent.** DDS should work with regional centers to make sure that governing board meetings have full transparency. This means that governing board meetings should support robust public comment on decisions they make. To support public comment, DDS and regional centers should make sure that the public:

- Has sufficient access to meeting materials in advance of meetings
- Has sufficient time to give public comment during meetings about items not on the agenda and prior to any votes taken at the meeting
- Is able to attend meetings remotely

The following requirements should be established, by amending the Lanterman Act or through a DDS directive. These requirements should be monitored and enforced by DDS:

- All information that will be presented at a board meeting should be placed on the regional center's website at least seven days before that meeting. DDS should monitor whether this provision is followed and alert the regional center and the public when it is not.

- If information that is being discussed at a meeting is not provided to the public at least seven days in advance of that meeting, any votes surrounding that information should be considered null and void. This means that the votes won't count.
- A minimum of 30 minutes should be allotted for general public comment at each board meeting. This could happen before the meeting begins or at the end of the meeting. This will give the public the opportunity to bring up issues that are not on the agenda. Boards should make a good-faith effort to allow every member of the public who wants to give comment to be able to do so.
- Time limits for each public comment should be decided by the board in a public meeting. People served by the regional center should be allowed more time to provide public comment.
- Public comment periods should be required before every vote by the board. The board should be presented with information and have a discussion. Then before the vote, the public should be given an opportunity to comment on the issue before the board. The board may take the public comment into account when voting on that issue.
- If a public comment is made that requires an action item, a response should be provided by the board at the following board meeting or within a specified timeframe.
- Boards should be encouraged to offer their board meetings virtually or as a hybrid to encourage public participation.
- For board meetings that are held online or as a hybrid meeting, the chat should be open, at a minimum during the public comment period. This will accommodate people who are unable or unwilling to provide their comment verbally.

## **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.

**1. Make Sure Information From Regional Centers Is Transparent and Accessible.**

DDS make sure that information shared by regional centers with people served is accessible and transparent. Regional center staff should be held accountable to meet the communication needs of people served. To make sure that regional centers and staff are providing information in a transparent and accessible way:

- Regional center staff should ask people served about the best way to meet their communication needs.
- Information should be accessible to people served and their families at all times. This information should include, at a minimum:
  - How to access services
  - How services and supports can meet needs
  - Eligibility for services
  - Reasons for denials
  - Changes and updates (before they happen)
  - The rights of people served
  - Roles and responsibilities, for people served and service providers

To be accessible to people served and their families, the information needs to:

- Be more transparent and available.
- Be provided in multiple ways and at multiple times. Accessible ways include a printable version, video, voice recording, one on one, mailed, with graphics/without graphics, and use of accessible fonts.

- Be shared without judgment when a person served asks about the information that has been previously shared.
- Be easier to access, as in find or locate. To request or locate information, there needs to be a search or easy way to obtain information that is needed and figure out where to go to get this information.
- Account for sensory differences, such as sensitivity to color or the number of images.
- Account for how people process information, such as taking things literally.
- Make instructions clear. For example, if a form needs to be completed in a blue or black pen, then the form should say that.
- Include the name and contact information for who the person served can follow up with if they have any questions or want to discuss the information further.

2. **Improve the Information Technology System.** DDS should develop and maintain a single statewide information technology ("IT") system for California's 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>15</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.
- 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.

3. **Make the Service Access and Equity Grant Program More Transparent.** DDS should strengthen the Service Access and Equity Grant Program. This means that 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

---

<sup>15</sup> [For more information about the CalHHS Data Exchange Framework Data Sharing Agreement \(https://www.cdii.ca.gov/committees-and-advisory-groups/data-exchange-framework/\)](https://www.cdii.ca.gov/committees-and-advisory-groups/data-exchange-framework/)

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 they got 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.

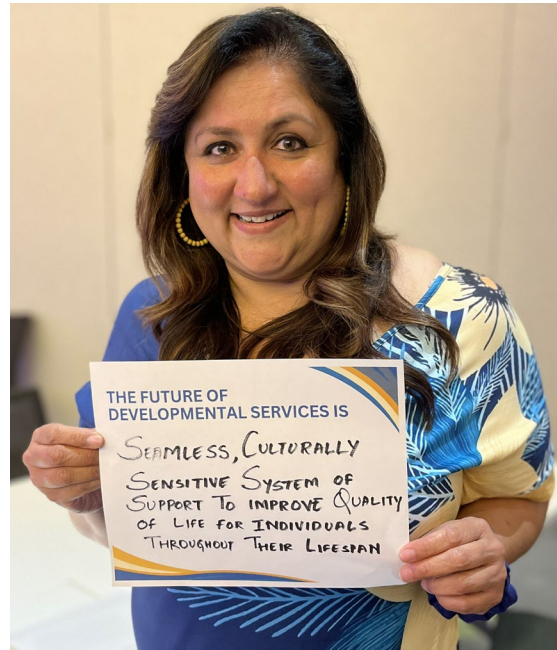
## Inform the Future of the Developmental Services System

The MPDS should inform the future of the developmental services system. This means that the recommendations in the MPDS can keep working to make the system better, even if the future brings unexpected changes. The future could bring new barriers or new opportunities for the system. This topic in the MPDS focuses on how to keep improving the system in the future, no matter what barriers or opportunities might be ahead.

The goal for this topic is that the developmental services system will continue to improve over time. An important part of this is improving the way that data and other information about the system is collected. Recommendations in this topic include ways that the systems that support people with I/DD can improve how data and information are collected. Recommendations in this topic also include ways to improve how data and information is used.

Recommendations in this topic area include:

- Ways to prepare for changes in the future
- Ways to understand why gaps or barriers in the system are happening
- Ways to get better information and data to study what is happening in the system and why
- Ways to improve how data and information are used by the system



## Funding for I/DD Services in California

Medicaid is a partnership program between the federal and state government. Together they pay for health care and behavioral health services, as well as supports for people with I/DD. In California the Medicaid program is called Medi-Cal. It provides health insurance coverage for 14.8 million low-income Californians. This includes children and their parents, pregnant women, seniors, people with disabilities, and non-elderly adults.

Medi-Cal pays for many things including primary care, specialty, hospital, and pharmacy are behavioral health and other services. These services are also referred to as State Plan services. Medi-Cal also provides Home and Community Based Services (HCBS) for people with disabilities, including those with I/DD. These services are also referred to as Waiver services that DDS provides. These services and supports include helping people with daily activities, such as dressing, eating, and shopping for food. They also include supports to get and keep jobs in the community, assistive technology, transportation, making homes more accessible, and more.

Today DDS is funded and provides services under two Medicaid Waivers:

- HCBS Waiver for Californians with Developmental Disabilities, and
- SDP for People with Developmental Disabilities

DDS also has a third Medicaid option called 1915(i) that serves people who are Medicaid eligible but don't qualify for the HCBS or the Self Determination Waivers. This is sometimes called a state plan amendment or option. All three programs provide similar services.

