Power and Influence in the California IDD Community

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**Introduction**

 Power and influence are well documented and complex forces where one entity acts upon another, often with resistance, to make a change (Cartwright, 1959). In this analysis, I will use power and influence as a lens to examine several different stakeholder groups within the intellectually and developmentally disabled (IDD) community to better observe their power and influence within the larger bureaucratic system of IDD services in California. My aim with this analysis and corresponding power mapping tool is to examine six large stakeholder groups within the IDD system and explore how each uses different types of power to effect change within the IDD bureaucracy in California. Each type of power works specifically because of the parties involved and their relationship with one another. This analysis will allow readers to better identify influential stakeholder groups and explore how they wield power and influence to effect IDD policy in California.

 This paper first provides background information on what IDD is and what the IDD system looks like today as well as a brief history of the IDD system. Then, I will introduce the basics of power and influence theories according to French and Raven (1959). Following the background section, I will cover the importance of studying power in this context because of the diffuse power structure in the IDD community. Next, I will analyze the six stakeholder categories, applying sources of power concepts summarized by Elias (2008). Lastly, I will conclude by connecting these power concepts back to the original stakeholder (people with IDD) and making suggestions for the most effective use of power as supported by the research. The final appendix is an interactive power map showing the IDD stakeholders and the various levers for change available to each based on sources of power they are most able to access and apply.

**What is an Intellectual or Developmental Disability?**

 Intellectual and Developmental Disabilities are categorized together for the purpose of providing services to a group of Californians, but are separate categories. To examine how IDD power and influence work in California we will focus on the criteria for Regional Center services which are the way people with IDD receive services in California. There are a few key diagnoses to keep in mind, but this is not all-encompassing. Intellectual disability, Cerebral Palsy, Epilepsy, and Autism Spectrum Disorder are the four primary diagnoses, but included in California’s definition of IDD are a “fifth category” of disability and includes all diagnoses which closely mimic the symptoms and treatment of those with Intellectual disability (DDS, 2021). Often, this fifth category contains genetic disorders, traumatic brain injuries, significant learning challenges, and other disorders (Disability Rights California, 2016). In addition to having a diagnosis that fits into the IDD category, someone must also have substantial disability in three of the following areas: Communication (receptive and expressive), learning, self-care, mobility, self-direction, independent living skills, and economic self-sufficiency (DDS, 2021). Both the diagnosis and substantial disability must be significant enough to be considered lifelong conditions and are subject to reevaluation if the individual’s condition improves. The last qualification is that the diagnosis of the individual and their substantial disability must have occurred prior to the age of 18 (DDS, 2021).

**Who are People with IDD?**

People with IDD are children and adults, parents and grandparents, famous movie stars, and grocery store clerks. IDD is calculated at about 1.3% of the population (Anderson, Larson, MapleLentz, & Hall-Lande, 2019) and can be seen everywhere. However, some of the struggles of people with IDD are less obvious, but more acute than their demographic constitution. Employers still hire IDD candidates 10 times less often than those with no disabilities (BLS, 2021). People with IDD are seven times more likely to be victims of rape and sexual assault than their non-disabled peers (Shapiro, 2018). The institutionalization of people with IDD ended only recently in 2018. People with IDD in California are on the path of beginning full community integration, but there is still a long way to go. In order for people with IDD and their advocates to continue building a culture of dignity and respect within California, it is important to understand what mechanisms are available to make a change as well as what sources of power and influence exist to push California towards a more equitable future.

**A Brief History of IDD**

In 1966, California established the first regional centers in southern California with the purpose of caring for those with IDD in a community setting as opposed to institutional care at developmental centers (DCs) which was the norm at the time. This legislative change, known as the Lanterman Act, was the start of the inclusion of people with IDD in community life in California (DDS, 2021). The Lanterman Act created the IDD bureaucracy and, once it was legislated into existence, many new institutionalized sources of power and influence dynamics emerged. Today, the laws which directly relate to the IDD entitlement program are found in the California Welfare and Institution Codes (W&I) (California Legislative Information, 2021). These codes are a source of *legitimate* power (French & Raven, 1959), one of six different types of power used by IDD stakeholders which will be outlined in greater detail in the following sections.

