

## Workgroup 1 Homework Summary

### Priority 3

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**Priority 3: Ensure individuals have choice and control over their lives by making self-determination the core of the developmental disabilities system.**

#### What is the Problem?

#### Summary of Homework Responses

1. Individuals with disabilities are not treated as equals, and as a result, they are told what to do and not respected:
  - a. Individuals receiving services are not being heard.
  - b. Persons with disabilities are not seen as equals, so in order to receive services, they are not permitted to do everyday things of an able-bodied person (getting married, working, or receiving family financial help).
  - c. The system has become authoritative and looks at individuals served as “less than.” That mindset and culture must change if individuals are to have true choice and control.
  - d. The belief that we do not know what we need, a general “for your own good” attitude, pressuring us not to self-advocate because our needs hurt ableistic feelings.
  - e. Individuals served and their circle of support should be in the driver’s seat not the other way around. Service Coordinators wield their power over families.
  - f. Families are forced to describe their children in a demeaning way in order to qualify for services. This is damaging and discriminatory.
  - g. It is assumed that parents are responsible for their children’s lives, even though their child/the client may be completely independent. Also that it is the parent’s responsibility to take care of their disabled child, even though disability tends to run in families and receiving help is already stigmatized enough.
2. The system is not user-friendly, which gets in the way of individuals making their own choices and decisions. It is difficult to know what is offered and how to navigate the system.
3. There are barriers to getting and paying for services, which limits choice and control.
  - a. Distance between service centers.
  - b. Lack of available services in the area.
  - c. Lack of employment opportunities.

- d. Mental health service centers aren't equipped to meet every consumer's needs.
  - e. People want to work with traditional providers of services, but the providers say we take credit cards, etc. not SMS invoices.
  - f. If you want a particular service, you have to pay for it immediately. They can't wait for 2 or 3 months for payment.
4. The people who most often experience these problems are low-income families, those looking for employment, or where they don't have funds.

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**What is Causing these Problems?**  
**Summary of Homework Responses**

1. Traditional providers know very little about disability, disability services, and how people with disabilities can participate in certain activities (swimming lessons, for example).
2. Not enough involvement from service centers and organizations to create choices.
3. Individuals with disabilities are not given the full and accurate information they need to make choices.
4. Regional center staff and information make assumptions that limit choice and control. For example, it is assumed that:
  - a. The client already has knowledge about how things work at the regional center, when they don't.
  - b. The client is able to communicate their disability and their needs better than they can.
  - c. Parents are the ones making the decisions for the individual.
5. The rules about services limit choice: for example, if you are only allowed to do an activity 5 days a week, there is no choice.
6. Individuals with disabilities are not listened to. Our voices are not heard:
  - a. Especially when we speak up against bad behavior and call out abuse.
  - b. Even in this Master Plan process, the community is able to give a lot of input, but sometimes it gets drowned out from people other than the individuals receiving services. We must listen and learn from the actual community.
7. Regional Center system service coordination is compliance based and not person-centered. The culture needs to change to that of support instead of authoritarianism.
8. Clients can't relocate to a new regional center without worrying if their Self-Determination Program (SDP) budget and services will be recognized and supported
9. Public perception.
10. Offering services that have poor success rates.
11. Lack of knowledge about mental illness.

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**What Data and Information Do We Need to Understand These Problems?**  
**Summary of Homework Responses**

1. Service/program data:
  - a. Where are they available
  - b. How many people use them
  - c. Who uses them
  - d. How often are they used
  - e. Gender of the people who use each service/program
2. Service needs and satisfaction data:
  - a. How many people are satisfied with the self-determination program, or quality assurance
  - b. Complaints that consumers make
  - c. Services requested versus services received
3. Ask people with mental illnesses to give their input on current obstacles and how to improve the system.
4. What are the participation numbers and program outcomes for places that have more established Self-Determination Programs? How did these established programs fix problems they encountered so we can learn from them?
5. Why did only about 100 people pursue SDP, after about 1,000 attended orientation? What were the reasons for this, and how can the system address those reasons so that people who want to participate in SDP are able to?
6. About 5% of individuals receiving regional center services are black, and about 10% of participants in the Self-Determination Program are black. We need to look at data specially on why minorities tend to not utilize the regional center services.

