Workgroup 1 Homework Summary

Priority 1: Build trust in Regional Center systems and other systems, particularly for people of color.

1. Problem Statement: What experiences currently create distrust in regional center (RC) systems and other systems? Which groups are having these experiences?

1. Regional centers and service coordinators don't always explain all of the services they offer.
2. The generic resources rule causes families to jump through multiple hoops and still not get services they need.
3. Pediatricians don't refer families to regional center (RC) services because they lack knowledge about RCs and disabilities.
4. Consumer Services Coordinators (CSC) have case overloads. This creates a lack of contact, delayed response time, canceled appointments, etc.
5. There is lack of follow-through: the system promises something different than what the person or family receives.
6. For people who do not have documentation, there is mistrust of the system/government as a whole.
7. There is inconsistency between regional centers and within regional centers, by different service coordinators. Clients get different answers and/or see other individuals/families get "better" services.
8. There are gaps in communication and long wait times between when the individual program plan (IPP) or planning team meeting happens and when services are initiated.
9. The system does not use language or definitions in a way that can be easily understood, and it does not always translate well to other languages.
10. There are violations of client privacy.
11. There are violations of least restrictive environment - denial of autonomy.
12. Staff treat clients like burdens.
13. Clients are denied reasonable accommodations.
14. Regional centers focus on compliance over person-centered care.
15. There is a culture of "no" at the regional centers.
16. Regional centers show distrust towards self-advocates and their families.
17. Regional centers and vendors retaliate when clients speak up – and there is no effective way to address it.
18. There is a heavy focus on provider training without effective implementation.
19. Staff give out wrong or misleading information with no accountability.

20. There are language barriers and not enough service offerings that meet cultural needs.
21. There is systemic bias and discrimination.
22. There are delays in services, lack of timely responses, and excessive paperwork.
23. Agencies deny services but won’t give you proof of denial.
24. The regional center treats me like a child and assumes my parents are involved when they are not; the RC doesn’t support me as an adult making my own goals and decisions. Staff listen more to the parent than the client.
25. If I seem too competent or meet my goals, staff do not think I need help.
26. Staff are not neurodiverse (ND) affirming: I am a person, not a condition.
27. There is ableism: An individual is considered “less than” for being disabled.
28. The system lacks flexibility in helping older individuals or immigrants apply for eligibility who do not have paper documentation from their childhood.

2. Causes of the Problem: What is causing these problems?

1. A history of poor experiences can make it difficult to repair a relationship. People are made up of their stories and when those stories include a lack of follow-through and negative experiences with the regional center, that is difficult to repair.
2. Training
    - The medical system isn’t trained properly to diagnose and refer people with disabilities.
    - Staff training is limited and often focuses on the logistical components of the job rather than building strong “soft skills.”
    - There is extremely minimal training on disabilities in general, especially from a neurodiversity perspective.
    - There isn’t enough training about the roles and responsibilities of regional center staff for people who receive services and their families.
3. DDS has top-down bureaucracy and overwhelming directives.
    - There are too many directives. Policies are overly complex and redundant. This creates confusion.
    - DDS often makes policy decisions without meaningful input from individuals with IDD, their families, and advocates.
4. Regional centers have failed to adapt.
    - The regional center system hasn’t changed its services or adopted best practices. This inflexibility prevents meaningful engagement with families and inhibits the development of new approaches that could build trust.

- Regional centers have not adopted technology to improve processes, communication, or access to information. This prevents families from engaging effectively with the system, reinforcing a sense of powerlessness.