**Definitions of Power and Influence**

In 1959, French and Raven wrote what they believed to be the five taxonomies of power (later expanded to six) which continue to be a fundamental way of understanding the subtleties of power and influence within any organization (Elias, 2008). The IDD system is an excellent context for exploring how many of these power dynamics are enacted at work. First, it is important to understand how French and Raven define sources of power. The six types of power are:

* *Reward* – When the powerholder promises some sort of compensation in exchange for compliance.
* *Coercive* – When the powerholder threatens punishment to gain compliance.
* *Legitimate* – When the powerholder has a justifiable right to request compliance.
* *Expert* – When the powerholder relies on their superior knowledge to gain compliance.
* *Referent* – When the powerholder uses a mutual identity to gain compliance.
* *Informational* – When the powerholder has access to information that can be shared/withheld to gain compliance. (Elias, 2008)

As noted earlier, power is complex. Large state agencies may use many combinations of power to accomplish several different tasks in ways that vary according to whom they are acting upon.

It is also important to note that power is complex to categorize because of interaction effects. For example, any of the six categories put forth by French and Raven (1959) can be manipulated by *personal power* where an individual is very charismatic or beautiful. This source of individual power makes requests seem more like asking a personal favor rather than commanding legitimate compliance. The dynamics of interactive power are especially important to consider relative to IDD because of how the special circumstances of individuals in the IDD community change the power dynamics around them.

**Why Examine Power and Influence Structures in IDD?**

Large bureaucratic systems, like the IDD programs in California, are complex and change is often measured in decades due to the sheer size of the administration and the tricky nature of any entitlement program reform. However, this slow pace of change may also result from the fact that the IDD population—presumably key changemakers within the system—have disabilities that inhibit many forms of self-advocacy other groups have free access to. We can use the framework introduced by French and Raven (1959) to consider how the IDD population may lack access to frequently applied sources of power. For example, reward power is difficult for most people with IDD to wield because traditional rewards (money) are a scarce resource for a group who predominately rely on Supplemental Security Income (SSI) as a primary source of income. Without assets (SSI recipients are limited at total assets of $2,000), activities like lobbying or media promotion are prohibitively expensive. Coercive power is also unlikely to be tapped because many with IDD are seen as non-credible. An example of this is court proceedings on competency where IQ and other factors take away someone’s ability to be credible. Expert power is another difficult source for IDD populations to tap because people with IDD rarely go on to get law degrees or medical doctorates which are fields that serve as a basis for many legitimate sources of power. The six power structures put forth by French and Raven (1959) are a useful framework to help understand that being IDD involves some difficulties that most of society can ignore.

Despite the many barriers outlined above, this significant disadvantage in personal power and influence has given rise to strong support systems within California for the advocacy of those with IDD. Below I will introduce six different IDD stakeholders and examine the types of power they access and apply inside the IDD bureaucracy.

**IDD Stakeholders**

 There are six primary groups I address in relation to their power and influence within the California IDD system. These are:

**Power and Influence Stakeholder Groups in the IDD Community in California**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Section 1 | Section 2 | Section 3 | Section 4 | Section 5 | Section 6 |
| Individuals with IDD & their Families  | Regional Centers  | Lobby Firms | State Agencies | Legal Bodies | Others |
|  | Service Coordinators | The ARC | DDS | CA Legislature | Private Health Insurance |
|  |  | The Lanterman Coalition | SCDD | W&I Codes | Public School System |
|  |  | ARCA |  | Administrative Judges | County Mental Health |
|  |  | Disability Rights of CA |  | Lanterman Act |  |

**Section 1: Power and Influence Held by People with IDD and their Families**

People with IDD are entitled to services in California designed to meet their unique needs for community living and integration into all parts of daily life. Regional center (RC) services are the places these services come from. In California, the Department of Developmental Services (DDS) contracts with 21 RCs to coordinate these services for clients and their families. These clients of the RC are the grassroots of the power structure in the IDD ecosystem. These self-advocates are collectively the single largest group (~330,000 people) of advocates in California and the efforts of these individuals and their families have built the IDD system in California as we know it today.

 Consumers, as defined in the W&I code language, are people with IDD who, through the Lanterman Act, are entitled to special treatment in California. The Act and corresponding W&I codes give people with IDD specific rights to advocate for themselves and protection against unfair treatment. In addition, these laws create other agencies designed to foster the fair treatment and inclusion of those with IDD into the greater community.

