Workgroup 4 Recommendation: Operational Definitions of Service Types

Workgroup Focus Area: Individuals and their families experience consistent, transparent, accountable, and data-driven systems that focus on outcomes.

Workgroup Priority #1: Ensure the system has a consistent, equitable, and transparent interpretation of the responsibilities of Regional Centers and service providers by establishing a common set of statewide regional center standards, services, and rates that are accessible and fair[1] to all of individuals, and provided using clear, simple and inclusive language that is understandable to all of our diverse communities.

Priority #1 Plain language version: Make sure all regional centers follow the same rules about what services they offer, what those services do, who can get those services, and how those services are paid for. We want the rules to be clear and fair, to be available to everyone, and to use language everyone can understand.

Step 1: Define a Universal Goal for the Priority (Where we want to be)

People get the services and supports they need, when they need them, so they can lead the lives they want.

People, family members, regional centers, and providers should all have a common understanding of what a particular service is, what it should do, and who can receive it.
- Clear definitions that use simple, consistent language will help individuals and families make informed choices about what services they need, and how they can access them.
- Clear definitions can help create consistency about how services are offered across regional centers. They can also help us gather correct and more reliable information about each service. This will help us have better information about what "good access and service delivery" should look like for each type of service.
- Operational definitions for some services are more practical than for others
- There should be flexibility for definitions to accommodate the unique needs of individuals.

In order to achieve these wider system goals:

- Operational definitions of service types should be created for a wide range of service types. They will be written in a way that is accessible to everyone. Plain language versions will be created, and more technical descriptions will be developed for Regional Centers and providers to ensure clarity. The operational definitions should supplement the operational definition of service types already developed by CCLN and the PAVE project[2]
- These operational definitions will include a clear, measurable, and objective description of the service, including the type of support it can provide, and the way that support should be provided. It also will include criteria used to determine if the person is eligible to receive that service. This will allow the collection of measurable, reliable and accurate data about services received.
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Step 2: Develop a Problem Statement for the Priority (Where we are now)

- Services with the same name can mean different things at different regional centers.
- Some differences are small, while others are big.
- Some regional centers place limits on certain services, while other regional centers do not.
- Some differences have a bigger negative impact on people because of their disability, race, language, where they live, or other parts of their identity.
- It is hard for people with disabilities and families to make informed choices about the services they receive when there is no clear way to tell what those services are and how to get them.
- Currently Service providers have to follow different rules if they are vendorized in different regional centers, requiring them to have admin processes that keep processes separate for different regional centers.
- There is a fear in the wider community that having any form of "standardization" of services would mean that services would be less person-centered, flexible and tailored.

Step 3: Identify the Root Causes of the Problem

- Services are not always clearly and consistently defined in California state law, regulation, or DDS guidance. This often leads to misinterpretation of law and guidance at Regional Center, provider and user levels.

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[1] The term "fair" is used here to mean equitable. It is not used to mean that everyone gets exactly the same but that that everyone gets just enough of the right support for them to live a safe, healthy, included, connected and self-determined life. Attention is paid to ensuring that those who need more support to experience these outcomes get more support.

[2] Finalized first versions of these exist for Supported Living Services, Independent Living Services, Supported Employment services and In-home Respite Services (PAVE Operational Definitions). Drafts for personal assistance and coordinated family supports also have been developed, ready for consultation.

- There is an assumption that in order for services to be flexible and tailored this means that they cannot be clearly described as having core underlying characteristics and working methods that promote good outcomes. This results in confusion between consistency and uniformity.
- Regional Centers are independent organizations (set up in this way on purpose and for good reason) with responsibility for managing their own budgets, taking account of the unique needs and challenges in their region. It is not surprising that over time there has been some drift in how services have been described, operationalized and authorized.
- State oversight currently is not sufficiently applied to make sure that a service is defined and provided in a way that is consistent with Federal and State rules.
- There is likely to be a resistance to change – the Lanterman Act is extremely important in California and people do not want to lose the importance of the Act. Such standardizations may be seen as a threat by Regional Centers.
- Developing standard definitions is time-consuming and complex – especially if we take into account the views of different stakeholders.
- Some changes happened to what services could offer during COVID that were not necessarily consistent with the original definition of that type of service. This has potentially caused confusion.

Who is being left behind:

- Some people with disabilities;
- Racial and ethnic minority groups;
- Immigrants;
- Those whose preferred language is not English;
- Those with low and very low incomes; and
- People who live in rural areas.