In California, it costs about 15 billion dollars every year for the developmental disabilities system to operate. Federal Medicaid funds are about 5 billion dollars, or one third of all funds for the developmental disabilities system.

In California people eligible under Lanterman Act are entitled to receive services regardless of their Medi-Cal or Waiver eligibility.

These recommendations focus on how people with I/DD can more easily access state plan services. This will bring more federal Medicaid funding to California. These recommendations are also about how to better connect and coordinate

waiver and state plan services. This will help all the systems work together to help people live better lives and reach their goals.

**1. Make It Easier for People With I/DD to Enroll in I/DD Waivers and Medi-Cal.**

DHCS, Counties, DDS, and regional centers should work together to make it as easy as possible for individuals to enroll in I/DD Waivers and Medi-Cal through one simple process with supports.

- DHCS, DDS, regional centers and counties should provide individuals with accessible information in plain language. This will help them make informed choice about Medicaid/Medi-Cal and DDS Waivers eligibility and enrollment.
  - Information sharing can include supports from people with lived experience (peer supports), information hubs, informational toolkits, workshops, process visuals, short plain language documents, and instructional videos.
- DDS and regional centers should provide information to individuals, families, and other community partners so that they can understand why Medicaid is important for long-term sustainability of the I/DD system and services.
- DDS and DHCS should explore options for raising income limits above current levels to allow more people to be Medicaid eligible, including through the “working disabled program.” This program allows people with disabilities to work and make money without losing their access to Medi-Cal.
- DDS and DHCS should work together to make sure that person's experience and outcome of eligibility and enrollment process are equitable. This means that their experiences are not defined by their race, ethnicity, language, gender, age, health condition, or any other identity or background. The State should evaluate data to identify and remedy any disparities.
- DHCS, DDS and regional centers should do a study to see how much funding can be received if the State and regional centers prioritize enrolling eligible individuals into Medi-Cal and DDS Waivers.

2. **Regional Centers Support People With I/DD to Get Medi-Cal.** DDS should make sure that regional centers prioritize supporting individuals and families with Medi-Cal eligibility and enrollment process. To make this happen, DDS should:
  - Provide regional centers with enough resources and staff to support individuals and families in navigating the eligibility and enrollment process.
    - This will help make the process as quick and easy as possible. Some up-front funding may be needed to start the process before more federal funding is brought to the State.
  - Find regional centers that are good at providing a fast and well-supported eligibility process.
    - DDS should share what these regional centers do and how they do it with other regional centers.
    - DDS should establish and support a community of practice to continuously improve processes across regional centers.
  - Develop outcome metrics and ways to hold regional centers accountable for supporting individuals and families with eligibility and enrollment.
  - Make sure that service coordinators and other regional center staff receive quality training on Medi-Cal, and Waiver eligibility and enrollment.
    - This should include training on how to complete necessary forms and paperwork for eligibility.
3. **Improve Words Used to Talk About Eligibility.** CalHHS should work with its departments to change language about Medi-Cal and Lanterman eligibility. The new language should be simple and not intimidating. Language that has negative meaning for some people or might trigger trauma should be revised. For example:

- Words like “institutional deeming,” and “waiver” can be intimidating and can mean different things to different people
  - Words like “mild,” “moderate,” and “severe” should be removed from the titles of Lanterman-qualifying diagnoses and the eligibility process
4. **Clarify Rules About Eligibility.** DDS should issue guidance to regional centers to make sure that people served are able to receive services quickly and without interruption. Whether people receive regional center services should not depend on Waiver and Medi-Cal eligibility. This guidance should clarify that:
- Waiver and Medi-Cal eligibility process or the type of Medicaid authority individual enrolls in should not delay or restrict access to regional center services
  - People should be able to start receiving regional center services while waiting on Medicaid eligibility process to be completed
  - Regional Centers will do pre-screening for services so that people can start receiving some basic supports quickly, even as they are going through eligibility process
  - Eligibility and enrollment process should not impact continuity of services at eligibility redeterminations
5. **Use Waivers to Make Seamless Service Systems.** 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.

6. **Use Grant Funding for Pilot Projects.** The State of California, including DHCS and DDS, should explore and prioritize the use of grant funding for innovative projects and pilot projects. This will allow the State to try new services or ways to deliver services. The State should develop a resource where community partners, including diverse community organizations and nonprofits, can find information on federal or other funding opportunities or grants to apply for. This can be a web site or a regular newsletter. As part of this work, DDS should partner with researchers, universities, specifically University Centers for Excellence in Developmental Disabilities, to explore innovative service models and opportunities.

## **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.

1. **Prepare for Cuts to Medicaid.** If the federal government makes cuts to the Medicaid program and funding, DDS should follow these 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.
- 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.
- Give people informed choice 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.

2. **Protect Early Start.** If funding for the Early Start program is reduced or eliminated, California should prioritize continuing the services and supports provided to children and their families through this program with state funding. California should do this because the State recognizes the value and importance of providing comprehensive services and supports to children from birth up to 3 years of age and their families through the federally funded Early Start program.

## 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.

1. **Gap Analysis on Services for People With I/DD.** 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

2. **Gap Analysis on Behavioral Health Services for People With I/DD.** The State should conduct a gap analysis of behavioral health services that are available to individuals with I/DD. This means identifying gaps in:

- Supports
- Services
- Residential living arrangements

It should include all behavioral health services, including:

- School-based mental health services
- Community based behavioral health services
- Crisis and emergency services
- Residential services

The gap analysis should also look at the adequacy of the behavioral health workforce with a particular focus on the adequacy of workforce trained to provide services to individuals with I/DD.

3. **Gap Analysis on Early Start for Children With I/DD.** The State should conduct a “gap” analysis about the availability of services for children ages 3-5. This should include children who have received Early Start services. The gap analysis should look at:

- The availability of current services. These include services that are available from:
  - Regional centers
  - School districts

- Other state or federally funded pre-school programs
  - Medi-Cal
  - California Children Services (CCS)
  - Waiting lists for services
  - New services that families want
4. **Gap Analysis on School for Children and Youth With I/DD.** The State should conduct a gap analysis of the ways people with developmental disabilities are served by the school system in California. This study will:
- Show where schools are doing well
  - Show where schools are not providing fully inclusive, person-centered learning experience for students with I/DD
  - Look at data related to supports and outcomes for students with I/DD. This should include:
    - Graduation rates
    - Type of diploma achieved
    - Transition rate to jobs or post-secondary education
- This study should be done with input from individuals with I/DD and their families from diverse backgrounds.
5. **Gap Analysis on Post-Secondary Services for Young Adults With I/DD.** The State should conduct a gap analysis about the availability of post-secondary services and supports people want. The gap analysis should look at:
- The services that are currently available
  - Waiting lists for those services
  - New services that people with I/DD want to achieve their post-secondary pathway

Following the gap analysis, CalHHS and its departments should develop recommendations to address any gaps.

