UNFAIR HEARINGS

How People with Intellectual & Developmental Disabilities Lack Access to Justice in California

A report researched and co-authored by
Disability Rights California
Disability Voices United
Integrated Community Collaborative
Stanford Intellectual and Developmental Disabilities Law and Policy Project

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ORGANIZATIONAL AUTHORS

DISABILITY RIGHTS CALIFORNIA (DRC)

Disability Rights California defends, advances, and strengthens the rights and opportunities of people with disabilities. DRC works for a world where all disabled people have power and are treated with dignity and respect. In this world, people with disabilities are supported, valued, included in their communities, afforded the same opportunities as people without disabilities, and make their own decisions.

DisabilityRightsCA.org

DISABILITY VOICES UNITED (DVU)

Disability Voices United is a California organization directed by and for people with disabilities and their families. We advocate for choice and control over our lives, meaningful outcomes that matter to us, and systems that are equitable and accountable to us.

DisabilityVoicesUnited.org

INTEGRATED COMMUNITY COLLABORATIVE (ICC)

The Integrated Community Collaborative is comprised of parents, siblings, and self-advocates who support those navigating the developmental disabilities system on a peer-to-peer basis through its Intergradora Program. The ICC's organic community outreach efforts address cultural and language barriers to obtaining equitable services.

IntegratedCommunityCollaborative.org

STANFORD INTELLECTUAL AND DEVELOPMENTAL DISABILITIES LAW AND POLICY PROJECT (SIDDLAPP)

The mission of the Stanford Intellectual and Developmental Disabilities Law and Policy Project (SIDDLAPP), based at Stanford Law School, is to promote student engagement, stimulate rigorous policy analysis and academic research, and spearhead legal advocacy on the rights and welfare of individuals with I/DD. SIDDLAPP's faculty affiliates share the conviction that many problems in the I/DD law and policy arena are best approached from an interdisciplinary perspective that incorporates first-hand insights from the I/DD community.

Law.Stanford.edu/SIDDLAPP

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NOTE ON LANGUAGE IN THE REPORT

The Integrated Community Collaborative, which is composed mostly of multi-generational Latino parents and self-advocates, uses the terms Latino and Latina to refer to individuals of Latin American cultural or ethnic identity. The ICC embraces this rich culture, and uses "Latino" to include the self-identification of all genders within the community it is a part of and represents. This paper does so as well in partnership with the ICC, and in recognition that many in the community identify with those terms. However, more generally, Disability Rights California uses the term Latinx when referring to the community as a whole because it is a gender-neutral word that promotes greater acceptance of non-binary Latinos by being gender-neutral and thus inclusive of all genders of Latin American cultural or ethnic identity in the United States. The (x) replaces the (o/a) ending of Latino/Latina that are typically grammatically gendered in Spanish.

We have chosen to use the more empowering terms "self-advocate" or "person served" to refer to individuals with intellectual and developmental disabilities who receive services funded by regional centers. This term is used broadly to also include chosen representatives or family members.

EXECUTIVE SUMMARY

> *"I felt I had no voice there. There was so much intimidation."*
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> *"How am I supposed to trust our service coordinator or my regional center again?"*
>
> *"The judge spoke very fast and the interpreter could not translate everything he said, so I did not understand anything that was happening."*
>
> *"When the regional center has a team of lawyers and you can't afford an advocate, it's not really a 'fair' hearing."*

These statements were made by people with disabilities and their families — all people of color — about their attempts to enforce their rights in the state-run system that serves people with intellectual and developmental disabilities (I/DD) in California. This is not the intent of state law. On paper, Californians with I/DD have a right under the Lanterman Act to services funded by the state and federal governments through regional centers. Decisions about services are supposed to be decided collaboratively by an Individual Program Planning (IPP) team. In cases of disagreement, people with. I/DD have the right to access a process called a "fair hearing" at which an impartial administrative law judge is supposed to ensure they have their rights to services.

But in practice, people with disabilities and their families find the fair hearing system to be overly complex, opaque, and biased. **Access to justice is instead rationed to only those who can afford a lawyer, leaving those who are already underserved – people of color, or those who are poor or lack education – with little chance of successfully challenging a regional center decision.**

The term "unfair hearing" actually comes from parents of color who feel that the system is biased against them, and their claims appear to be supported by research conducted by the four disability rights organizations who co-authored this report. Our research was based on an analysis of information available on the websites of the Department of Developmental Services (DDS), the 21 regional centers, and the Office of Administrative Hearings (OAH); insights from attorneys who represent individuals with I/DD; and the results of a survey and follow up interviews with self-advocates and family members.

Our key findings reinforce widespread concerns that the fair hearing process is failing to provide adequate access to justice to people with I/DD.

- More than 90% of all survey respondents reported at least one problem with the IPP process, with the most common complaint being that **no one authorized to make a decision on behalf of the regional center attended their IPP.**
- The informal dispute resolution process does not encourage swift and equitable solution to a disagreements. Instead, many told us that the lawyers representing the regional centers did not make good-faith efforts to settle disputes.
- ***Many respondents believe that the fair hearing system magnifies systemic inequalities and is inaccessible, opaque, and biased in regional centers' favor.*** More than half reported concerns about their inability to afford legal representation while the regional center used public funds to hire attorneys and confusion about how the fair hearing process worked. These problems were more frequently reported by people of color.
- **72% of fair hearings are withdrawn,** likely showing that many individuals and families give up because of the complexities of the process and the inability to hire a lawyer. **People served win, or partially win, fewer than 5% of cases filed.**

Fair Hearing Outcomes: January 1, 2018-August 25, 2021

OUTCOMES	# OF CASES	% OF CASES
All Outcomes	3733	100%
Withdrawn	2671	71.55%
Denied	477	12.78%
Dismissed	201	5.38%
Pending	198	5.30%
Granted	126	3.38%
Split	60	1.61%

- Many respondents also reported that administrative law judges were unknowledgeable and always looked to the regional center for information. Many respondents also felt that the judge was biased toward the regional center.
- **Family members who speak languages other than English complained about the lack of qualified interpreters at IPP meetings and hearings**. Respondents also expressed concerns about written materials not being provided in their preferred language.
- Many individuals experienced problems *after* fair hearings, such as an inability to appeal a ruling because they could not afford a lawyer, a refusal by the regional center to comply with the judge's order, or an unjust denial of the right to seek services from their regional center at a later time, even if their circumstances changed.
- **There is almost no meaningful oversight of the fair hearing process.** DDS has failed to comply with its statutory duties to train administrative law judges annually and to make all fair hearing decisions public. People served have no meaningful opportunity to provide feedback. No independent entity exists that can investigate problems and remedy harms arising from the hearing process.

IMPROVING ACCESS TO JUSTICE IN THE REGIONAL CENTER SYSTEM: OUR RECOMMENDATIONS

DDS has also recognized the fundamental flaws with the fair hearing system and opened the door to redesigning the process. In June 2021, through their Home and Community Based Services Spending Plan, DDS recommended a significant overhaul of the fair hearing process, acknowledging that "the current fair hearing process/dispute resolution process is cumbersome, difficult to navigate, and intimidating for communities where questioning 'authority' is difficult or not acceptable. Families share that they believe they don't feel they have enough representation as compared to the regional centers." With the impetus from DDS, now is an opportune time to shine a light on these concerns and reform the fair hearing process.

Our major recommendations are presented in the chart below, which compares, side-by side, the features of the current system to our proposed reforms.