5. Regional centers interpret and implement inconsistently.
    - Due to vague or overwhelming directives from DDS, regional center leadership interpret and implement directives differently. This results in inconsistent practices across regional centers and even among service coordinators within the same center, leading to significant inequities in service access and quality.
    - Poor communication and coordination within regional centers lead to conflicting guidance, repeated requests for the same documentation, and a general sense of chaos.
    - We play this game of “telephone:” The service coordinator must pass a request for services information to her supervisor who must take it to someone else. My request may no longer be what I originally said to my service coordinator. I have been denied services that were not the same as what I asked of my service coordinator.
6. Culture of mistrust and division
    - Many service coordinators and regional center staff operate in a defensive mode. This makes it hard for families to trust that their needs are being prioritized.
    - Families and advocates who question or challenge decisions are often labeled as "problematic" and may face retaliation, such as delays in services, changes in service coordinators, or increased scrutiny. This culture of retaliation reinforces the perception that the system is not an ally but an adversary.
7. Lack of accountability or consequences
    - There is not enough oversight of regional centers. There is no independent mechanism to evaluate service quality, handle complaints, or address systemic issues meaningfully.
    - When families report complaints or express concerns, the response is often slow, dismissive, or insufficient. This reinforces the belief that the system is unresponsive and unaccountable.
    - It has become “normal” for regional center staff to provide incomplete, misleading, or incorrect information to families, often to deflect criticism, simplify workloads, or maintain control. When families discover these discrepancies, it reinforces the belief that the system is deceitful or incompetent.
    - There are no consequences for regional center staff who are rude or provide misleading or incorrect information, leading to a culture where such behavior becomes standard practice rather than the exception.
    - There is no regular public forum for clients to talk about their abuses. Many events claim to be about self-advocacy but turn into just another venue to give us lectures.

8. Budget constraints
    - The regional centers operate under tight budgets. Essential services are denied or reduced to save money. This causes mistrust among families.
    - Service coordinators are overwhelmed by high caseloads, excessive administrative demands, and insufficient support. This leads to burnout and high turnover rates. There are frequent changes in coordinators, delays, and a lack of continuity in care.
9. Misalignment of goals among DDS, regional centers, and families
    - Instead of empowering individuals with IDD to make choices about their own lives, the system remains focused on fitting people into predefined services and categories.
    - Even when policies are designed to be person-centered, their implementation often falls short. Families see the gap between what is promised and what is delivered. This creates distrust.

3. Needed Data/Information: What data do we need to better understand and show evidence of this problem?

1. Service Delivery and Access Data:

- **Approval and Denial Rates of Services**: Detailed data on the approval, denial, and modification rates of services requested by families, broken down by service type, regional center, demographic characteristics (e.g., race, ethnicity, language, socioeconomic status), and reasons for denials. This data would help identify patterns of disparity or inequity in service provision.
- **Service Timeliness Data**: Information on the average time taken from the initial service request to approval, and from approval to actual service delivery. This should include data on any delays and the reasons behind them, helping to highlight systemic inefficiencies or barriers to timely service provision.
- **Frequency of Service Reductions or Terminations**: Data on how often services are reduced, modified, or terminated, including documented reasons for these actions and whether families were consulted or informed in advance. This would provide insight into potential punitive or arbitrary decision-making processes.
- **Caseload Data**: Caseload ratios from all regional centers. Regional centers need to be able to provide this data without fear of being penalized for not complying with a service coordinator-to- consumer caseload ratio that is all but impossible to maintain in today’s job market.

2. Accountability and Oversight Data:

- **Complaints and Grievance Data**: Comprehensive data on the number, types, and outcomes of complaints and grievances filed by families against regional centers. This should include data on the time taken to resolve complaints, the level of satisfaction with the resolution process, and any follow-up actions. This data will provide a clear picture of the system's responsiveness and accountability.

- **Incident Reports and Resolution Data**: Information on incidents reported by families, staff, or third parties (e.g., abuse, neglect, retaliation, miscommunication), along with data on investigations, resolutions, and any disciplinary actions taken. Lack of resolution or inadequate follow-through would indicate gaps in accountability.
- **Audit and Compliance Reports**: Regular, independent audit reports of regional centers' adherence to DDS directives, service delivery standards, and financial management. These reports should highlight discrepancies, instances of non-compliance, or areas needing improvement.