6. **Gap Analysis on Services for Older Adults With I/DD.** The State should conduct a gap analysis about the availability of services that older adults need and choose. This should include:

- The availability of more flexible service options
- The need for new service models
- Needed living options, including living arrangements for people with Down Syndrome or other I/DD who also have dementia

## 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.

1. **Collect Data to Attract People to Disability Services Careers.** The State should conduct a study with specific recommendations for types of financial incentives that could be provided to people in disability-related careers. This could include:

- Tax breaks
- Loan forgiveness
- Work visas
- Housing assistance

The State should use the results of the study to create an action plan. The plan should have specific timelines and goals for improving the financial incentives for people going into disability-related careers.

2. **Collect Data on Hiring and Keeping Regional Center Staff.** The State should conduct a study of the regional center service coordinator role at all regional centers. This 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 coordinator.

3. **Collect Data on the Service Coordinator Caseload Sizes.** 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

4. **Collect Data on Homelessness.** DDS should improve data collection to track:

- Prevention of homelessness
- Events that cause risk of homelessness
- Homelessness
- Housing outcomes
- Housing threats
- Who gets housing resources
- Who needs housing services
- Other needs of people with I/DD related to homelessness

DDS should use this data to:

- Make sure policies are fair
  - Improve access to housing programs
  - Target services
5. **Use Data to Better Understand Unmet Need.** DDS should conduct a study to measure the gap between the number of individuals served by regional centers and the number of individuals who are eligible for services. This study should collect statewide data and data by regional center catchment area. This baseline data would be tracked over time to measure regional centers' effectiveness in closing the gap. Currently, no data exists on what percentage of all eligible individuals this number represents. Without a sound estimate of the total number of eligible individuals, the State is unable to know the gap in unmet need or effectively strategize on how to close that gap.
6. **Increase Access to Data.** DDS should increase access to high-quality data for individuals, the public and researchers. This means that 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.
- Collect, manage, and keep data safe for research and analysis.

## **Recommendation Needing Further Consideration**

There are nearly 170 recommendations in the Master Plan. The Committee and co-chairs spent many hours discussing the recommendations. They worked hard to understand different opinions on all the recommendations. They were able to reach a consensus on all the recommendations except for one. A “consensus” means that enough people agree to support something that it can move forward. The Committee’s definition of consensus was that the recommendation was supported by two-thirds of the members. The recommendation that the Committee did not reach a consensus on is about letting people served by the regional center choose to receive service coordination from outside of the regional center.

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. These are the two versions of the recommendation:

- 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.

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

# What Comes Next for the Master Plan for Developmental Services?

The MPDS is a community-driven vision to improve how California supports people with I/DD and their families into the future. In the spirit of a California for All, the MPDS:

- Is inclusive
- Is forward-looking
- Reflects the diversity of our State
- Reflects the cultures of our communities
- Reminds us of our values, including:
  - Service and support
  - Understanding
  - Compassion

The MPDS weaves together the stories from many members of the community into shared recommendations to improve the programs and resources they need to thrive and achieve their goals.

The MPDS will help inform progress toward:

- Better services and supports
- Improved coordination across systems
- The attainment of desired life outcomes

These improvements require the continued partnership and collaboration of our entire community. The Master Plan will be used to inform existing work, new work, and future work. The Master Plan provides both the community's desired

objectives and recommendations on how to achieve them, on many topics. Here are some examples of the workgroups that the MPDS will inform:

- The Lived Experience Advisory Group (LEAG). This workgroup is an expanded and renamed Consumer Advisory Committee. LEAG will help with:
  - Developing plain language materials.
  - Commenting on policy.
  - Contributing to the Life Outcome Improvement System (LOIS) project.
  - The LOIS project is an IT project. It will modernize the case management and money systems used to deliver regional centers services. LOIS will provide people served and their families with access to their information and communication with regional centers.<sup>16</sup>
  - Centering the experiences of people with I/DD in our collective work.
- The Quality Incentive Program workgroup. This workgroup develops and provides incentives for achieving individual outcomes.
- The Regional Center Performance Measures workgroup. This workgroup develops and provides incentives for regional centers that make improvements on issues which are important to the community.
- The Quality Assurance Advisory Group. This workgroup will inform work to improve the knowledge and experiences of people with I/DD and families receiving services.
- Several advisory groups engaged with the Service, Access, and Equity Division of DDS.

DDS also will reconvene the MPDS Committee two times per year. These meetings will share updates on work related to the MPDS recommendations. Using the information shared in these meetings, DDS will submit an annual report

---

<sup>16</sup> [For more information about LOIS \(https://www.dds.ca.gov/newsletter/a-look-ahead-at-2025/\)](https://www.dds.ca.gov/newsletter/a-look-ahead-at-2025/)

to the Legislature. This report will be submitted in March of each year, beginning in 2026, and ending in 2036.

The Administration greatly values the community's contributions to the MPDS. The Administration encourages continued participation in these and other efforts that enhance the lives of people with I/DD and their families. DDS will continue to seek out input from diverse members of the community to include in focused conversations. To learn more and to join these ongoing engagement opportunities, go to the DDS Events website (<https://www.dds.ca.gov/dds-events/>).



# Appendices

## Appendix A: Master Plan for Developmental Services Committee Members

The Master Plan for Developmental Services Committee consisted of a diverse group of individuals appointed by the CalHHS Secretary. Committee members brought different backgrounds and experiences to help build the Master Plan.

Committee Members	
Amy Westling	Kecia Weller
Areva Martin	Kelly Kulzer-Reyes
Barry Jardini	Larry Yin
Beth Burt	Lisa Cooley
Brett Eisenberg	Marie Poulsen
Brian Zotti	Mark Klaus
Cheryl Brown	Mark Melanson
Claudia Center	Marty Omoto
Dora Contreras	Norma Ramos
Edith Arias	Oscar Mercado
Elena Tiffany	Sara Speck
Elizabeth Hassler	Sascha Bittner
Eric Ramirez	Season Goodpasture
Fernando Gomez	Shella Comin-DuMong

Committee Members	
Gloria Wong	Sylvia Yeh
Joe Perales	Tiffany Whiten
Joyce McNair	Victor Lira
Judy Mark	Will Leiner
Kavita Sreedhar	Yvette Baptiste

For biographies of the workgroup members visit: <https://www.chhs.ca.gov/wp-content/uploads/2024/07/1-Master-Plan-Committee-Member-Bios-7-16.pdf>.