The main recommendation involves moving the fair hearing process from the Office of Administrative Hearings (OAH) to the Department of Social Services (DSS). The DSS fair hearing process, which is used for many other systems, including IHSS and CalFresh, is seen by many advocates as more accessible and less formal. While the DSS process also uses administrative law judges and has some other similarities to OAH, there are significant differences that we believe will do much to level the playing field.

We offer other critical recommendations to improve access to justice for individuals with I/DD and help mitigate longstanding racial/ethnic disparities. Our research findings highlight the fact that people of color are disproportionately shut out of the system, and our proposed reforms would help address this problem so that those from underserved communities would have a greater ability to enforce their rights.

PROCESS	CURRENT SYSTEM	RECOMMENDATIONS
Regional centers' responses to requests from people served	Service coordinators often don't have authority to make decisions at IPP.	Decision-makers must be present at all IPPs.
	Some decisions about services are made outside of IPP meetings by separate regional center committees, without the participation of the person served, and comprised of people who often don't know the person.	All decisions about services must be made in IPP team meetings that include the participation of the person served.
	Regional centers can conduct "denial by delay" and take an unlimited amount of time to respond to a request for services.	Regional centers must respond to requests from the person served for services with a clear yes or no answer within a specific timeframe.
	Notices of Action often fail to explain the factual basis and legal rationale for denying a particular individual's request for services.	If a Notice of Action fails to explain in plain language the factual basis for denial, in any subsequent hearing, the burden shifts to the regional center to prove the disputed service is not necessary.

PROCESS	CURRENT SYSTEM	RECOMMENDATIONS
Informal dispute resolution procedures	Regional centers currently have little incentive to settle. They employ a full-time hearing specialist to help the regional center prevail at fair hearings and face no consequences for past failures to provide needed services.	Regional centers are required to pay a penalty or provide back services to address past failures so they are more motivated to settle.
	The person served can request, and regional centers must offer, an informal meeting. However, this meeting typically does not resolve the issues.	Informal meetings can be requested by the person served, but are not mandatory.
	Often, the person served discloses their arguments and evidence without regional centers disclosing theirs.	Two days prior to mediation, regional centers must provide the person served with a mediation statement that explains the factual basis and rationale in plain language for denying the services.
	Mediation can be requested by a person served, but they only take place if the regional center agrees to participate.	Mediation is mandatory for both sides, and is conducted by a neutral third party. Both sides must disclose their arguments, but those disclosures remain confidential and cannot be used at the hearing.
Fair hearings	Office of Administrative Hearings has a contract with DDS to hold fair hearings.	The Department of Social Services state hearing division will conduct hearings for DDS with their Administrative Law Judges and the procedures used in hearing processes for other systems.
	The regional center and person served are required to exchange evidence and witness lists five days prior to hearing.	Regional Centers must provide the person served with a position statement two days prior to the hearing which includes all documentary evidence and a list of witnesses the regional center intends to use during the hearing. The person does not have the same obligation and can appear at the hearing with witnesses and documents.
	Although the hearings are not bound by the formal rules of evidence, OAH hearing officers typically require both parties to use formal processes like those used in trials and impose formal timelines for the disclosure of evidence and witnesses.	Hearings will be conducted in an impartial and informal manner in order to encourage free and open discussion by participants.
	Continuances of fair hearings can only be allowed with good cause.	The person served will be allowed a one-time continuance of the hearing with no cause.
	Regional centers, at taxpayers' expense, can hire private attorneys to represent them at fair hearings. Persons served have extremely limited access to legal representation. Even if a person served is well-off and has the ability to privately pay for attorneys, very few lawyers practice in this area.	Regional centers will not be allowed to have an outside attorney represent them at hearing unless the person served has one as well.
	No information is available on why a large majority of fair hearing requests are withdrawn, whether because of an early resolution or intimidation by the process.	DDS shall collect data on the reasons why persons served withdraw from fair hearing and report the data to the appropriate legislative committees and the public.
	The person served is required to pursue all legal claims against regional centers and vendors through the fair hearing process, including claims that have nothing to do with disputes over regional center eligibility or services, such as civil rights violations, alleged discrimination, and physical or emotional injuries.	The person served should not be forced into the hearing process for claims that are not about regional center eligibility or entitlement to services. They should be able pursue such claims through state or federal courts if they choose.

PROCESS	CURRENT SYSTEM	RECOMMENDATIONS
Aftermath & Appeals of Fair Hearings	*If the regional center prevails at fair hearing:* – the only way for the person served to get the decision reviewed is by filing a writ to superior court, a complicated process that requires an attorney, and which must be paid for out of pocket. – the person served usually cannot recoup their attorney's fees even if they prevail in superior court.	*If the regional center prevails at fair hearing:* – Individuals will have the same post-hearing rights as others in the DSS hearing process, such as the ability to obtain a rehearing from a DSS judge within 30 days. – If the person served appeals the ruling of the ALJ to superior court and wins, the regional center must pay for the person served's attorney's fees.
	If the person served prevails at fair hearing: – OAH has no authority to ensure that the regional center complies with the decision. – the regional center can appeal the decision to superior court and hire private attorneys at taxpayers' expense.	*If the person served prevails at fair hearing:* – DSS is authorized to take action to ensure the regional center complies with the decision. – If the regional center appeals the ruling of the ALJ to superior court, and the person served wins, the regional center must pay for the person served's attorney's fees.

PROCESS	CURRENT SYSTEM	RECOMMENDATIONS
Oversight of Fair Hearing Process	Although OAH is required to make redacted copies of all fair hearing decisions available to the public upon request, 20% of decisions since 2018 have not been made available.	DDS shall compile and distribute to each regional center and make publicly available a current indexed digest of decisions, as well as provide an online search tool where the public can access published decisions for every case with information about claimants' race/ethnicity.
	DDS is required to provide annual training on Lanterman Act issues to ALJs and to consult with DRC, SCDD, and other self-advocate/family organizations on those trainings. However, no trainings have occurred for several years.	ALJs shall receive trainings on the Lanterman Act at least annually. DDS, DRC, SCDD and other self-advocate/family organizations shall co-develop and co-lead the trainings, and report the topics and frequency of those trainings to the Legislature.
	Trainings have not covered systemic racial/ethnic disparities or implicit bias.	The trainings shall address racial/ethnic disparities and include the participation of diverse people served and their families.
	There is no independent neutral office to analyze or investigate problems with the fair hearing process.	DDS Director or designee reviews all fair hearing decisions.
	Persons served and family members have no formal way to provide OAH with input or recommendations on how to improve fair hearing procedures.	DSS shall establish a fair hearings advisory committee comprised of a majority of persons served and family members, as well as advocates, and regional centers.

The recommendations in this paper point to ways California's developmental disabilities system can promote equal access to justice and can build both trust and capacity. The state must see access to justice as essential to achieving equity. We urge the state to make this commitment now.

UNFAIR HEARINGS FULL REPORT: INTRODUCTION

> *"I felt I had no voice there. The judge talked down to me. There was so much intimidation. They listened to the regional center more than me."* - Statement from a Latino parent

These statements were made by a parent who took the regional center to due process because her family does not have the appropriate services for her autistic son, who experiences regular behavioral challenges and is often in crisis. The administrative law judge did not allow a member of the family's circle of support to attend the hearing. The parent reported feeling that the judge was very biased against her son. Her son, who comes from an underserved community, lost the fair hearing and continues to struggle to get the services he needs to stay out of crisis.

Another parent, a monolingual Spanish speaker, filed for due process against her regional center so that her son could make his own choices on how to spend his Self-Determination Program funds. The family and regional center had already reached agreement on the budget amount, so how her son chose to spend those funds would have no financial impact at all on the regional center, or on the state. Nevertheless, the regional center challenged her son's decision about how to spend the money in the approved budget. The regional center hired a private law firm to represent them, and also brought the fair hearing specialist, service coordinator, and Director of Client Services to a hearing that lasted about 20 hours over three full days.