 The next section will cover three forms of power frequently applied by people with IDD and their families. The first is self-advocacy which does not fit neatly into one category of power, but will be described below. The other two ways in which people with IDD can advocate for themselves using legitimate (legal) sources of power are the fair hearing process (via a Notice of Action (NOA)) and formal complaint process to the state (known as a 4731 complaint).

***Self-Advocacy***

The primary way people with IDD are able to make a change on their own behalf is through self-advocacy. This relies on the personal power of the individual to navigate the IDD system and find ways to amplify their voice amongst the competing agendas of others. This type of power is accessed in every way French and Raven (1959) describe, but I will outline just a few examples. A client might directly ask a congressman for more services and threaten to vote for a different candidate (coercion). A client might hire a lawyer to interpret the laws differently to gain access to new services (legitimate/expert). A client could pay privately to get exactly what they need and circumvent the RC system entirely (reward). However, self-advocacy is most powerful through the use of legitimate power built into the W&I codes. These codes give multiple avenues to create change and below are two examples.

***Administrative Court Hearing via Notice of Action (NOA)***

 To understand fair hearings, it is important to first note that RCs are obligated to provide services to their clients as it relates to their disability for the specific purpose of providing the same opportunities and supports for independence and inclusion all those without disabilities have fair access to (California Legislative Information, 1997). A fair hearing is meant to address a circumstance where a service or support is being denied to an individual and the individual or their family believes strongly that the requested service or support is justified under W&I codes. Decisions made by the administrative court judge are individual and do not set an official precedent, however, they do open the doors for other clients to take similar successful action in the future. In addition, administrative court proceedings are attended by lawyers of the RC, and sometimes family, so this effort is costly on both sides.

***4731 Complaint Process***

The 4731 complaint is a legitimate coercive source of power which refers to the W&I code 4731 allowing for a client-driven grievance procedure overseen by DDS and responded to by the director of a RC (California Legislative Information, 2021). When clients are experiencing unreconcilable difficulties, working with the RC via the 4731 is a way to get the next level of authority involved. Each RC is under contract with DDS to provide services and so DDS is ultimately responsible for their behavior. The 4731s are individually tracked and addressed by DDS with the RC and initiate a process of review for the individual complaint. These complaints are rare and cause a direct response from the executive director of the RC as to how the problem is being addressed. The number and nature of 4731 complaints are also a part of the contract review process that DDS goes through with RCs. This makes the 4731 a powerful tool for clients to effect change at their RC.

**Section 2: Power and Influence Held by Regional Centers**

There are 21 RCs in California that operate across county/city lines to serve large swaths of California. The Alta California RC headquartered in Sacramento, for example, serves clients in 10 different counties and dozens of cities. This area is called a catchment area. Each RC is a private nonprofit solely contracted with the state of California to provide services to people with IDD. As such, each contract is unique, and services offered by each RC are different. This lack of uniformity emphasizes the regional differences in California and allows the RCs to tailor services to best fit their catchment area.

***Unmet Needs***

RCs use their power and influence in a number of ways, three of which are their obligation to report unmet needs to DDS, participation in the Association of Regional Center Agencies (ARCA), and through the delivery of services via Service Coordinators (SCs) who are employees of the RC.

 The unmet needs which are submitted to DDS are statistics that represent the changes and trends within the system of client needs that are going unnoticed. An example would be dental services. The more clients who go without dental services, the larger these statistics become and DDS has more pressure to address this lack of services by increasing rates, hiring more dentists, forming new partnerships, etc. Another lever pulled by RCs is the volume at which they present these unmet needs. It can be as quiet as a spreadsheet, or the data can come with letters from client rights advocates and their attorneys. This presentation of *informational power* (French & Raven, 1959) by the RC puts more pressure on DDS to act in the suggested manner. It could also be seen as a coercive source of power because the supplementary information coming with the unmet needs often outlines vulnerability to legal action or other liability.

***RC Participation in ARCA***

Another way RCs are able to use power and influence is by their executive directors participating on the board of directors for ARCA which is the primary lobby arm of the RC system. ARCA’s board is made up of all 21 RC executive directors and is used as a think tank/workgroup on addressing systemic issues in the IDD system. The agenda of ARCA is centered around advocating for RCs, pushing pro-IDD legislation, and promoting the entitlement system under the Lanterman Act (ARCA, 2021).