3. Staff Training, Practices, and Performance Data:

- **Service Coordinator Training and Certification Records**: Data on the types, frequency, and content of training provided to service coordinators, timeline on when those are offered post-hire, as well as records of ongoing professional development, evaluation, and certification. This data can identify gaps in training or discrepancies between training and actual practice.
- **Staff Turnover and Satisfaction Data**: Information on staff turnover rates, reasons for leaving, and job satisfaction surveys – and how this data has trended over the last 15-20 years. High turnover and low satisfaction may correlate with systemic issues such as burnout, poor management, or inadequate support, which ultimately affect service delivery quality and consistency.
- **Performance Evaluation Data**: Data on how service coordinators, mid-managers, and senior management are evaluated, including key performance indicators (KPIs) related to family satisfaction, service delivery timeliness, person-centered planning, and overall accountability.
- **Vendor Training Materials**: Public disclosure of vendors' training materials so they can be evaluated, and clients can consent to them.

4. Family and Individual Experiences Data:

- **Family Knowledge**: Data that tells us what parents already know about disability services before they get to the RC.
- **Family Satisfaction Surveys**: Regular, anonymous surveys of families and individuals receiving services that capture their satisfaction with various aspects of the regional center system, such as communication, service delivery, timeliness, fairness, cultural competence, and trust. These surveys should include quantitative ratings and qualitative feedback.
- **Focus Groups and In-Depth Interviews**: Conduct focus groups and interviews with families, self-advocates, and community organizations to capture nuanced, qualitative experiences that may not be fully reflected in surveys. Narratives and testimonials can provide powerful evidence of systemic issues and mistrust.
- **Service Accessibility Data**: Data on barriers to accessing services, such as language support, cultural competence, geographic distance, and digital literacy.

This should be broken down by demographics to understand the unique challenges faced by different communities in navigating the system.

5. Policy Implementation and Impact Data:

- **Consistency of Policy Implementation Across Regional Centers**: Comparative data on how different regional centers interpret and implement DDS directives, policies, and programs. Significant variations in implementation could indicate a lack of standardization and accountability.
- **Impact of Policy Changes on Service Delivery**: Data assessing the effects of specific policy changes or new directives on service delivery outcomes, family satisfaction, and systemic efficiency. This can involve before-and-after analyses to identify unintended consequences or gaps.
- **Equity Analysis of Policy Impacts**: Disaggregated data that assess whether certain populations (e.g., racial and ethnic minorities, low-income families, non-English speakers) are disproportionately affected by policy changes or inconsistencies in service provision.
- **Coordination of Services**: Data that tells us how many consumers are working with both the Department of Rehabilitation (DOR) and their regional center as a coordinated team.

6. Communication and Information Dissemination Data:

- **Accuracy and Clarity of Information Provided**: Data on the frequency and types of misinformation or conflicting information provided to families, along with the channels used (e.g., meetings, emails, phone calls). Families could report instances where they received incorrect information or conflicting advice from different service coordinators.
- **Effectiveness of Communication Channels**: Data on the preferred and most effective communication channels for families and individuals (e.g., in-person meetings, digital platforms, phone, printed materials) and whether regional centers are effectively utilizing these channels to provide accurate and timely information.

7. External Evaluations and Community Feedback:

- **Independent Evaluations of the Regional Center System**: Data from external evaluations conducted by independent bodies (e.g., academic institutions, advocacy organizations) that assess systemic issues, identify areas of improvement, and propose actionable recommendations. These evaluations should be conducted regularly to provide an objective analysis of the system's performance.
- **Feedback from Community-Based Organizations (CBOs)**: Data collected from CBOs that work closely with regional center clients, as these organizations often have direct insights into systemic challenges, patterns of discrimination, gaps in services, and best practices that could inform systemic improvements.

8. **Document Review**:

- Reviewing forms for the Self-Determination Program (SDP) that have a signature line that expects an adult without parent involvement to complete a form; terms currently used such as “consumer,’ ‘employer,’ and ‘parent’ are not clear. Every form has different signature lines.