The mother brought her non-lawyer facilitator to help, but she did not understand the legal jargon and was interrupted constantly by the judge who scolded her for not understanding the rules of evidence and examining witnesses. The parent said that the paid Spanish interpreter, who was interpreting while she was driving, was distracted and barely explained what was being said. The parent also reported that her service coordinator, who is supposed to be advocating for her child, testified against her son. The judge ruled against the autistic child and in favor of the regional center. The parent explained,

> *"How was I supposed to fight against a real lawyer and all of those staff? How am I supposed to trust our service coordinator or my regional center again? How come the regional center can pay for a lawyer but I can't? And all of this wasn't even over spending more money on helping my son."*

An autistic self-advocate filed for hearing when a regional center denied her request to fund additional training for the staff who support her throughout the day. The purpose of this training was to help her staff understand how the trauma she experienced in her childhood affects her today, as well as to improve the working relationship between this individual and her staff. The regional center denied this request. Her service coordinator, after consulting with an internal regional center committee, told the individual that she needed "behavior services" to help her manage the "difficult behaviors" that were interfering with her relationship with her staff, and that her staff could only receive training about her "behavior plan." She was then told that she should secure behavioral services from her insurance.

When the self-advocate filed for hearing, she requested an informal meeting with the regional center and a mediation with a neutral third party. The regional center agreed to the informal meeting but denied her request for mediation. At the informal meeting, the regional center representative listened as she pled her case, and asked her questions about her attempts to obtain these services from other sources. However, he refused to answer any of the self-advocate's questions that would have helped her prepare for her case. When the case went to hearing, the regional center was represented by the same person who attended the informal meeting. He used all of the information she gave him at the informal meeting against her at the hearing.

These stories illustrate how the complex, opaque, and often biased fair hearing system is failing people with developmental disabilities. Access to justice, a fundamental right, is instead rationed only to those who can afford a lawyer, leaving those who are already underserved – people of color, or those who are poor or lack education – with little chance of successfully challenging a regional center decision.

This is not the intent of state law. Californians with I/DD have a right under the Lanterman Act to services and supports funded by the state and federal government through regional centers. Decisions about services are supposed to be decided collaboratively by a team. In cases of disagreement, the individuals served are entitled to access a process called "fair hearing" at which an impartial administrative law judge is supposed to ensure that they have the ability to enforce their rights.

The term “unfair hearing” actually comes from parents of color who feel that the system is biased against them and their children. Parents are living day-to-day trying to support their children with I/DD and are not equipped to challenge the regional center in a one-sided process they don’t understand and is one-sided. Many self-advocates with I/DD feel like they are shut out of a system that is fighting against them when it is supposed to be fighting for them.

California’s Department of Developmental Services (DDS), the state agency that funds regional centers, has recognized this fundamental unfairness and opened the door to redesigning the fair hearing process. In June 2021, through their Home and Community-Based Services Spending Plan, DDS recommended a significant overhaul of the fair hearing process. DDS acknowledged that,

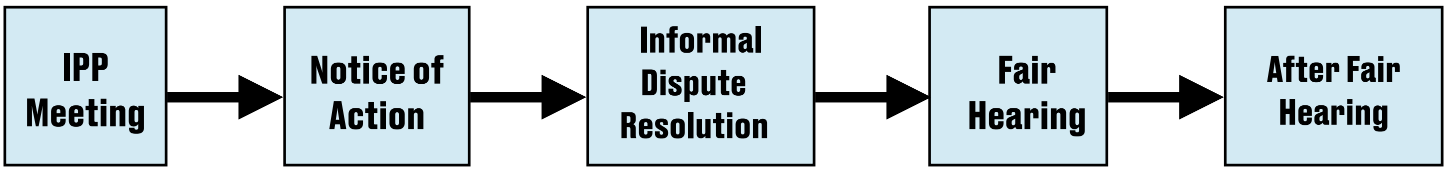
> *“the current fair hearing process/dispute resolution process is cumbersome, difficult to navigate, and intimidating for communities where questioning ‘authority’ is difficult or not acceptable. Families share that they believe they don’t feel they have enough representation as compared to the regional centers. For example, regional centers have highly educated staff defending their decisions and families in the lower socio-economic threshold don’t have the financial means to ‘fight the system.’ ”*

With the impetus from DDS, now is an opportune time to shine a light on these concerns and move forward with a significant overhaul of every level of the decision-making process. This report will explore how people with I/DD are being systematically denied access to justice – not just at fair hearings, but during every process where important decisions are made about their rights. Based on a comprehensive survey and follow-up interviews, we will describe these problems in detail, drawing on a variety of sources that include first-hand reports from survey participants. We also provide a set of specific policy and oversight recommendations that, if implemented at the state and regional center levels, would make the system much fairer and more accessible to the individuals it serves.

OVERVIEW OF THE IPP, INFORMAL DISPUTE RESOLUTION, AND FAIR HEARING PROCESSES

Individuals with intellectual and developmental disabilities (I/DD), and their family members typically interact with decision makers many times throughout their lives. Therefore, it is helpful to understand how the Lanterman Act and regulations lay out how decisions on services should be made, and how the system works if there is a disagreement.

The diagram below illustrates, in roughly chronological order, the stages when individuals with I/DD served by regional centers and their family members interact with key critical decision makers:



The IPP (Individual Program Plan) Meeting

The IPP meeting is the first stop a person with a developmental disability makes once they have been found eligible for regional center services and must occur within 60 days of the eligibility determination.[1] The IPP planning team is required to discuss the individual’s choices, preferences, goals and dreams, and then decide as a team which services and supports will best help the individual achieve them. Importantly, the IPP planning team is supposed to include not just the individual (or their representative) and the service coordinator, but also someone who is authorized to make decisions for the regional center, and any supporters that the individual chooses to bring to the meeting (such as friends, family, or other advocates). The meeting culminates in the drafting and signing of the IPP, an official document that reflects what was discussed and agreed to by the planning team. The IPP should list the agreed-upon services and supports that will help the person served achieve their goals and identify which entities (including the regional center) will provide and fund them. The IPP must be reviewed at least once every three years, however, people have the right to call an IPP meeting whenever they desire. The regional center is required to hold the meeting within 30 days of after a request is made, or seven days if necessary for the person’s health and safety or because the person is a risk of being placed outside of their home.[2]

Notice of Action

A regional center must provide a written Notice of Action when it makes a decision that can negatively affect an individual's right to receive services or supports, such as a denial of eligibility or a service.[3] Depending on the situation, the regional center has between 5 and 30 days to send the Notice of Action.[4] By law, the Notice of Action is supposed to state not only the decision the regional center has made, but also what documents the regional center used to make a decision, which laws authorize them to make that decision, and how those laws apply to the person's situation. The Notice of Action is also supposed to tell the person how, where, and when to file an appeal; how the appeals process works; how to prepare their case in preparation for an appeal; and where to get help with advocacy.[5] After receiving a Notice of Action, an individual generally has ten days to request an appeal in writing.[6] They must fill out a Fair Hearing Request Form, which asks why the fair hearing is being requested and whether they would like to participate in two forms of informal dispute resolution in an effort to resolve the dispute before the fair hearing: an *informal meeting* with the regional center; and/or *mediation* with a neutral, independent mediator who will try to help the parties reach an agreement.