## Appendix B: Master Plan for Developmental Services List of Workgroup Members

Workgroup Members	
Aderonke Adejuyigbe	Jesse Rocha
Alessandra Aldai	Jesse Weller
Alex Mountford	Jonathan Padilla
Alison Morantz	Joyce Cabrera
Ana Seda	Kaitlynn Truong
Angel Montoya	Kathleen Barajas
Angelina Ordonez	Katie Hynes
Araceli Garcia	Kendra Wagner
Carolina Navarro Garcia	Kiara Hedglin
Cheryl Ann Whittle	Lauren Loza
Chloe Carrier	Lety Garcia
Chloe Medina	Lisa Macafee
Christine Couch	Mariana Molina Nava
Christopher Chu	Mirela Bere
Cindy Cox	Mitra Ordibehesht
Derek Hearhtower	Renu Moon
Dominique Mellion	Shannon Cogan
Dustlyne Beavers	Suad Bisogno

Workgroup Members	
Erendida Gonzalez	Susan Stroebel
Gaby Abdel-Salam	Suzy Requarth
Glenis Ulloa	Teresa Anderson
Harold Ashe	Tiffany Swan
Hyun S. Park	Tina Ewing-Wilson
Isabel Torres	Tracey Mensch
Jamie Johnson	Viri Salgado
Jay Kolvoord	

Most members of the Committee also served as members of workgroups.

## Appendix C: Stakeholder and Community Engagement

Throughout this process, we have made it a priority to hear from the community. We did this by gathering public comments and feedback through outreach efforts. Over eight months, we held 47 community meetings, about one per week, to ensure a wide range of experiences were included in the MPDS. These meetings have brought together people from diverse backgrounds, including:

- Individuals from underrepresented communities
- Service providers
- Policy experts
- Self-advocates, and their families

By listening to so many different perspectives, we are shaping the MPDS with a strong focus on fairness and inclusion. The goal of the Master Plan is to build a developmental services system that is fair, consistent, and accessible to all Californians with I/DD. Our commitment to community engagement made sure that the experiences of those most impacted by the system are heard, valued, and included in every step of the process.

For more information and to access these engagements, visit:  
<https://www.chhs.ca.gov/home/master-plan-for-developmental-services/#>.

Host	Community	Date
Department of Developmental Services Hispanic/Latino Focus Group	Hispanic/Latino advocates that meet regularly with DDS to provide input	06/07/2024
California Foundation for Independent Living Centers	Directors and senior leaders of California's Independent Living Centers	06/13/2024

Host	Community	Date
Association of Regional Center Agencies	Regional Center Executive Directors	06/20/2024
Department of Developmental Services African American Focus Group	African American advocates that meet regularly with DDS to provide input	06/28/2024
Integrated Community Collaborative	Hispanic/Latino Spanish speaking families and self-advocates	07/11/2024
Service Access & Equity Monthly Meeting	Representatives of DDS -Service Access and Equity grant recipients	07/12/2024
Family Resource Centers Network of California	Directors and senior leaders of California's Family Resource Centers	07/17/2024
Summer Institute on Neuro- Developmental Disabilities	Families, self-advocates, & professionals attending MIND institute conference	07/19/2024
Westside Resource and Empowerment Center Parent Support Group	Ethiopian parents, family members, and people with developmental disabilities	08/16/2024
Disabilities Voices United Communication Access Connect	AAC users and their families	08/20/2024
El Arc de California	Committee members of El Arc representing the Latino community	09/03/2024
State Alliance Team for Aging	Representatives of state and local entities serving older adults and people with disabilities	09/04/2024

Host	Community	Date
Golden Gate Regional Center Advocates	Service providers and advocates serving the San Francisco Bay Area	09/10/2024
Let Your Ideas Be Known	Disability Rights California hosted a webinar for families, self-advocates, and activists	09/12/2024
PRAGNYA Coffee, Chai, and I	Families and self-advocates from the South Asian communities and greater San Jose area	09/21/2024
"Voices for Change" Event	Families and individuals from the Chinese, Japanese, and Vietnamese communities	09/21/2024
State Council on Developmental Disabilities (SCDD)	Membership of the SCDD	09/24/2024
Korean Community Collaboration	Families and Individuals with disabilities in the Korean community	09/27/2024
California Association of Health Facilities (CAHF)	Non-profit trade association representing skilled nursing facilities and intermediate care facilities for people with I/DD	10/02/2024
Cafecito	Hispanic/Latino Spanish speaking families and self-advocates	10/03/2024
Sac6 Area Listening Party	Convening for self-advocates from six counties in the Central Valley	10/04/2024
National Council on Severe Autism (NCSA)	Advocates and professionals who provide recognition, policy and solutions for individuals, families and caregivers affected by autism and related disorders	10/07/2024

Host	Community	Date
Tribal Developmental Disabilities Symposium	Tribal community members in I/DD community and Tribal I/DD service providers	10/10/2024
Valley Mountain Regional Center SDP LVAC	Local Volunteer Advisory Committee to the Regional Center (SDP LVAC) in the self-determination program	10/17/2024
North Los Angeles County Regional Center SDP LVAC	Local Volunteer Advisory Committee to the Regional Center (SDP LVAC) in the self-determination program	10/17/2024
South San Francisco Families Engagement Forum	Parents of individuals with I/DD from South San Francisco and surrounding area	10/24/2024
El Arc de California Coalition Leaders Board	Self-advocates, family members, service providers and community members that focus on civil rights of people with I/DD in the Latino community	10/29/2024
Sac6 Area Listening Party	Convening for self-advocates from six counties in the Central Valley	11/01/2024
Service Coordinators Focus Group	Focus group for SEIU member service coordinators from ten regional centers	11/01/2024
California Foundation for Independent Living Centers CA Community Living Network	Professionals from across the state who had provided independent living services under the original California Supported Living Arrangement (CSLA) pilot program	11/04/2024

Host	Community	Date
Korean Community Listening Session	Forum for Korean families and individuals receiving DD services	11/07/2024
CFILC Quarterly Meeting	Update on the Master Plan to leadership of California's Independent Living Centers	11/07/2024
Autism Society San Francisco Bay Area	Nonprofit organization of parents, family members and professionals of people within the autism community in the Bay Area	11/12/2024
Developmental Disabilities Councils of the of the East Bay Convening	Convening with the Developmental Disabilities Councils of Alameda and Contra Costa Counties	11/13/2024
North Bay Regional Center Board Meeting	North Bay Developmental Disabilities Services Board Directors	11/18/2024
Westside Family Resource and Empowerment Center	African American/Black families support group to ensure people with intellectual and developmental disabilities	11/21/2024
The Lanterman Coalition	Stakeholders who work to preserve the Lanterman Act for people with intellectual and developmental disabilities	11/22/2024
Congreso Familiar	Service providers who serve Spanish speaking families that have children or family members with disabilities	12/02/2024