ARCA provides leadership to the system due to the fact that the ARCA board is comprised of each RC executive director being a member of their board. The singularity in the board makeup gives ARCA a great deal of credibility when it comes to IDD issues at the RC level because, with their participation, comes the implicit support of all 21 RCs. ARCA is particularly effective at navigating the relationship between the RC system administration and DDS legislative direction. For example, when DDS decides how to fund caseload ratios of clients to service coordinators, ARCA can expertly give real-time examples of those staffing ratios and where more funding is needed most. DDS relies on the analysis of ARCA to avoid systemic issues, such as the Medicaid Waiver freeze in 1997, where federal funding ceased due to flow to California, due to issues including high caseload ratios (ARCA, 2013) (LAO, 2020). When ARCA meets and decides how to interpret a new directive, they are asserting their expert power on the IDD system. The interpretive powers of ARCA and their collective will give each executive director access to making policies that impact the entire IDD system.

***Service Coordinators***

RCs focus on service delivery through their employees called service coordinators (SCs). SCs are responsible for the coordination and implementation of individual program plans (IPPs) of clients within their RC and collectively throughout the state. IPPs are legal documents for the provision of services which gives SCs a great deal of control over what services are rendered, denied, or explored by individual clients statewide. Each SC carries a caseload of about 90 clients and acts as systemwide gatekeepers for those individual clients. The training, institutional knowledge, and willingness of SCs to act dictates how services are going to be rendered to clients within the IDD system. RCs, who employ SCs, hold a great deal of *reward* and *legitimate* power over these employees while SCs hold *informational* power over the clients of the RC. This combination of upward and downward power dynamics gives the RCs a great deal of influence in how services are delivered and what services are developed for the future statewide. RCs are strictly on the side of public administration and do not directly influence policy, but RCs do have entities at work on their behalf on the policy side.

**Section 3: Power and Influence Held by Lobbying Firms**

Lobbying firms also play a large role in the power dynamics which run throughout the California IDD system. IDD legislation is pushed forward by constituents all over the state, however, lobbyists are typically the ones who write, amend, and recommend the actual policies. The Arc, a federal organization devoted to the advocacy of IDD issues nationwide, is the parent agency of The Arc of California, which is a large presence in the IDD political environment and coordinates legislative efforts across the state. The Arc of California is one of the most active groups and most influential in the state as observed through their capitol briefs, legislative advocacy campaigns, their annual IDD policy conference, and their extensive lobbying efforts with the legislature. The Lanterman Coalition is another large lobbying agency representing about 25 different associations, lobbying groups, nonprofits, and other firms who advocate on behalf of the IDD agenda, but in many different ways. For example, ARCA is a member of the Coalition and represents the interests of specifically RCs and their executive directors. There are many other organizations, like the Down Syndrome Alliance, United Cerebral Palsy, Autism Speaks, and Fetal Alcohol Spectrum Disorder Network, that contribute to the collective voice in California, lobbying lawmakers to push more diagnosis-specific changes to services and supports.

 Lobbying firms have many different sources of power and two of them are the ability to make direct contact with legislators and the ability to rally local grassroots for awareness. Lobbying firms can directly access the California Legislature’s House Sub Committee on Intellectual and Developmental Disabilities which is where much of the IDD specific legislation comes from. This well-worn channel gives lobbyists direct access to the assembly members who are making laws for the IDD system. Lobbyists, like those from The Arc, apply strong *referent* power (French & Raven, 1959) which draws in grassroots organizers and can direct that energy towards the legislature. ARCA, too, uses *informational* power (French & Raven, 1959) derived from institutional knowledge to push legislators towards an outcome. There is a great deal of reciprocity between the lobbyists and grassroots advocates as well. With the support of the grassroots advocates, the lobbyists gain legitimacy. In return, the lobbyists are able to arrange for transportation, create marketing materials, provide lunch, and engage in other such activities to empower local support networks and help push IDD legislative agenda items to the forefront.