Informal Dispute Resolution

Informal dispute resolution only occurs if the individual or their representative requests an informal meeting and/or mediation on the Fair Hearing Request Form. If a person requests an informal meeting, the regional center *must* find a date that works for them, send the person/representative written notice of that date, and ensure that the regional center's director (or someone who can act on the director's behalf) attends the meeting. However, the regional center has almost unlimited discretion about how they conduct an informal meeting. Afterwards, the regional center has five working days to issue a decision. In contrast, a mediation only occurs if the regional center *and* the person served agree to it. Mediators typically come from the same pool of administrative law judges at the Office of Administrative Hearings that conduct fair hearings. Even though the mediator is an administrative law judge, the mediator does not act as a judge during the mediation. The mediator's role is, instead, to give the parties an opportunity to discuss the dispute and try to reach an agreement that is acceptable to both sides. To help the parties reach an agreement, the mediator can facilitate a conversation about the facts, issues, reasons for the regional center's denial, and reasons for the appeal. However, a regional center does not have to provide any document before the mediation that explains its position. Finally, in order to allow for a free and open exchange of ideas, all discussions at mediation are supposed to be kept confidential and anything said cannot be used as evidence during a later hearing.

Fair Hearing

A fair hearing takes place before an administrative law judge (ALJ), also called a hearing officer, who is contracted with OAH. The fair hearing must take place within 50 days, unless the ALJ agrees, at the request at one of the parties, to schedule it at a later date. The regional center and person served are required to exchange evidence and witness lists five days prior to the hearing, and the individual has a right to ask for their records, which must be provided within three days. Although the hearing is supposed to be informal, many ALJ's use legal jargon, and the regional center is often represented by an attorney or experienced staff member who has attended many other hearings in the past. The ALJ must prepare a written decision no more than 10 working days after the hearing ends, and no more than 80 days after the date when the person served or their representative requested the hearing. The written decision must summarize the facts; indicate what evidence the ALJ used to make a decision; explain what decision was made on every issue or question; and identify the laws, regulations or policies that supported the decision.

After the Hearing

If the person or their representative disagrees with the decision made by the ALJ, they have 90 days to file a specialized legal document called a *writ of administrative mandamus* (sometimes also called a *mandate*) to superior court.[7] Filing this document gives them the opportunity to appeal (challenge) the ALJ's decision in superior court, typically with the help of a lawyer. If the superior court judge agrees with the individual, the judge can order DDS to set aside the decision of the ALJ and take other actions to help the individual get the services or supports they need. The regional center also has the right to appeal an ALJ decision to superior court, which likely requires them to hire a private attorney to represent them and use public funds for the expenses.

ACCESSING JUSTICE IN THE REGIONAL CENTER SYSTEM: WHAT WE LEARNED

To assess how well California's regional center system is ensuring access to justice, we gathered and carefully analyzed information from several different sources:

- *Public-facing websites* maintained by the Department of Developmental Services; the twenty-one regional centers that DDS funds and oversees; and the Office of Administrative Hearings, described in more detail below, which contracts with DDS to conduct fair hearings
- *Responses to an online survey* administered to 207 individuals across the state who applied for regional center services, or family members/guardians of individuals who applied for regional center services
- *Responses to telephone interviews with a subset of survey respondents* who chose to include their name and contact information on the survey form so that they could be interviewed by members of the research team
- *Legal insights and materials* from recent cases obtained from law-related websites
- *The experience of attorneys and advocates* from our respective organizations who assist or represent individuals with I/DD in IPP meetings, informal meetings, mediations, hearings, and appeals against regional centers. For example:

    - From July 1, 2020 to June 30, 2021, Disability Rights California's (DRC) Office of Clients' Rights Advocacy provided legal support or representation to over 5,000 individuals with I/DD or their authorized representatives in response to nearly 8,000 requests for help. Approximately 2,500 of these requests involved regional center services and supports. DRC also represents individuals with I/DD in state and federal court actions involving the I/DD service delivery system.

    - Disability Voices United (DVU) leads community meetings, trainings, and conferences for thousands of individuals with developmental disabilities and their families. DVU hears directly from the community about their experiences at IPP meetings and with the fair hearing system and provides trainings on the process in order to help people access needed services and supports. DVU staff have also served as expert witnesses at fair hearings on behalf of people with IDD.

    - The Integrated Community Collaborative (ICC) supports and educates self-advocates with developmental disabilities and families through their peer-to-peer *Integradoras* Program. The ICC has assisted hundreds of families with their IPPs and some in fair hearings and has witnessed first-hand how inaccessible the system is, particularly to Latinos*, other people of color, and immigrants who have been systemically underserved.

    - The Stanford Intellectual & Developmental Disabilities Law and Policy Project (SIDDLAPP) recently launched a student-led initiative at Stanford Law School called the Racial and Disability Justice Pro Bono Project (RAD Justice). Since the fall of 2020, law student participants in RAD Justice have attended IPPs, conducted live trainings, and created written materials for lay advocates in partnership with the ICC. They have carried out this work under the supervision of Louise Katz., Esq., who has over twenty years of experience helping families to access regional center services.

We used information from all of these sources to determine how well the system is providing access to justice. Throughout the investigation, we used the access-to-justice "yardsticks" described in the Appendix – accessibility, even-handedness, timeliness, adaptability, and equity – as theoretical guideposts to inform our analysis.

REGIONAL CENTERS RESPONSE TO REQUESTS: IPPs AND BEYOND

- More than 90% of all survey respondents reported at least one problem with the IPP process.
- More than two-thirds of all respondents said that no one who was authorized to make a decision on behalf of the regional center attended their IPP; instead, decisions were often made later on by personnel with whom the respondent had no contact.
- A least 85% of all respondents from 19 regional centers stated they had no idea what information they should bring to an IPP, were not invited or allowed to bring any supporters to the IPP, experienced delays in scheduling an IPP or getting the regional center to respond to a request for services, and were not treated with respect during an IPP.
- About 45% of all respondents from 16 regional centers complained that a Notice of Action they received after an IPP failed to explain *why* a service was denied, and/or did not enable them to make an informed decision about whether to request a fair hearing.
- Most of these problems were more frequently cited by Latino and/or non-white respondents.
- Overall, our findings revealed pervasive problems with the accessibility, even-handedness, timeliness, and equity of the manner in which regional centers respond to requests for services.

The single most frequently cited problem, cited by 68% of all survey respondents (140 respondents) from 19 regional centers, was that contrary to the requirements of state law,[8] ***no staff member who could make decisions on behalf of the regional center attended their IPP.*** Instead, the staff member who attended the IPP informed the person served that decisions would be made by a different staff member after the IPP meeting. Many survey respondents criticized this widespread practice. In the words of one, "The system is ridiculous. Apparently, the case worker has to go to a secret meeting where the parents/clients cannot attend."

"ALL DECISIONS ABOUT SERVICES SEEM TO BE MADE AFTER IPP MEETINGS BY SOME SECRET COMMITTEE OR A SUPERVISOR WHO DOESN'T KNOW THE CLIENT AT ALL, NOT THE PEOPLE IN THE IPP MEETING."

Many respondents complained about frequent delays in the regional centers' decision-making processes both before and after IPPs. For example, about 65% of respondents (from 19 regional centers) reported that: their regional center delayed scheduling their IPP; they experienced at least a one-month delay in the start date of an agreed-upon service because the regional center took so long to complete paperwork; and/or they waited for months for the regional center to make a decision on a service requested in the IPP. "It has taken months and months with still no services," one respondent explained. "We keep getting conflicting information on services even with a supervisor in attendance at meetings. . . . Seems like a lot of word games and waste of time with the sole purpose of denying or delaying services to those in need." In the words of another respondent, "[My RC] takes months to schedule an IPP or respond to a request and reply after an IPP is held . . . they predetermine what they are going to do and take months to let us know after an IPP." This "denial by delay" has been reported for many years by advocates.