Host	Community	Date
Associate of Regional Center Agencies - 2024 Partners in Policymaking graduates	Leadership training program for adults with developmental disabilities and families to become community leaders and catalysts for systems change	12/05/2024
University of California, Irvine Center for Autism and Neurological Disorders	UC Irvine Center for Autism Latino support group	12/12/2024
Self-Advocate Listening Party- Inland Regional Center	A convening of self-advocates from Inland Regional Center to discuss and share their experiences	01/21/2025
Hlub Hmong Center	Hmong advocacy organization which focuses on policy and systems change in public-serving institutions to tackle social justice disparities	01/23/2025
National Council on Severe Autism (NCSA)	Advocacy organization focused on addressing unique challenges faced by families and individuals with autism	01/28/2025
University of California, Irvine Center for Autism Health and Neurological Disorders Empowering Women of Color Support Group	Black, African American, and Biracial parents and caregiver support group for those who have children with a neurological disability	01/28/2025

Host	Community	Date
Interagency Coordinating Council on Early Intervention	Members are appointed by the Governor. The council is comprised of parents of children with disabilities, early intervention service providers, health care professionals, state agency representatives, and others interested in early intervention	02/07/2025
University of California, San Francisco (UCSF) Virtual Conference  Developmental Disabilities: An Update for Health Professionals	Healthcare professionals who support the developmental disability population in California	03/06/2025

## Public Comment

We created an accessible public comment process to support community engagement throughout the development of the MPDS. Each of the 12 full committee meetings had public comment periods at the beginning and end. This allowed for meaningful participation. Each of the five workgroups also met monthly, with public comment periods at each meeting to ensure transparency and community involvement. A record of public comments is available here: <https://www.chhs.ca.gov/home/mpds-committee-workgroup/#>.

Additionally, individuals could submit suggestions or recommendations by email at [DSMasterPlan@chhs.ca.gov](mailto:DSMasterPlan@chhs.ca.gov). This approach made sure everyone's input was heard and considered in shaping the MPDS.

## Appendix D: Process for Supporting Self-Advocates

### The Support Facilitator Role

The Support Facilitator role was created to help people with I/DD participate fully in the Master Plan process. This approach effectively supported self-advocates in sharing their knowledge, experiences, and ideas with confidence. Facilitators:

- Simplified complex information
- Prepared self-advocates for meeting
- Increased self-advocate participation in decision-making

### Who Were the Support Facilitators?

For the time-limited Master Plan process, there was an immediate need to provide support to self-advocates. To meet this need, professionals, and students with experience in education, training, and coaching individuals with I/DD were recruited. Their familiarity with the developmental disabilities system, including services and supports, helped them guide self-advocates effectively.

Support Facilitators were not decision-makers in the Master Plan process. They assisted self-advocates without influencing their opinions or contributions. Their role was to simplify materials, explain meeting topics, and help self-advocates determine when and how to share their perspectives. Facilitators provided support before, during, and after meetings to make participation more accessible and inclusive. Over time, some self-advocates required less one-on-one support as they gained confidence and independence.

### How Support Facilitators Helped

#### Before Meetings

- **Monthly Group Pre-Meetings:** Self-advocates and facilitators met before each Master Plan Committee meeting to go over the agenda, learn new skills, and talk about key topics. Facilitators:
  - Explained complex issues in plain language

- Helped self-advocates prepare
- Provided notes with their comments to use during the meeting
- **One-on-One Support:** Some self-advocates met individually with facilitators to review materials, simplify ideas, and ask questions. Facilitators adjusted their support based on each self-advocate's needs.

### During Meetings

- **Helping With Discussions:** Facilitators made sure self-advocates could follow the conversation and understand key points.
- **Encouraging Participation:** They prompted self-advocates to share their thoughts and encouraged them to speak up.
- **Providing Real-Time Support:** Facilitators clarified information to help self-advocates stay engaged.
- **Workgroup Leader Practices:** Workgroup leaders encouraged self-advocates' participation by inviting their feedback first.

### After Meetings

- **Organizing Feedback:** Facilitators helped self-advocates go over key points and prepare for next steps.
- **Building Confidence:** They gave positive feedback and encouragement to help self-advocates grow in their roles.

### Why This Support Was Important

- **Increased Confidence:** Self-advocates became more comfortable speaking in meetings.
- **Better Understanding:** They could fully participate because they understood the topics being discussed.
- **Leadership Growth:** They developed skills to advocate for themselves and others.

- **Stronger Collaboration:** They learned from and worked with fellow self-advocates.

## Looking Ahead

Self-advocates believe this support should continue and be available in other leadership and decision-making spaces, such as:

- Regional center Boards
- Consumer Advisory Committee
- Other civic committees

Many self-advocates shared that they would not have been able to fully participate in the MPDS process without this assistance. Looking ahead, peer support models should be explored. This will make sure that self-advocates can support one another in future policy and planning efforts.

## Appendix E: Glossary

- **Ableism** – A form of prejudice which happens when people with disabilities are treated unfairly because they have a disability. Ableism can also happen when people who do not have disabilities are favored over people who have disabilities. For example, choosing a job candidate without a disability over a job candidate with a disability, even though the candidate with a disability is more qualified.
- **Applied Behavioral Analysis (ABA)** – A therapy that helps to understand behavior and to make positive changes to behavior. ABA can help people with autism and other I/DD develop positive skills like communicating and taking care of themselves. ABA can also help to replace negative behaviors with positive behaviors. ABA is personalized for each individual and their unique needs.
- **Assistive Technology (AT)** – Tools, devices, or other items that help people with disabilities. AT can be as simple as a special pencil grip or as complicated as an artificial leg.<sup>17</sup>
- **Augmentative and Alternative Communication (AAC)** – All of the ways that someone communicates besides talking. Augmentative means to add to someone's speech. Alternative means to be used instead of speech. AAC methods can include gestures, pictures, symbols, electronic devices, and changes to the environment that make it easier for people to communicate. People of all ages can use AAC if they have challenges with speech or language skills. Some people use AAC throughout their life. Others may use AAC only for a short time. An example of when ACC might be used is when someone has surgery on their jaw and cannot talk while they recover.
- **Behavioral Health** – A term that includes mental health, issues with drug or alcohol use, and how stress affects the body. Behavioral health care focuses on preventing, diagnosing, and treating these issues.