**Section 4: Power and Influence Held by State Agencies**

State agencies also play a massive role in how power and influence move within the state. Given that the IDD infrastructure is legislated into existence by the Lanterman Act (DDS, 2021) the state agencies that administer that system are a strong source of legitimate power. The Department of Developmental Services (DDS) is the primary conduit of top-down changes to the IDD system and the State Council on Developmental Disabilities (SCDD) is their counterpart for quality assurance, advocacy, and strategic planning.

***Department of Developmental Services***

DDS can interpret the law, make administrative changes, and make requests of the legislature for changes to the system as a whole. Possibly the biggest role which DDS plays in the power dynamics of the IDD system is the interaction with the RC system. DDS is the contractor of RC services and the fiscal agent of the RC. RCs are beholden to DDS for annual contract renewal for services. Also, all the funding for RC services comes through DDS in a reimbursement arrangement giving a large degree of both reward and coercion power to DDS. DDS is also using legitimate power because the RCs are under contract with DDS.

Power can also be applied more gently than just in the form of reward and punishment. Sometimes, the request from DDS is more of a guideline and represents expert power because DDS is acting as the expert on the subject and the RC is following along because both agencies are working towards the same goal of helping those with IDD. Guidelines rely more on shared expectation or trust rather than laws or statutes. However, expert power can go awry. For example, if DDS were to give a guideline that seems to strictly benefit the agenda of DDS and not the needs of those with IDD, this expertise could be seen as negative instead of positive expert power (Elias, 2008).

***State Council on Developmental Disabilities***

Another state agency, the State Council on Developmental Disabilities (SCDD), is a unique player in this area. SCDD has many responsibilities which include advocating systemic change, increasing self-advocacy for people with IDD, creating the overall strategic plan of the RC system, and helping with quality assurance, public information, and oversight. The broad goals of the agency are to move the IDD system forward by using local and statewide advocacy.

 SCDD indirectly applies power through the alliances it makes within the community. The strategic plans and advocacy work are not directly powerful in the sense that they change laws or create access where there was none. Instead, the power is referent in that the strong identity which SCDD brings to the table is something that others can leverage. For example, The Arc might be able to use the strategic plan of the RC system to address a needed change in the RC framework leading to policy changes. DDS might also use the quality assurance reports from SCDD to show that more oversight is needed in specific living arrangements which leads to more funding.

 In addition, SCDD has regional representatives who travel and meet with RC clients and try to parse out what is working and what is not. These representatives are critical in the monitoring of services and, due to the low profile of SCDD, these regional representatives are key to amplifying the voices of clients statewide. SCDD is unique because it is one of the few state agencies which has an actual mandate for advocacy due in large part to federal government financing (State Council on Developmental Disabilities, 2021). This mandate gives clients and those who ally themselves with SCDD a great deal of power because the *referent* power held by SCDD is a gateway to many other sources of power within the state IDD infrastructure.

**Section 5: Power and Influence Held by Legal Bodies**

The Lanterman Act is the cornerstone of the IDD system and was named after Frank. D. Lanterman who was an assemblyman in California from 1950-1978 (Wallis, 2021). At the urgings of parents of children with disabilities, Frank Lanterman put forth the legislation which created RCs and began the elimination of state developmental centers. Assembly members hold great power and influence in the IDD system because they make the laws that govern the entire system.

 It is important to know that Frank Lanterman was a man who, single-handedly, created the IDD system as we see it (Frank D. Lanterman Regional Center, 2016). Beyond reelection, assembly members are more likely to listen to their constituents for more personal reasons. IDD represents about 1% of the population and the families of elected officials are no exception. Many assembly members have family members who are diagnosed with Autism, Intellectual Disability, Cerebral Palsy, Epilepsy, and other similar disabilities. These lawmakers have a personal stake in seeing their influence push IDD policies to the forefront and use referent and reward power to do this.

**Section 6: Power and Influence Held by Others**

The groups from previous sections all wield power and influence within the IDD system, but it is also important to note the groups which act outside the system. Groups that act outside the IDD system have the effect of creating a fence around the service system because of the “payor of last resort” mandate given to RCs. The payor of last resort means that all other generic resources must be exhausted prior to funding services to a client of the RC.