Some respondents with limited English proficiency reported that translation services during IPPs were inadequate or nonexistent. A number of respondents who identified their primary language as Spanish added comments about inadequate translation services. For example, one Spanish-speaking respondent reported, "The Regional Center does not provide a translator for the meeting. The coordinator is the one that translates and does not translate what the other person says." Community-based organizations that work with non-English speaking families report similar concerns, stating that even when an interpreter is provided, they are often not certified and do not accurately provide interpretation for the person served and family.

Another frequent complaint — cited by 38% of respondents who provided input on notices of action — was that ***a Notice of Action they received informing them of a service denial did not clearly explain*** **why *the service was denied*.** Relatedly, 55% of those respondents (from 15 regional centers) reported that because the process was so difficult to understand, they reacted to the notice in a way that was poorly informed or driven by fear of confronting the regional center in an adversarial way. In the words of one respondent, "[I] was given the assessment and denial with very little information about appealing the decision." On one hand, 31% of the respondents who gave feedback on notices of action (from 15 regional centers) reportedly requested a fair hearing "because it seemed like the only way to get the services [they] wanted," even though they weren't sure what it was or what it would require or them. On the other hand, 29% of those respondents (from 13 regional centers) did *not* request a fair hearing because "it seemed too hard to try to go up against the Regional Center in front of a judge."

INFORMAL DISPUTE RESOLUTION PROCEDURES

- Overall, our findings call into question whether the informal dispute resolution mechanisms available under state law are serving their intended purpose of encouraging the swift and equitable resolution of disagreements between regional centers and person served.
- About 60% of all survey respondents from 18 regional centers experienced problems with the informal hearing and/or mediation process with many not understanding the goal of these processes or how they work.
- Without any access to legal representation, many individuals found it difficult or impossible to make use of these procedures. All of these problems were particularly acute among non-white and/or Latino survey respondents: 65% of non-white and/or Latino respondents reported problems with the informal hearing and/or mediation process, compared to 40% of white (non-Latino) respondents.
- Many respondents said that the lawyers representing regional centers did not make good-faith efforts to settle disputes. Some also questioned the impartiality of third parties involved in the mediations.
- Our survey responses bring to light pervasive problems with the accessibility, even-handedness, and equity of the informal dispute resolution mechanisms available under state law.

Many self-advocates and families cannot access informal dispute resolution mechanisms because they can't afford to hire attorneys to assist them. Of the 140 respondents who provided input on the informal dispute resolution process, 56%, from 15 regional centers, reported that they could not afford to hire a lawyer to help them at either an informal meeting or a mediation. "I have a hard time in organizing my evidences," said one respondent. Another explained, "I couldn't afford to pay a specialist to attend," and "I ran out of funds before the mediation."

A sizable number of informal hearings or mediations do not occur on a level playing field, because self-advocates and families do not understand how they work and/or have trouble obtaining critical documents necessary to support their claim. For example, 67% (from 17 regional centers) of the 140 respondents who shared experiences with the informal dispute resolution process, reported that they requested an informal meeting and/or mediation even though they did not understand who would be in charge of the meeting, what their rights were, or what they should do to prepare. In addition, 45% of these respondents (from 16 regional centers) reported that they had trouble preparing for a mediation and/or informal meeting because the regional center did not include the Interdisciplinary Team Notes in their file or refused to provide it upon request. "I got the feeling that my informal meeting was just perfunctory and they had already decided the answer was going to be "NO" before we started," noted one person served. Another said, "[The] [i]nformal meeting was a fishing expedition where I had to defend my position and offer evidence why I need the [service]. Regional center went to the meeting and didn't do anything." Yet another commented, "[T]hey bring [a]ttorneys who run the meeting for them, meet ahead of time and give scripted responses." And another parent reported, "There was a judge at mediation and he was on [the regional center's] side and boasted about how wonderful they were."

"I [GOT]THE FEELING THAT MY INFORMAL MEETING WAS JUST PERFUNCTORY AND THEY HAD ALREADY DECIDED THE ANSWER WAS GOING TO BE 'NO' BEFORE WE STARTED,"

The survey responses also highlight the advantages of giving people with I/DD the option of holding mediations or informal hearings by video conference rather than in person. On one hand, about 25 respondents from 12 regional centers could not bring someone they wanted to a mediation or informal meeting that was held in person because the regional center said they were not allowed, or it was too difficult for the supporter to attend. On the other hand, 30 respondents from 12 regional centers noted that someone they wanted to attend an informal meeting or mediation *could* attend because the proceeding was held by video conference.

TRANSPARENCY, FAIRNESS AND ACCESSIBILITY OF FAIR HEARINGS

- The two most commonly-cited problems—stated by the majority of all respondents who commented on the fair hearing process—were the inability to afford legal representation, and confusion about how the fair hearing process worked.
- A sizable proportion of respondents had trouble presenting their case effectively because key supporters could not attend, the regional center would not provide them with the Interdisciplinary Team Notes, and/or the judge seemed biased in the regional center's favor.
- All of these concerns were cited more often by Latino and/or nonwhite respondents: 40% of Latino and/or non-white respondents reported problems with the fair hearing process, compared to just 29% of white (non-Latino) respondents.
- Most fair hearing requests are withdrawn, and only 5% of requests for fair hearing result in a person with I/DD winning their case. Publicly-available data on the outcomes of fair hearings give rise to the concern that collectively, many of the barriers discussed in this report are impeding individuals' ability to make full use of the fair hearing process.
- About 37% of all respondents from 14 regional centers reported deficiencies in the accessibility, even-handedness and transparency of the fair hearing process

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Individuals' lack of knowledge about the fair hearing process, and their inability to hire lawyers to assist them, were the most commonly-cited barriers to justice in the fair hearing process. 50% of the 102 respondents who gave feedback about the fair hearing process (from 13 regional centers) reported that even after requesting a fair hearing they did not understand how it would work or what they should do to prepare. As one survey participant explained, "[The] Regional Center hired a law firm to represent them at Fair Hearing. It's unfair and a gross misuse of public funds against parents with no legal background to navigate a complex system for fair hearing. Parents essentially need to learn how to become a lawyer and paralegal." Another similarly observed, "When the regional center has a team of lawyers and you can't afford an advocate, it's not really a 'fair hearing.'" Another Spanish-speaking respondent noted that "[the regional center] has lawyers and a team of specialists at fair hearings who turn them into unfair hearings because my son is only represented by me, just a mom, against the whole team and a lawyer paid by [the regional center]."

> **"WHEN THE REGIONAL CENTER HAS A TEAM OF LAWYERS AND YOU CAN'T AFFORD AN ADVOCATE, IT'S NOT REALLY A 'FAIR HEARING.'"**

About one-third of respondents who completed the "fair hearing" section of the questionnaire reported that the judge at a fair hearing they attended was biased in the regional center's favor. Non-white and/or Latino respondents reported this experience more frequently. For example, 13% of non-white and/or Latino respondents felt that the judge was biased in the regional center's favor, compared to just 10% of white (non-Latino) respondents. Overall, 40% of Latino and/or non-white respondents reported problems with the fair hearing process, compared to just 29% of white (non-Latino) respondents. One parent interviewed told us, "I felt I had no voice there. There was so much intimidation."