9. **Medical System Data**:

- Data that tells us what medical providers know about RCs and disability services and their referral habits.
- Data about the medical system’s disability screening practices, and which populations get referred for RC services and which don’t.
- Data on the effectiveness of the medical referrals by contacting various populations to find out how they experienced the referrals.

5. **Ideas for Recommendations: What are possible solutions to this problem? What are your ideas for building trust in Regional Center systems and other systems, particularly for people of color?**

Building trust in the regional center system and other service delivery systems, particularly for people of color and marginalized communities, requires a multifaceted approach. Trust can be rebuilt by creating an environment that emphasizes transparency, accountability, cultural competence, genuine engagement, and person-centered care.

1. **Offer a consistent menu of services at every regional center.**
   - Make sure all regional centers offer the same services to everyone across the state.
   - Create a menu of services with qualifications listed so we do not have to rely on our service coordinators’ opinions only.
   - Create a requirement that all regional centers offer services for developmentally disabled people to socialize with each other.
2. **Increase public outreach and education.**
   - Launch commercials or public service announcements in multiple languages about disability service systems.
   - Include information about disabilities and service systems in pediatricians’ offices and other medical centers, clinics, and prenatal clinics.
   - Train medical students earlier in their career about DD/ID and RCs so they develop knowledge sooner. Teach them by having people with disabilities do the training.

3. **Address generic services.**
   - Expand knowledge of generic resources by RC service coordinators and medical personnel.
   - Find a balance when it comes to requiring families to access generic resources prior to accessing regional center services. It leads to a lot of jumping through hoops and confusion, not just by families and people who receive supports but by regional center staff as well. In addition, some generic resources are not equipped to meet the needs of people we support.
4. **Offer interventions for emotionally abusive family environments.**
   - Create a hotline for clients who are dealing with emotionally abusive parents.
   - Offer training for emotionally abusive parents.
   - Offer emergency housing for clients with emotionally abusive parents.
5. **Improve service performance and accountability.**
   - Regional Centers should have self-advocacy meetings where we talk about how to improve services. There is no forum for us to talk about our abuses. They're likely afraid we'll make them look bad. It's safer talking to each other than to more people who may abuse us. We should be able to create new rights. We now have the right to dignity, but that is too vague. We should be able to say what that means to us and have it officially be voted on as a right for all clients.
   - Create an online communication system for complaints so people can make complaints in written format without being ignored.
   - Create universal quality standards. Quality is entirely based on the IPP. They would never say to a day program, for example, that you have to put shades on your fluorescent lights, or reduce the volume on televisions, or let clients avoid eye contact unless it's in the IPP.
   - Create performance incentives related to RC community outreach with a focus on building positive relationships and presence within the community.
6. **Institute more effective provider training and education.**
   - Educate staff and vendors on neurodiversity and respecting neurodiverse culture.
   - Deliver customer service training for regional center staff.
   - Offer training programs ready to use when a client complains about particular issues.
   - Focus on service coordinator training.
7. **Support individuals' self-determination.**
   - We should be able to write our own goals. Not have service coordinators write them for us with some of our input.
   - Revise forms and procedures to provide clear direction on who to talk to and how to get help or information if you don't understand.

- Offer accommodations so that a person can apply for services without parental support. Person may need support at the point of intake – prior to eligibility – so that the person applying can navigate the system. You may need support from the first phone call, the intake, the application for services.
- Support the decisions made by the individual instead of expecting parents to be making all of the decisions.
- End the ban on “age-inappropriate materials” in day programs. Many of us have special interests that focus on things marketed to children.