---

<sup>17</sup> [For more information about AT \(https://www.who.int/news-room/fact-sheets/detail/assistive-technology\)](https://www.who.int/news-room/fact-sheets/detail/assistive-technology)

- **Bias (Implicit and Structural)** – Implicit bias is when someone has prejudices for or against a person or group without realizing it. Structural bias is when systems have been designed to benefit one group over others. These hidden biases can affect how people make decisions and act.
- **CalABLE** – An investment account designed for people with disabilities. CalABLE accounts are made possible by the federal Achieving a Better Life Experience (ABLE) Act. A CalABLE account allows money to be saved for qualified, disability-related expenses. The money in a CalABLE account is not counted towards eligibility for public benefits, so people can save money without losing their benefits. The money in the account grows without being taxed and can be used tax-free for approved disability expenses.<sup>18</sup>
- **Career and Technical Education (CTE)** – An educational program spread out over several years. The program involves a set of classes that combine core academic knowledge with technical and occupational knowledge. The goal of the program is to provide students with a pathway to education after high school and careers.<sup>19</sup>
- **Caregiver** – A person who helps someone with an illness, injury, or disability with their daily needs. Caregivers can provide short-term or long-term support. Caregivers can be family members or people who are paid to provide support.
- **Caseload** – The number of people or cases a worker or organization is responsible for. For example, a regional center service coordinator's caseload is the number of people they are assigned to support at one time.
- **Circle of Support** – Family, friends, and other important people who support a person with a disability. Having support from others can help a person with a disability be more successful and independent. For example, people in a circle of support can provide help with problem

---

<sup>18</sup> [For more information about CalABLE \(https://calable.ca.gov/about/\)](https://calable.ca.gov/about/)

<sup>19</sup> [For more information about Career and Technical Education \(https://www.cde.ca.gov/ci/ct/\)](https://www.cde.ca.gov/ci/ct/)

solving or participating in the community. A circle of support is one type of “natural support.”

- **Consumer** – An individual with I/DD who is eligible for regional center services. The term consumer has replaced the prior term “client.” The term consumer references not only the individual, but the individual’s authorized representative. Authorized representatives include parents, guardians, and conservators.
- **Consumer Advisory Committee (CAC)** – The Director of DDS created the CAC in 1992 to give consumers a voice at DDS. The CAC gives DDS information about important issues that affect Californians with I/DD and provides consumers with information about things DDS is doing. The CAC makes decisions from information they receive from the community about DDS issues and community priorities. The CAC’s Vision is “My Life-My Way.”<sup>20</sup> Each regional center also has its own CAC made up of consumers in its catchment area.
- **Conservatorship** – A legal term for when a judge appoints another person to make decisions for a person who might have a hard time making decisions for themselves. The person the judge appoints is called the conservator. The person who the conservator makes decisions for is the conservatee. A judge can only appoint a conservator if other, less-restrictive options will not work.<sup>21</sup> If they are needed, DDS and regional centers are committed to person-centered conservatorships that respect the rights and choices of conservatees.<sup>22</sup>
- **Contract** – A legal agreement between people or groups that requires them to do (or not do) something.
- **Competitive Integrated Employment (CIE)** – A program that helps people with I/DD find jobs where they work alongside people without disabilities and earn at least minimum wage. DDS, DOR, and CDE work together to make employment in an integrated setting, at a competitive wage, for

---

<sup>20</sup> [For more information about Consumer Advisory Committees \(https://www.dds.ca.gov/consumers/consumer-advisory-committee/\)](https://www.dds.ca.gov/consumers/consumer-advisory-committee/)

<sup>21</sup> [For more information about conservatorship \(https://selfhelp.courts.ca.gov/conservatorships\)](https://selfhelp.courts.ca.gov/conservatorships)

<sup>22</sup> [For more information about person-centered conservatorships \(https://www.dds.ca.gov/newsletter/a-more-person-centered-conservatorship-program/\)](https://www.dds.ca.gov/newsletter/a-more-person-centered-conservatorship-program/)

people with I/DD a high priority for the state. The goals of the program include helping people with I/DD get the support they need to have more opportunities and to find jobs, especially as they become adults. Another goal is to make it easier for businesses to hire people with I/DD. In this program, schools, rehabilitation districts, and regional centers work together to support people with I/DD effectively.<sup>23</sup>

- **Community of Practice** – A group of people who are working on a topic, like equity. The group meets regularly to discuss the topic and learn together.
- **Community Supports** – Services provided by Medi-Cal that help people with health-related social needs.<sup>24</sup> These services are meant to improve people's well-being and avoid more costly care. These supports include:
  - Help finding and keeping housing
  - Access to medically tailored meals to support short term recovery
  - A variety of other community-based services
- **Coordinated Family Supports (CFS) Program** – A service option for adults (age 18 and older) who live in their family home and receive regional center services. CFS provides:
  - Support for developing skills at home
  - Help coordinating and getting services, including “generic services”
  - Assistance with community access
  - A service plan to reduce or remove barriers, address challenges, and meet goals

---

<sup>23</sup> [For more information about Competitive Integrated Employment \(https://www.chhs.ca.gov/home/cie/\)](https://www.chhs.ca.gov/home/cie/)

<sup>24</sup> [For more information about Community Supports \(https://www.dhcs.ca.gov/CalAIM/Documents/DHCS-Medi-Cal-Community-Supports-Supplemental-Fact-Sheet.pdf\)](https://www.dhcs.ca.gov/CalAIM/Documents/DHCS-Medi-Cal-Community-Supports-Supplemental-Fact-Sheet.pdf)

CFS services are individualized, flexible, and tailored to each person's language, culture, and needs, to help them stay in their family home.<sup>25</sup>

- **Coordinated Career Pathway (CCP)** – A service that helps people transition from work activity programs, below minimum wage jobs, or high school (within the last two years) to CIE. CCP includes two services:
  - Career Pathway Navigator (CPN)
  - Customized Employment Specialist (CES)

CCP services last 18 months, with the option to extend up to 24 months.<sup>26</sup>

- **Crisis** – A crisis is a time of intense difficulty, trouble, or danger. Often “crisis” refers to a high intensity behavioral health challenge which an individual is experiencing. For example, if someone is at risk of harming themselves or someone else.
- **Data** – Data is information which can be used to understand patterns and to make decisions. Data can include measurements or statistics. It is important to have good data to understand what is happening in a system and what might need to be improved.
- **Demographic** – A specific section of a population with a shared characteristic. For example, age, race, and gender are all demographic characteristics.
- **Department of Education (CDE)** – A California state government department that oversees public education and is responsible for the education of millions of children. The CDE oversees:
  - Funding
  - Testing

---

<sup>25</sup> [For more information about Coordinated Family Supports \(https://www.dds.ca.gov/services/coordinated-family-support-service/\)](https://www.dds.ca.gov/services/coordinated-family-support-service/)

<sup>26</sup> [For more information about Coordinated Career Pathways \(https://www.dds.ca.gov/services/coordinated-career-pathways-ccp-services/\)](https://www.dds.ca.gov/services/coordinated-career-pathways-ccp-services/)

- Improving and supporting public school programs
- Providing resources to schools, teachers, and parents<sup>27</sup>
- **Department of Health Care Access and Information (HCAI)** – A California state government department that focuses on expanding equitable access to quality, affordable health care for all Californians.<sup>28</sup>
- **Department of Health Care Services (DHCS)** – A California state government department that provides equitable access to quality health care. DHCS is responsible for the state’s Medicaid program, Medi-Cal.<sup>29</sup>
- **Department of Rehabilitation (DOR)** – A California state government department that provides employment support services and advocacy to Californians with disabilities. DOR works with people served and other community partners to support employment, independent living, and equality for people with disabilities.<sup>30</sup>
- **Department of Social Services (DSS)** – A California state government department that provides services to low-income and vulnerable California residents.<sup>31</sup> The CDSS oversees:
  - The CalWORKs cash aid program
  - The CalFresh food electronic benefits program
  - In-Home Supportive Services
  - The child welfare system
- **Disabled Persons Protection Commission (Massachusetts) (DPCC)** – An independent state agency that investigates and responds to abuse of adults with disabilities (ages 18 to 59) in Massachusetts. Created in 1987,