Some respondents with limited English proficiency reported that translation services during fair hearings were inadequate or nonexistent. For example, one Spanish-speaking respondent reported, "At a [fair] hearing I could not effectively advocate for my son's services because [it] turned out that the judge spoke very fast, and interpreter could not translate everything the judge said, so he could not understand anything that was happening....I left without understanding anything that was happening at the fair hearing." Another Spanish-speaking respondent similarly complained, "My child's fair hearing lasted three days. The translation was very bad in two days. People were not certified translators. This is very serious!!" This concern was not limited to Spanish speakers; a participant whose primary language was Vietnamese similarly reported, "I request an interpreter, but [the regional center] denied....I do not understand ABA report. I ask RCOC give me document in Vietnamese. But...[the regional center] never give me IPP and other document in my native language....Nobody help me in the hearing. I do not speak and understand English....My son have 2 months until the hearing date, but [the regional center] never give Vietnamese document for the hearing...."

"AT A [FAIR] HEARING I COULD NOT EFFECTIVELY ADVOCATE FOR MY SON'S SERVICES BECAUSE [IT] TURNED OUT THAT THE JUDGE SPOKE VERY FAST, AND INTERPRETER COULD NOT TRANSLATE EVERYTHING THE JUDGE SAID."

The research team's investigation of online sources, as well as the results of Public Records Act requests, brought to light the following additional concerns:

Most fair hearing requests are withdrawn, and only 5% of requests for fair hearing result in a person with I/DD winning their case. This underscores concerns about the accessibility and even-handedness of the fair hearing process. Publicly-available data on the outcomes of fair hearings give rise to the concern that collectively, many of the barriers discussed in this report are impeding individuals' ability to make full use of the fair hearing process. As shown in the table below, only about 5% of those who file for fair hearing are awarded at least some of the support they were seeking by an administrative law judge. Perhaps even more concerning, about 72% of all requests for fair hearing are withdrawn. DDS and OAH do not ask the person served why they are withdrawing their fair hearing request, but the surveys and our experience suggest that the fair hearing process is so inaccessible and intimidating that many individuals end up withdrawing their claims regardless of the merits of their case. As one survey respondent explained, "I went to the first [hearing] on [the] phone, which was so anxiety-inducing I lost countless sleep and had to withdraw my case before I could even make my argument."

PEOPLE WITH DISABILITIES WON ONLY 17.5% OF CASES THAT WENT BEFORE AN ADMINISTRATIVE LAW JUDGE. REGIONAL CENTERS PREVAILED IN 45% OF CASES AND ANOTHER 19% WERE DISMISSED BY THE JUDGE.

Fair Hearing Outcomes: January 1, 2018-August 25, 2021

OUTCOMES	# OF CASES	% OF CASES
All Outcomes	3733	100%
Withdrawn	2671	71.55%
Denied	477	12.78%
Dismissed	201	5.38%
Pending	198	5.30%
Granted	126	3.38%
Split	60	1.61%

One-fifth of all fair hearing decisions issued since 2018 are unavailable to the public, impeding the ability of individuals with I/DD or their family members to prepare for fair hearings by analyzing judges' decisions and reasoning in prior cases. DDS is statutorily required to make redacted copies of all fair hearing decisions available to the public upon request.[9] Because DDS contracts with OAH[10] to conduct fair hearings on its behalf, it relies on the office to post redacted copies of fair hearing decisions on its public-facing website. Yet only 78.9% of the fair hearings contained in an ostensibly comprehensive list provided by DDS had written decisions that were available online. As one attorney who specialized in the regional center system noted, "To make a successful legal argument, you need to find past cases with facts and legal issues that are as close to your own situation as possible. When a chunk of fair hearing decisions is missing or unavailable, it's even more challenging to figure out or predict how ALJs may view your specific type of case or fact pattern. And if this is hard for attorneys, it's probably overwhelming for people without legal representation."

> **"WHEN A CHUNK OF FAIR HEARING DECISIONS ARE MISSING OR UNAVAILABLE, IT'S EVEN MORE CHALLENGING TO PREDICT HOW ALJS MAY VIEW YOUR SPECIFIC TYPE OF CASE. AND IF THIS IS HARD FOR ATTORNEYS, IT'S PROBABLY OVERWHELMING FOR PEOPLE WITHOUT LEGAL REPRESENTATION."**

There are also significant concerns about the scope of fair hearings. ***Some individuals with I/DD have been deprived of a civil remedy for harms that fall beyond the scope of issues administrative law judges are qualified to resolve.*** Individuals with I/DD served by regional centers are unfairly deprived of their civil rights because of over-broad interpretations of a legal process called "administrative exhaustion." In a recent case, a regional center person served nearly died after her service provider starved and abused her. Her attorneys filed suit in federal court alleging civil rights and tort violations against three defendants: DDS, the regional center, and the provider. However, the defendants argued, and the judge agreed, that the Lanterman Act requires any and all possible claims involving regional center services to be decided through the fair hearing process. As a result, the judge dismissed the case with no ability for the person served to re-plead her case. This makes no sense in light of the purpose of the Lanterman Act, which provides a fair hearing process for disputes over eligibility for, the need for, or the adequacy of regional center services. Fair hearings were never designed to be forums for hearing civil rights or other legal claims that happen to involve regional center services or service providers. Under this decision, people with I/DD are denied access to justice, as they literally cannot have their "day in court" with regard to civil rights and other legal violations, meaning no ability to get payment of money to make up for a loss or to get the court to require that something specific is done, stopped, or prevented.

> **FAIR HEARING WAS NEVER DESIGNED TO BE A FORUM FOR HEARING CIVIL RIGHTS OR OTHER LEGAL CLAIMS THAT HAPPEN TO INVOLVE REGIONAL CENTER SERVICES OR SERVICE PROVIDERS.**

AFTERMATH AND APPEALS OF FAIR HEARINGS

- 46 survey respondents, from 12 regional centers, reported deficiencies in the accessibility, even-handedness, and adaptability of the conditions they faced after a fair hearing.
- Many respondents who lost fair hearings reported that they could not afford to appeal the adverse decision while the regional centers could use government funds to hire attorneys.
- Some respondents who lost fair hearings also reported that the regional center unjustly denied them the opportunity to bring a similar claim at a later date, even when their circumstances changed or new evidence came to light.
- The few respondents who reported winning fair hearings or settled their cases felt it was unjust that the regional center provided nothing to compensate them for the denial of the services previously.
- Other victorious respondents reported that their regional center refused to comply with the terms of a settlement agreement or court order, but there was no clear pathway to ensure that the terms were enforced.

If a person with I/DD won a fair hearing, the regional center did not have to give them anything extra to make up for when their rights were denied. Of the 72 survey respondents who provided input about after a fair hearing, 40% (29 respondents from 11 regional centers), who won their fair hearings, felt it was unfair that the regional center did not have to provide any compensation for the months (or years) when the individual was denied the services they deserved. Importantly, the absence of any compensatory services (or damages) for past rights violations provides regional centers with no incentives to resolve disputes in a timely way. Therefore, it can pave the way for "denial by delay," a major barrier to an equitable system.

Some respondents reported that even after they reached a settlement or prevailed at a fair hearing, they still did not receive the services they needed because the regional center refused to comply with the judge's order or the terms of the settlement agreement. Although the survey instrument did not explicitly ask respondents whether their regional center complied with a favorable fair hearing decision, a number of respondents volunteered that their regional center failed to follow the judge's order. For example, one participant noted, "After I won the fair hearing, where [regional center] had a lawyer and I did NOT, RC did not give me the service and I needed a lawyer to make that happen." Noted another survey participant, "After the fair hearing, the regional center completely ignored the judge's ruling in our favor. So I had to submit a Section 4731 complaint [to DDS] requesting the RC to comply. . . DDS ended up sending a letter to me saying that they don't get involved with matters adjudicated through the fair hearing process." Yet another respondent reported, "There is no way to enforce the settlement."