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**What Are Your Ideas for Recommendations?**  
**Summary of Homework Responses**

1. Revamp the system so the client makes the decisions about services, not the regional center.
  - a. Make the voice of the client the most important voice in any conversation about a decision related to them.
  - b. Shift the culture to be solution-oriented, not pointing blame when a problem is identified.
  - c. Give clients their choice of vendors, services, and individual providers—including choice of service coordinators. When there are options, the client should pick, not the regional center.
  - d. Let the consumers share their thoughts on how they can strive to be successful.
2. Create more flexibility and creativity in service options:
  - a. Allow more freedom for the consumers to show their talents and skills in different ways.
  - b. Rework the system in place to allow for more flexibility.
  - c. Make sure people can be creative with their services.
  - d. Allow the consumer with the mental illness to do things on their own.
3. Expand opportunities by involving the broader community more:
  - a. Educate community businesses about “self-determination” programs and funding options.
  - b. Allow the public to get involved in activities that give more insight into mentally challenged people.
  - c. Have more public involvement.
4. Make sure that people are aware of the variety of services from the Self-Determination Program (SDP) they can choose, without restrictions.
  - a. Make sure people know they can have flexibility with their services.
  - b. Make sure people know they can use non vendored providers for services, for example if their goal is getting a job and they know someone who is good with resumes, letter writing or practice interviewing they can use them even if they aren’t vendored; another example, if they want to learn to cook they can get help from someone to help them learn to cook and not have to go to a day program to learn how to cook.

5. Create a clear and inclusive list of services that can be included in the Self-Determination Program (SDP), ensuring the least restrictive rules so people do not lose services they already receive. The list should be written in simple, culturally and linguistically appropriate language, and consistently used by all 21 regional centers to prevent confusion or different interpretations. This way, clients will be able to relocate to a new regional center without worrying if their SDP budget and services will be recognized and supported, ensuring equitable access to services for all clients, regardless of their regional center location.
6. Support individuals in driving their own decision-making:
  - a. Pay for every consumer to have a peer-advocate represent their needs.
  - b. Provide self-advocacy training for all transition aged individuals who receive regional center services.
7. Better educate and train staff:
  - a. Require every employee of vendors and regional centers to experience neurodiversity affirming training.
  - b. Create a newsletter run by team of clients that goes to all employees to teach them how to respect our autonomy.
  - c. Train staff to understand how and when an individual's disability can show up – and how the episodes may fluctuate but the disability is always present. I need to be able to opt for the services when I need them.
8. Invite and incorporate feedback from consumers:
  - a. Set up structures and processes in which we listen and learn from the actual community of individuals receiving services.
  - b. Offer intuitive options for the community served to provide feedback and suggestions.
  - c. Service coordinators could make it part of their annual meetings to do a questionnaire on what services are missing/the regional center is not currently providing to determine what needs are not being met at this time. (Be specific with the questions, not vague/generalized)
  - d. Get insight from the families of individuals with mental illness and challenges and how they deal with this family member.
9. Create and implement a system of accountability:
  - a. There seems to be no consequence for service providers who break trust. I should be the main point of contact when this happens, not the service provider who caused harm.
  - b. Establish a rating system for service coordinators and regional centers by the community they serve.
10. Update systems and services with best practices:
  - a. Revise old systems and improve them with new knowledge or technology.

- b. Take a look at older systems that might provide a glimpse into how society has changed over time regarding mental health.
- c. Provide services that are proven to be more successful than others.
- d. Find what elements work best for learning new subjects.