8. **Adopt a more lifespan approach to services.**
    - Make sure service coordinators are cross trained about people throughout their lifespan, even if they don’t routinely work with different age groups. Service coordinators should learn about services for older adults with DD/ID.
    - Offer new customer orientation as people and their families become eligible for services; as you age, you are invited to the next session of orientation based upon your age and which regional center team will serve you.
9. **Establish lower caseload ratios for all age groups.** It’s been proven that a lower caseload is often correlated with higher satisfaction, needs don’t diminish with age, if anything they increase.
10. **Create more affordable housing** for people who have DD/ID that is not always in an urban area and is close to transit options.
11. **Better support individuals who are older or immigrants in meeting eligibility criteria without all the necessary paperwork**. They may need alternatives for proving their disability from childhood.
12. **DOR and regional centers should collaborate for the support of the consumer**. It should be a group effort so that the individual will learn to be independent and then can be successful in the long term.
13. **Allow vendors to provide online services**. I do autistic peer mentoring and want to be a vendor, but I have chronic fatigue and no car. We autistics need to be able to talk to each other and advocate for each other.

14. **Establish Transparent and Independent Oversight Mechanisms**

    - **Create an Independent Oversight Body**: Establish an independent body composed of self-advocates, family members, community-based organizations, and experts to regularly audit regional centers and review their compliance with DDS directives, service quality, and financial management. This body should have the authority to make binding recommendations and enforce corrective actions.
    - **Regular Public Reporting**: Require regional centers to publish regular, transparent reports on their performance, including service delivery metrics, complaints and resolutions, budget allocations, and community engagement

efforts. Reports should be accessible and presented in multiple languages to reach diverse communities.

- **Implement a Clear Accountability Framework**: Develop a standardized accountability framework for service coordinators, mid-managers, and senior management that includes key performance indicators (KPIs), performance evaluations, and consequences for poor performance. This framework should be monitored by the independent oversight body to ensure impartiality.

15. **Enhance Cultural Competence and Community Engagement**

- **Mandatory Cultural Competence Training**: Implement mandatory, ongoing cultural competence training for all regional center staff, from service coordinators to senior management. Training should be co-created and facilitated by community-based organizations (CBOs) that specialize in working with diverse communities. It should cover topics such as implicit bias, cultural humility, culturally responsive communication, and understanding the unique needs of communities of color.
- **Hire and Retain Diverse Staff**: Ensure that the staff at all levels of the regional center system reflects the diversity of the communities they serve. This includes hiring more bilingual and bicultural service coordinators, individuals with lived experience, managers, and senior leaders. A diverse workforce can better understand and empathize with the experiences of families of color and provide more culturally appropriate support.
- **Partner with Community-Based Organizations**: Collaborate with trusted CBOs that have deep roots in the community and have established trust with families of color. These organizations can serve as intermediaries to facilitate communication, provide culturally relevant support, and help bridge the gap between the regional center and marginalized communities.

16. **Implement Person-Centered and Trauma-Informed Practices**

- **Redesign Service Delivery Around Person-Centered Planning**: Shift from a compliance-based approach to a person-centered approach where the needs, preferences, and goals of the individual with IDD and their family drive service planning and decision-making. This involves actively involving families in developing Individual Program Plans (IPPs) and ensuring their voices are central in all decisions.
- **Adopt Trauma-Informed Care Practices**: Integrate trauma-informed care principles across the regional center system. Staff should be trained to recognize the impact of trauma, including systemic racism and discrimination, on individuals and families. Trauma-informed care can help create a more compassionate and supportive environment that builds trust.
- **Empower Self-Advocates and Families**: Create mechanisms for self-advocates and families to have meaningful roles in policy development, service design, and decision-making processes. This could include advisory councils, participatory budgeting, and regular town halls that influence how regional centers operate.

17. **Improve Communication and Information Accessibility**

    - **Develop Clear and Consistent Communication Strategies**: Create standardized guidelines for service coordinators to ensure that families receive consistent, accurate, and complete information about services, rights, and processes. These guidelines should be regularly reviewed and updated.
    - **Utilize Multiple Communication Channels**: Ensure information is accessible in multiple formats (e.g., in-person meetings, phone calls, emails, digital platforms, printed materials) and languages to cater to diverse communication preferences and needs. The use of culturally relevant communication tools and methods can improve understanding and trust.
    - **Create a Transparent Complaint and Grievance Process**: Develop a clear, accessible, and user-friendly process for filing complaints and grievances that includes a timeline for resolution and follow-up. Families should be informed of their rights and options without fear of retaliation.