> **"AFTER THE FAIR HEARING, THE REGIONAL CENTER COMPLETELY IGNORED THE JUDGE'S RULING IN OUR FAVOR. SO I HAD TO SUBMIT A 4731 COMPLAINT ... DDS [...SAID] THAT THEY DON'T GET INVOLVED WITH MATTERS ADJUDICATED THROUGH THE FAIR HEARING PROCESS."**

People with I/DD who lost fair hearings could not afford to pay lawyers to appeal their decisions, yet regional centers use public monies to hire attorneys. Of the 72 survey respondents who shared experiences about the aftermath of a fair hearing, 42% (30 respondents from 11 regional centers), who lost fair hearings, reported that although they disagreed with the decision of the administrative law judge, they could not afford to pay a lawyer to mount an appeal. As one Spanish-speaking respondent explained, "I would have loved to appeal but I didn't know any pro bono lawyers who could help me."

> **"I WOULD HAVE LOVED TO APPEAL BUT I DIDN'T KNOW ANY PRO BONO LAWYERS WHO COULD HELP ME."**

Some people with I/DD who lose fair hearings reportedly are denied the opportunity to enforce their rights at a later time. About 10% of respondents (18 respondents from 10 regional centers) who lost fair hearings reported that they were denied the opportunity to make a similar request at a later time, even if new information came to light or their circumstances changed. This practice not only violates state law, but also undermines access to justice by preventing the fair hearing system from adapting to changes in individuals' and families' life circumstances.

OVERSIGHT OF THE FAIR HEARING PROCESS

- **Significantly, there is little oversight over the fair hearing process.** The fact that no independent entity exists with the authority to investigate problems and remedy harms may help to explain the absence of meaningful oversight and accountability.
- DDS has failed to comply with its statutory duties to annually train administrative law judges on the Lanterman Act and recent changes to the law.
- DDS and OAH have neglected to make all fair hearing decisions publicly available.
- Individuals served by the system have not been given a meaningful opportunity to provide feedback on the shortfalls of the fair hearing system.

Although DDS is statutorily required to provide annual training on developments to the Lanterman Act for fair hearing judges, records indicate that no such training occurred for at least six years between 2014 and 2020. Moreover, these trainings are developed and provided exclusively by DDS, with no meaningful input from self-advocates, families, or disability rights advocates. As a result, people with disabilities and their families feel that ALJs do not "get" the substantive issues and systemic barriers that they face. Self-advocates and families report feeling that ALJs are not adequately familiar with the Lanterman Act and more specialized services available under it. There have been significant changes to the Lanterman Act in recent years, including the enactment of the Self-Determination Program and many changes in the recent 2021-22 fiscal year budget. Yet many individuals with I/DD, families, and advocates report that ALJs seem unaware and even perplexed by the changes in the law.

PEOPLE WITH DISABILITIES AND THEIR FAMILIES FEEL THAT JUDGES DO NOT "GET" THE SUBSTANTIVE ISSUES AND SYSTEMIC BARRIERS THAT THEY FACE.

ALJs seem unaware of the significant racial and ethnic disparities that exist in the developmental disabilities system and they are perceived as racially biased by some of our respondents. There is no requirement for ALJs to receive training about the systemic ethnic disparities in Purchase of Service expenditures that have persisted in the regional center system for at least ten years. And while all regional center staff must now undergo implicit bias training, there is no such requirement for ALJs. Additionally, the responsibility for providing annual ALJ training is delegated entirely to DDS, with minimal opportunities for self-advocates, their representatives, organizations run by them, and disability advocacy groups to be "consulted" and no ability to have meaningful input into training content. The one-sided nature of who gets to train ALJs contributes to perceived, and potentially actual, bias in how the law is interpreted and how cases are ultimately decided.

The fact that over 20% of all fair hearing decisions issued since 2018 are unavailable, despite a statute that requires all opinions to be provided to the public, further illustrates the magnitude of oversight deficiencies. The Department of Developmental Services (DDS) is required to make redacted copies of all fair hearing decisions available to the public upon request.[11] Yet despite this requirement, only 78.9% of the fair hearings contained in an ostensibly comprehensive list provided by DDS had written decisions that were available online. Moreover, 13 fair hearing decisions that do *not* appear in a list obtained directly from DDS are available on the OAH website.

No independent office exists that can solicit feedback from a person served and families to identify and correct problems with the fair hearing process. As our survey results indicate, neither OAH nor DDS plays any direct role in enforcing settlement agreements or fair hearing decisions. Since there is no other state entity charged with investigating problems with the fair hearing process, some individuals who receive services from regional centers may have a right without a remedy, that is, a legal entitlement that they have no practical capacity to enforce. In practice, therefore, people served and family members have no formal way to offer input or recommendations on how to improve fair hearing procedures.

PEOPLE WITH DISABILITIES AND FAMILY MEMBERS HAVE NO FORMAL WAY TO OFFER INPUT OR RECOMMENDATIONS ON HOW TO IMPROVE FAIR HEARING PROCEDURES.

IMPROVING ACCESS TO JUSTICE: OUR RECOMMENDATIONS

The barriers and inequities built into the current hearing process have left too many people with I/DD and their families, particularly in the Latino community, feeling intimidated and powerless when they disagree with their regional center. To address these issues, the Governor, DDS Director, and legislature should consider significant changes to the ways the fair hearing process, as well as the key components of the IPP and post-hearing processes, are structured and operated.

Our major recommendations are laid out in the chart in the Executive Summary, beginning on page 4 in this report, which compares, side-by side, the features of the current system to our proposed reforms and to understand the impact these changes would have on people with developmental disabilities, the regional centers, DDS, and other agencies.

One of our important recommendations involves moving the fair hearing process from the Office of Administrative Hearings (OAH) to the Department of Social Services (DSS). The DSS fair hearing process, which is used for many other systems, including IHSS and CalFresh, is seen by many advocates as more accessible and less formal. While the DSS process also uses administrative law judges and has some other similarities to OAH, it differs in ways that we believe will do much to level the playing field.

Our other recommendations are also critically important to improve access to justice for individuals with I/DD. The current system provides very few safeguards to enable individuals served by regional centers to protect their rights. Many of our other proposed reforms are designed to correct this problem by improving the ability of individuals with I/DD to obtain the services they are entitled to under state and federal law.

We believe that our recommendations would help to mitigate longstanding racial/ethnic disparities in the regional center system. Our research highlighted that people of color are disproportionately shut out of the system and denied access to justice. Our proposed reforms would help address this problem, so that *all* Californians with I/DD, including those from underserved communities, would have a greater ability to enforce their rights

California has a historic opportunity to reimagine the way the system works for those who have historically felt the least empowered in it. As DDS has recently acknowledged, people with I/DD and their families, “especially in the Latinx community, have shared they don’t believe there is a ‘safe’ place for them to go to assist with conflicts with regional centers.”

People with I/DD deserve a “safe” process for resolving conflicts with their regional centers-- one that is free of bias and where the balance of power is less skewed; where people have a meaningful voice in the decisions that affect their lives; where informal dispute resolution is incentivized over adversarial quasi-judicial proceedings; where the system feels open and helpful to people who represent themselves; and where people feel treated with dignity and respect. The recommendations in this paper point to ways California’s developmental disabilities system can better reflect those values and can build both trust and capacity. **The state must see access to justice as essential to achieving equity. We urge the state to make this commitment now.**

APPENDIX

MEASURING ACCESS TO JUSTICE: GUIDING PRINCIPLES

What *are* the procedural safeguards necessary to ensure a just system, particularly for communities that have been historically underserved? How do we determine whether a particular program is distributing resources in a way that is unbiased and equitable?