One example of this is private insurance companies that set standards of care for people with IDD and thus set boundaries for how RCs can address client services. If generic resources like private insurance cover a benefit, then RCs cannot fund it. Applied Behavior Analysis (ABA) services are a good example of this. School districts are another powerful group that provides services to children with IDD from ages 5-22. Schools are required to provide a free and public education (FAPE) as well as provide individual education plans (IEPs). This mandate puts a huge burden on school districts to provide specialized services to those with IDD, but due to the payor of last resort philosophy of the RC, the provision of services by the RC to school-aged children is greatly limited. For example, transportation services, day program services, independent living services, and vocational services are all provided by school districts leaving only a few services available through the RC, like respite services (DDS, 2020).

Another group that fences in the IDD system of supports are county mental health (CMH) offices. CMH is responsible for the wellbeing of those with mental health diagnoses which impact people with IDD three to five times more often due to higher rates of comorbidity (Munir, 2016). CMH sets guidelines on what services are offered to treat only the mental health component of an individual and often a person’s IDD diagnosis is specifically not addressed due to the complexity of care involved (Sacramento County Department of Health and Human Services, 2017).

 Each of these services has power and influence within the IDD system because of the way they create barriers around what can be provided. The IDD system is set up to be supplemental to all other things and so, when other groups act upon the system, it changes the way the IDD system as a whole operates. In this way, the RC loses power through the *institutionalization* of power where, through the legitimization of process or authority, another entity gains power within a system (Salancik & Pfeffer, 1977) (Pfeffer, 1992). For RCs, this is a desirable thing because the more services and supports that are available in the outside community, the less the RC is responsible for providing such services. Being subject to the changes of other entities can, however, be confounding for RCs and the IDD infrastructure to manage because changes like those noted above can come from many sources.

**Conclusion and Introduction to the Power Mapping Tool**

The path towards equity and inclusion for those with IDD is still under construction in California and partnerships will be the most effective route going forward. Large advocacy organizations like The Lanterman Coalition, The Arc, and United Cerebral Palsy have a long reach and utilize power sources well. These large partnerships can draw on referent, expert, and informational from their supporters and then leverage that power with the legislators to enact legal changes in the state.

The personal power of people with IDD in some ways goes against the research of French and Raven. Physical attractiveness, for example, served as a basis of power theory (Elias, 2008), but in the IDD community, power is derived more often from determination, respect for authority, and honest pleas for help. The self-advocates in the IDD system have a difficult time, but through the creation of entities like SCDD and Disability Rights California a platform exists for that purpose. Self-advocates will continue to rely on institutionalized power structures until they begin to access other forms of power in the future.

Perhaps the most powerful force in the IDD system is ancillary agencies around the RC system, like In Home Support Services (IHSS) (county program), State Supplemental Payments (SSP) (state program), Supplemental Security Income (SSI) (federal program), and the Medicaid Waiver Program (federal program), which directly set standards of care and models for payment or reimbursement. County, state and federal programs all have the power to reign in or expand services for people with IDD in California due to the payor of last resort statutes. Careful expansion or restriction of certain programs have an impact on IDD services in California and could be used to effect great change.

Power is not a physical thing, but it can still be picked up or put down on an individual basis. A single vote for a legislator is a form of power (reward/coercion). A lobbyist asking state congress for more funding based on evidence is a form of power (information/expert/referent). An individual executive at a state agency or local RC can decide to interpret the law differently which is also a form of power (legitimate). But individuals can also decide to not act and leave power on the table. The purpose of this analysis is to help demonstrate the different forms of power and hopefully show the reader how different types of power are used effectively to make a change. There are many avenues to making purposeful change in the IDD system, however, the most powerful tool available is action. Individuals, clients, advocates, legislators, administrators, and all the members of the IDD community must look at their own places in the IDD system and make a strategic decision on what kind of power to access.

This analysis represents a sizeable piece of the IDD influence ecosystem in California, however, it is by no means all-encompassing. There are very powerful groups left out of this analysis and likely other groups who have more power than they imagine. Future agents of change in the IDD system will be able to use this analysis of influence to identify paths to make systemic change and depending on the perspective, use the six types of power developed by French and Raven (1959) to their greatest advantage.

Appendix A contains a link to the power mapping tool developed in tandem with this analysis for a visual display of these forces in action. The tool describes each stakeholder and the above-mentioned source of power available to them and offers suggestions about the most promising routes to change.

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Appendix A

This is a working map of the I/DD power and influence system in the state of California.

<https://kumu.io/bjthompson831/idd-power-and-influence-map#untitled-map>