---

<sup>27</sup> [For more information about the California Department of Education \(https://www.cde.ca.gov/\)](https://www.cde.ca.gov/)

<sup>28</sup> [For more information about the Department of Health Care Access and Information \(https://hcai.ca.gov/about/mission-statement/\)](https://hcai.ca.gov/about/mission-statement/)

<sup>29</sup> [For more information about DHCS \(https://www.dhcs.ca.gov/Pages/AboutUs.aspx\)](https://www.dhcs.ca.gov/Pages/AboutUs.aspx)

<sup>30</sup> [For more information about DOR \(https://dor.ca.gov/Home/DepartmentOverview\)](https://dor.ca.gov/Home/DepartmentOverview)

<sup>31</sup> [For more information about CDSS \(https://www.cdss.ca.gov/\)](https://www.cdss.ca.gov/)

the DPPC reports to the Governor and Legislature and is led by an Executive Director. The DPPC:<sup>32</sup>

- Runs a 24-hour hotline for reporting abuse, neglect, or deaths
  - Investigates cases and oversees other agency's investigations
  - Provides protective services and training and education
  - Helps people recognize and report abuse and neglect
  - Maintains an Abuser Registry
- **Early Start:** A program that provides services for infants and toddlers with developmental delays or who are at risk for having a developmental disability and their families. Early start services are provided in a coordinated, family-centered system.<sup>33</sup>
  - **Eligibility** – Meeting the necessary requirements to get a service or a program. For example, to get regional center services or Medi-Cal, a person has to meet eligibility criteria.
  - **End of Life Planning** – Making a plan for what will happen when someone dies. This can include making decisions about things like:
    - Medical care at the end of a person's life
    - What will happen to a person's belongings and money at the end of their life
    - What kind of funeral a person or family wishes to have
  - **Enhanced Care Management (ECM)** – A Medi-Cal benefit for eligible people with complex health needs.<sup>34</sup> It provides:

---

<sup>32</sup> [For more information about the Massachusetts DPCC \(https://www.mass.gov/info-details/overview-0\)](https://www.mass.gov/info-details/overview-0)

<sup>33</sup> [For more information about Early Start \(https://www.dds.ca.gov/services/early-start/\)](https://www.dds.ca.gov/services/early-start/)

<sup>34</sup> [For more information about ECM \(https://www.dhcs.ca.gov/CalAIM/ECM/Pages/Home.aspx\)](https://www.dhcs.ca.gov/CalAIM/ECM/Pages/Home.aspx)

- A Lead Care Manager who coordinates all of the health and health-related care and services that a person gets
- **Family Resource Center (FRC)** – These centers work with local organizations to help parents and families with young children learn about early intervention services and how to use the Early Start system. FRCs are run by parents who have children with special needs. They offer information and support to other parents. Each center is different and meets the needs of its community. They can be located in various places like regional centers, schools, health facilities, hospitals, or homes. Support services are available in many languages and are tailored to each family's cultural needs.<sup>35</sup>
- **Federal Poverty Level (FPL)** – A threshold set by the federal government to measure an individual's or household's degree of poverty. Poverty means not having enough money to pay for very basic needs. The FPL provides a measurement that is used to determine if a person may be eligible for certain programs and benefits.
- **Financial Management Service (FMS)** – Participants in the Self-Determination Program must use a FMS to handle all payments for their services. The FMS:
  - Pays bills
  - Provides monthly spending statements
  - Handles taxes and legal compliance issues for staff

The FMS is independent but must be contracted by a regional center. There are three types of FMS providers:

- Bill Payer
- Sole Employer
- Co-Employer

---

<sup>35</sup> [For more information about Family Resource Centers \(https://www.dds.ca.gov/services/early-start/family-resource-center/\)](https://www.dds.ca.gov/services/early-start/family-resource-center/)

- **Home and Community Based Services (HCBS) Final Rule** – The “Home and Community Based Services (HCBS) Final Rule” is a federal rule that protects the freedom of people with disabilities who receive Medicaid services to:
  - Live as independently as possible in the community, and not be segregated in institutions
  - Make their own choices about their care and services
  - Have the same rights as anyone else when accessing support services
  - Have privacy and control in their lives<sup>36</sup>
- **Individual Program Plan (IPP)** – A planning document that is prepared in a standard format according to specific instructions. An IPP is developed by identifying a person’s unique needs. The IPP identifies the goals, services, and supports which the regional center will coordinate for a person served.
- **Incentive Program** – A program that encourages organizations to do something by giving them a reward or other benefit when they do it.
- **Individualized Education Program (IEP)** – A special education plan explaining the educational support which a student with disabilities will receive from their school. The Individuals with Disabilities Education Act (IDEA) is the national special education law. A key part of IDEA is the concept that every child with a disability has a legal right to a free and appropriate public education (FAPE). A student’s IEP explains what their school needs to do for them to receive FAPE. The IDEA requires certain information to be included in an IEP. The IDEA also requires that a student’s parents or guardians are involved in the IEP process.<sup>37</sup>
- **In Home Supportive Services (IHSS)** – A program that provides assistance in a person’s home to eligible people. For example, people with

---

<sup>36</sup> [For more information about HCBS \(https://www.dds.ca.gov/initiatives/hcbs/\)](https://www.dds.ca.gov/initiatives/hcbs/)

<sup>37</sup> [For more information about IEPs \(https://www.ed.gov/sites/ed/files/parents/needs/speced/iepguide/iepguide.pdf\)](https://www.ed.gov/sites/ed/files/parents/needs/speced/iepguide/iepguide.pdf)

disabilities. IHSS provides the support that people need to live safely in their own homes instead of moving to a care facility.<sup>38</sup>

- **Intake and Assessment Process** – The process which DDS and regional centers use to determine if a person is eligible for regional center services.
- **Intellectual and/or Developmental Disability (I/DD)** – A lifelong condition that:
  - Begins before age 18
  - Lasts for someone's entire life
  - Affects daily activities, like walking, speaking, taking care of yourself, or working

Examples of I/DD include conditions like:

- Cerebral palsy
  - Autism
  - Down Syndrome
  - Epilepsy
- **Institutional Deeming** – A process that checks a child's eligibility for Medi-Cal as if they lived in an institution and not in their family home. This allows children served by regional centers to qualify for Medi-Cal, even if their family's income is too high for them to meet the eligibility criteria under usual circumstances.<sup>39</sup>
  - **Institutions** – Places where people with I/DD or other conditions live where they are segregated from the community. When people live in institutions, they often have **limited freedom and control** over their lives.