18. **Promote Accountability Through Data Transparency and Community Feedback**

    - **Data-Driven Decision-Making and Reporting**: Regularly collect, analyze, and publish data on service delivery outcomes, access to services, disparities, and family satisfaction. Disaggregate data by race, ethnicity, language, and other relevant factors to identify inequities and target improvements. Share this data publicly to increase transparency and accountability.
    - **Incorporate Community Feedback into System Improvements**: Establish mechanisms for regularly soliciting feedback from families, self-advocates, and community partners through surveys, focus groups, and community forums. Ensure this feedback is actively used to drive continuous improvements in services and policies.
    - **Develop a Scorecard System for Regional Centers**: Create a publicly accessible scorecard system that rates regional centers on key performance metrics such as service quality, timeliness, cultural competence, community engagement, and complaint resolution. High-performing centers could be recognized, while underperforming ones would receive targeted support and oversight.

19. **Empower Families and Self-Advocates with Knowledge and Support**

    - **Develop Peer Navigator Programs**: Implement peer navigator or peer support programs where families and self-advocates with experience navigating the regional center system provide guidance and support to others. This peer-to-peer model can be particularly effective in building trust and sharing practical knowledge.
    - **Create Resource Hubs and Educational Workshops**: Develop accessible resource hubs and educational workshops to help families understand their rights, available services, and how to navigate the regional center system. These

resources should be culturally and linguistically tailored to meet the needs of diverse communities.
- **Expand Access to Independent Advocacy Services**: Increase funding and support for independent advocacy organizations that can represent families and individuals in disputes with regional centers. Having independent advocates can help ensure that families' voices are heard and that they are treated fairly.

20. **Implement Structural Reforms to Align Incentives with Person-Centered Outcomes**

- **Incentivize High Performance and Innovation**: Create financial and professional incentives for regional centers and staff who demonstrate excellence in delivering person-centered, equitable, and culturally competent care. Conversely, introduce consequences for regional centers and staff who fail to meet performance standards.
- **Pilot New Models of Service Delivery**: Encourage regional centers to pilot innovative models of service delivery that prioritize person-centered care, cultural competence, and family empowerment. Successful pilots should be scaled and replicated across other centers.
- **Redefine Metrics of Success**: Move away from traditional compliance-focused metrics and redefine success based on meaningful outcomes such as family satisfaction, quality of life improvements, and equity in service access.

21. **Regional center boards must take a more proactive and empowered role in representing both the regional centers and the diverse communities they serve.** To build trust and accountability, boards should:
- **Strengthen Community Representation**: Ensure diverse board membership that reflects the community, including self-advocates, families, and community-based organizations (CBOs). Engage with stakeholders regularly through forums and town halls to understand their needs.
- **Act as a Voice for the Community**: Advocate for inclusive and equitable policies that align with community needs and ensure decisions prioritize person-centered care and fairness.
- **Ensure Transparency and Accountability**: Hold regional center management accountable for service quality and compliance. Demand regular, public reporting on performance, complaint resolutions, and community engagement.
- **Facilitate Independent Oversight and Continuous Improvement**: Collaborate with independent bodies for regular audits and evaluations to drive improvements and accountability within regional centers.
- **Promote Collaboration with Community-Based Organizations**: Partner with trusted CBOs to improve outreach, support, and culturally relevant service delivery.
- **Advocate for Resources and Policy Changes**: Lobby for necessary resources and policy changes to address community-specific needs and disparities in service access.

Workgroup 1 Homework Summary

- **Empower Stakeholders**: Support peer-led programs and educational workshops to equip families and self-advocates with the knowledge and tools to navigate the system and participate in decision-making.