Step 4: Recommendations to Achieve the Goal

Operational definitions of service types may evolve over time. They may evolve with changes in law, regulations, research and good practice. They describe the current situation but may be important to inform advocacy for how the situation can be improved in the future.

Recommendations

1) Operational definitions of services types should clearly set out which elements are core and universal to each service type as well as where any element of a service might differ by regional centers. Most importantly definitions should allow for enough flexibility to ensure that services and support can be tailored to meet the needs and promote a good quality of life for each individual person.

2) Operational definitions of service types should clearly describe the following elements:

   a. Who can receive the services and where support can be provided (eligibility and location).
   b. Whether the service type can be provided as self-directed support or through self-determination program.
   c. What activities, tasks, interactions and life areas can be supported by the type of service.
   d. Any limitations to the support that can be provided by this type of service.
   e. How the services can be accessed
   f. What those receiving services and their families would experience if the service was being provided according to legislation and good practice.
   g. Where a service type is funded under an HCBS waiver, it is very clear what that service needs to be doing to be in line with HCBS values and standards.
   h. Sources used and where to find more information

3) Two versions of operational definitions of service types should be created:

   a. The primary audience for operational definitions of service types should be Regional Centers and Providers. The definitions should be detailed and specific enough to ensure clarity, minimize misunderstanding and therefore promote consistency across regional centers and providers.
   b. Plain language versions of operational definitions of service types should be provided in a range of different languages. Eligibility criteria should be included in the plain language versions so that individuals and family can be very clear as to whether they might be eligible for this service type. ,

   Both versions should have clear, consistent and equitable language that accommodates: cultural sensitivity; linguistic accessibility; accessibility for people with a range of disabilities; sexual orientation and gender identity inclusivity.

4) Operational definitions should be accompanied by a clear statement of data that is needed and collected in order to know:

    a. Whether services are being experienced by individuals and families the way they should be according to the definitions

    b. Whether having operational definitions have had an impact on the equity, quality and outcomes of services.

5) Training should be available and required on operational definitions for Regional Center leadership, service coordinators, providers and direct support professionals.

    a. Training (content and process) on new operational definitions should be informed by the experiences of providing and receiving the training on the four existing operational definitions that will be conducted as part of the PAVE Service Outcomes project.

    b. Training should be customized for each of these different audiences to make clear what they need to do to ensure services are provided according to the definitions.

    c. Regional Center (RC) leadership should be involved in the development and training of service definitions for their staff.

    d. Refresher/updated training should be provided on an ongoing basis, and provided when operational definitions are changed.

6) There should be a process for developing operational definitions that are accurate, clear and deliver a service system that is equitable, fair and transparent. The process should consider using a similar process used to develop PAVE operational definitions of service types. This would ideally include:

    a. A thorough environmental scan of legislation, regulations and guidance and existing definitions and good practice descriptions available nationally and internationally, is conducted. The environmental scan could be usefully supplemented by consultation with subject matter experts on each service type.

    b. A first draft of the definition is produced based on the environmental scan, including the sources used.

    c. The first draft is sent to a group of stakeholders to assess the accuracy of information and the completeness of sources used. This group should, at a minimum, include the Department of Developmental Services, the Association of Regional Center Agencies, advocacy organizations, self advocates and families, and others with expertise in each type of service for which definitions are being written and relevant state and federal regulation.

    d. Feedback from this stakeholder group used to produced Second draft.

    e. Second draft of full operational definition is sent to directors of all 21 Regional Centers and feedback sought.

    f. Plain language version is developed in collaboration with a groups self-advocates and families. Consider working with the State Council on Developmental Disabilities to carry out this stage.

    g. Third draft of both full definition and plain language version made available to wider community and feedback sought in a number of different ways. Feedback meetings and surveys should allow people to focus on one service type at a time.

    h. Version 1 of Operational Definition finalized, translated and made publicly available.

7) The process of developing the operational definitions should be independently facilitated.

These will be developed after initial review by the Master Plan Stakeholder Committee

Step 5: Define Short and Long-Term Milestones needed to implement the recommendations

Short-Term Milestones (next 1 to 2 years)

Long-Term Milestones (next 3 to 10 years)

Step 6: Community Outcomes help assess whether the goal is met. (Progress toward the universal goals and targeted goals for identified groups)

Step 7: Outcomes for Individuals Describe how the recommended changes would make a difference in how people with IDD experience services, policies, and programs