---

<sup>38</sup> [For more information about IHSS \(https://www.cdss.ca.gov/in-home-supportive-services/\)](https://www.cdss.ca.gov/in-home-supportive-services/)

<sup>39</sup> [For more information about institutional deeming \(https://www.dds.ca.gov/wp-content/uploads/2019/02/HCBS\\_WaiverDDEng\\_20190212.pdf\)](https://www.dds.ca.gov/wp-content/uploads/2019/02/HCBS_WaiverDDEng_20190212.pdf)

- **Lanterman Act** – A California law that says that people with I/DD and their families have a right to get services and supports they need. The Lanterman Act was passed in 1969. The law makes sure that people with I/DD receive personalized services based on their needs and choices. The law recognizes that people with I/DD may need supports to live full, independent, and productive lives.<sup>40</sup>
- **Medi-Cal** – California's Medicaid program. This is a public health insurance program which provides needed health care services for people who have low-income. Medi-Cal is financed jointly by the state and federal government.<sup>41</sup>
- **Medicaid Waiver** – Medicaid waivers are programs that provide additional services to specific groups of people. In California these are called Medi-Cal waivers. Examples of waivers include Home and Community Based Services (HCBS), Home and Community-Based Alternatives (HCBA), and other waivers.<sup>42</sup>
- **Navigator** – A person who helps people and families to understand the system and to access the services that they need.
- **Neurodiversity** – The idea that people's brains work in different ways and that these differences should be recognized and respected. The term is often used to describe conditions like autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), and learning disabilities.
- **Office of Clients' Rights Advocacy (OCRA)** – A part of Disability Rights California (DRC) that provides free help to people receiving regional center services. Clients' Rights Advocates (CRAs) work at each of the 21 regional centers to protect the rights of people served. OCRA services

---

<sup>40</sup> [For more information about the Lanterman Act \(https://www.dds.ca.gov/transparency/laws-regulations/lanterman-act-and-related-laws/\)](https://www.dds.ca.gov/transparency/laws-regulations/lanterman-act-and-related-laws/)

<sup>41</sup> [For more information about Medi-Cal \(https://www.dhcs.ca.gov/services/medi-cal/Pages/default.aspx\)](https://www.dhcs.ca.gov/services/medi-cal/Pages/default.aspx)

<sup>42</sup> [For more information about Medicaid waivers \(https://www.dhcs.ca.gov/services/Pages/Medi-CalWaivers.aspx?utm\\_source=Resources&utm\\_medium=SideBar&utm\\_campaign=Waivers\)](https://www.dhcs.ca.gov/services/Pages/Medi-CalWaivers.aspx?utm_source=Resources&utm_medium=SideBar&utm_campaign=Waivers)

include legal information, advice, and representation. OCRA has been supporting people served at regional centers since 1999.<sup>43</sup>

- **Person-Centered Planning** – A process that supports an individual to set goals for their future and decide what they need to achieve those goals. The process should be driven by the individual and reflect what is important to and for that person. Person-centered planning can include other people, such as family or friends, if the individual chooses to include them in the process. Person-centered planning should be used to inform a person's IPP with their regional center.
- **Pilot Project** – A small-scale test of a new program or service before it is fully launched. A pilot project can help to identify what works and what needs improvement.
- **Purchase of Service (POS)** – A purchase of service is created when a regional center pays a vendor to provide a service to a person served. POS data can be used to understand which groups of people served are getting services and supports.
- **Regional Center** – A private, non-profit agency that is under contract with DDS to coordinate services and supports for people with I/DD. Regional centers help individuals and families access services that support independence and quality of life. Each regional center serves a specific area in California. Regional center roles and responsibilities are defined in Sections 4620-4696 of the California Welfare and Institutions Code.<sup>44</sup>
- **Service Coordinator** – The person who is responsible for managing and monitoring an individual's IPP. The service coordinator works for a regional center, or an agency that contracts with a regional center to provide service coordination services.
- **Service Access & Equity Grants** – A program which was created to reduce disparities and increase equity in regional center services. This program awards \$11 million each year to regional centers and

---

<sup>43</sup> [For more information about OCRA \(https://www.disabilityrightsca.org/what-we-do/programs/office-of-clients-rights-advocacy-ocra/\)](https://www.disabilityrightsca.org/what-we-do/programs/office-of-clients-rights-advocacy-ocra/)

<sup>44</sup> [For more information about regional centers \(https://www.dds.ca.gov/rc/\)](https://www.dds.ca.gov/rc/)

community-based organizations to implement strategies to reduce disparities and increase equity in regional center services.<sup>45</sup>

- **Self-Determination Program (SDP)** – A regional center program that gives people served and their families more freedom and allows them to choose services and supports that help them to achieve their IPP goals. The SDP was created in 2013 and was initially limited to 2,500 individuals during a three-year trial period. As of July 1, 2021, it is available to all eligible individuals receiving regional center services.<sup>46</sup>
- **Systemic, Therapeutic, Assessment, Resources and Treatment (START)** – A program that provides crisis support to people served by regional centers. START teams provide person-centered, trauma-informed services and crisis support for people with I/DD over the age of six. START teams provide services 24 hours a day to people with I/DD who live in their family home or in an out-of-home setting.
- **Workforce** – All of the people who are available to work in a specific job field. In the Master Plan the workforce being talked about is the people who work in jobs providing support to people with I/DD.

---

<sup>45</sup> [For more information about the Service Access & Equity Grant Program \(https://www.dds.ca.gov/rc/disparities/disparity-funds-program/\)](https://www.dds.ca.gov/rc/disparities/disparity-funds-program/)

<sup>46</sup> [For more information about SDP \(https://www.dds.ca.gov/initiatives/sdp/\)](https://www.dds.ca.gov/initiatives/sdp/)

# Acknowledgements

We want to thank everyone who made the MPDS possible. Many different people gave their time and shared their experiences to help create this plan to improve California's system for developmental disabilities. The people who made the Master Plan a reality included:

- Countless leaders with I/DD
- Family members of people with I/DD
- Community members
- Members of the Disability Services workforce
- Researchers and educators
- Other stakeholders

Special thanks go to:

- The Committee and workgroup members who worked tirelessly to develop the recommendations in the plan
- Members of the public who participated and gave comments throughout the Master Plan process
- The community organizations that helped us host over 45 community engagement sessions with diverse communities across the state
- The writers, translators, and interpreters that made sure our work was in plain language and available in many languages
- The Support Facilitators who worked with self-advocates to make sure they had what they needed to participate during the Master Plan process
- The staff and consultants at DDS, DOR, and CalHHS who worked hard behind the scenes to support the Master Plan process