Even though government support programs can take many different forms and serve many different populations, five common-sense criteria can be used to evaluate whether they are providing resources or accommodations in a way that will be widely accepted as fair. These criteria, which have been used by experts to evaluate fairness across many different fields, include the following:

Accessibility: An accessible system promotes full participation by the population it serves. Transparency is critical to accessibility because individuals cannot successfully navigate a system that they do not understand. For example, those seeking support must know what is required to prove eligibility, or how to persuade program administrators of their need for a particular service or accommodation. But transparency alone is not enough; the people who need support must also be present, and have an opportunity to be heard, whenever important decisions are made about their lives. They must be in the room when program personnel determine eligibility or consider which types of services to provide.[12]

Even-handedness: An even-handed system is one that creates a level playing field. If a person disagrees with a decision made by the program's administrators, they must be given a full opportunity to make their case in front of a knowledgeable third party who is not biased in favor of either side and treats the person with respect. The neutral third party can either help the parties reach an agreement on their own or take on the role of a judge in deciding how to resolve the dispute.[13]

Timeliness: For many people seeking support, time is of the essence. They are often in urgent need of the goods, services, accommodations, or financial assistance they are seeking. They or their loved ones may be in imminent danger of losing their home, health, or livelihood. If the process of proving eligibility and of obtaining services is slow and unpredictable, people's health and security—or that of their family members—may be jeopardized. A *timely* entitlement system is one in which key decisions about eligibility or services are made within a relatively short, predictable time frame.[14]

Adaptability: Most individuals find that their ability to provide for themselves and their families is not fixed but changes — sometimes dramatically — across the life cycle. For example, a full-time worker who loses her job may struggle for the first time to make ends meet; a healthy adult who suffers a traumatic brain injury may suddenly find himself buried in medical bills; and a parent who has always provided around-the-clock care to a child with a disability may develop a serious illness that prevents them from fulfilling these duties. An adaptable system is one that accounts for these realities and can adjust the amount and type of assistance available to each person in response to changes in their life circumstances.[15]

Equity: In theory, programs should provide support on an equal basis to *all* individuals who qualify for assistance, regardless of their race/ethnicity or other demographic characteristics. In practice, however, it may be more difficult for individuals who live in poverty, belong to underserved racial/ethnic groups, or have limited English language proficiency to obtain the services they need. These individuals may find it more difficult to understand how the system works, may face higher levels of discrimination, may have cultural barriers to "fighting the system," or may be unable to afford to hire an attorney (or other advocate) to help them collect the necessary evidence to build their case. A system with equity is a system that delivers services in a way that does not magnify disparities.[16]

These five criteria — which have been used to analyze the fairness of many government programs that help individuals in need — are equally applicable to the system that provides services and supports to California residents with I/DD. Throughout this report, we use them as yardsticks to evaluate whether California's regional center system is providing access to justice to *all* individuals with I/DD by helping them enforce their rights when they turn to their regional centers for the services or supports.

ENDNOTES

[1] § 4646(c).

[2] § 4646.5(b).

[3] See §§ 4710(a)(2), 4710(b), 4710(a)(1), 4710(c). Under § 4646(g), regional centers must also provide a Notice of Action when people or their representatives indicate in writing that they do not agree with all components of the IPP.

[4] See §§ 4710(b), 4710(a)(1).

[5] DRC Manual, Chapter 12.

[6] § 4715.

[7] § 4712.5(a).

[8] Lanterman Act § 4646(d).

[9] Welf. & Inst. § 4712.5(d) (Deering, LEXIS through 2019 Sess.).

[10] Welf. & Inst. Code §§ 4712.5(d), 4714(b) (LEXIS).

[11] Welf. & Inst. § 4712.5(d) (Deering, LEXIS through 2019 Sess.).

[12] *See, e.g.*, Vicki Lens, *In the Fair Hearing Room: Resistance and Confrontation in the Welfare Bureaucracy*, 32 Law & Soc. Inquiry 309, (2008) (discussing this principle in the context of welfare in New York); Elizabeth Slagle Todaro, *Access to Justice in the Time of COVID-19*, 57 Tenn. B.J. 20 (2021) (discussing this principle in the context of public benefits for people with disabilities in Tennessee); Robert P. Capistrano, *Making the Fair Hearing More Fair*, 44 Clearinghouse Rev. 96 (2010-2011) (discussing this principle in the context of procedures to address due process barriers in public benefits programs).

[13] *See, e.g.*, Kristin L. Sayeski & Perry A. Zirkel, *Orton-Gillingham and the IDEA: Analysis of the Frequency and Outcomes of Case Law*, Annals of Dyslexia 1 (2021) (discussing this principle in the context of the Individuals with Disabilities Education Act); Anna E. Carpenter, *Active Judging and Access to Justice*, 93 Notre Dame L. Rev. 62 (2017) (discussing this principle in the context of improving judging practices to mitigate access to justice disparities); Robert P. Capistrano, *Making the Fair Hearing More Fair*, 44 Clearinghouse Rev. 96 (2010-2011) (discussing this principle in the context of procedures to address due process barriers in public benefits programs); Vicki Lens, *In the Fair Hearing Room: Resistance and Confrontation in the Welfare Bureaucracy*, 32 Law & Soc. Inquiry 309, (2008) (discussing this principle in the context of welfare in New York).

[14] *See, e.g.*, Robert P. Capistrano, *Making the Fair Hearing More Fair*, 44 Clearinghouse Rev. 96 (2010-2011) (discussing this principle in the context of procedures to address due process barriers in public benefits programs across the United States); Jorrit de Jong & Gowher Rizvi, The State of Access: Success and Failure of Democracies to Create Equal Opportunities: Innovative Governance in the 21st Century (2008) (discussing this principle in the context of public benefits programs across the United States).

[15] *See, e.g.*, Van Scoy *ex rel.* Van Scoy v. San Luis Coastal Unified Sch. Dist., 353 F. Supp. 2d 1083 (C.D. Cal. 2005) (discussing this principle in the context of the Individuals with Disabilities Education Act); C.Q. v. River Springs Charter Sch., No. EDCV1801017SJOSHKX, 2018 WL 5936665 (C.D. Cal. May 18, 2018), *aff'd sub nom*. C. Q. by & through Quezada v. River Springs Charter Sch., 771 F. App'x 788 (9th Cir. 2019) (discussing this principle in the context of the Individuals with Disabilities Education Act).

[16] See, e.g., Teal W. Benevides et al., Racial and Ethnic Disparities in Benefits Eligibility and Spending among Adults on the Autism Spectrum: A Cohort Study using the Medicare Medicaid Linked Enrollees Analytic Data Source, 16 PLoS ONE e0251353 (discussing this principle through empirical analysis in the context of Medicaid); Elizabeth Slagle Todaro, Access to Justice in the Time of COVID-19, 57 Tenn. B.J. 20 (2021) (discussing this principle in the context of public benefits for people with disabilities in Tennessee); Elena R. Platonova et al., Latinos' Satisfaction with Free Clinic Providers: An Analysis of Patient-Centered Medical Home Characteristics, 41 J Community Health 1290 (2016) (discussing this principle in the context of Spanish-speaking Medicaid beneficiaries); Rebecca L. Sandefur, Bridging the Gap: Rethinking Outreach for Greater Access to Justice, 37 U. Ark. Little Rock L. Rev. 721 (2015) (discussing this principle in the context of socioeconomic factors resulting in the access gap in legal assistance in the United States).