Disability Rights California
California's protection and advocacy system

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Long-Term Services and Supports Principles

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INTRODUCTION

Disability Rights California offers these principles for consideration of any proposal to integrate the financing, coordination or delivery of long-term services and supports (LTSS). This includes integration of LTSS into Medi-Cal managed care. In this context, integration generally means that a single entity, such as a managed care plan or a county, would be ultimately responsible for coordination and delivery of all LTSS needed by a particular consumer – the person who uses the services and supports.

According to the California Department of Health Care services (DHCS), LTSS consist of:

1. Institutional long-term care (e.g., nursing facilities, also called NF A&B);

2. Home and Community-Based Services (HCBS) waiver services, including Multipurpose Senior Services Program (MSSP*)* waiver services, Assisted Living waiver services, Nursing Facility/Acute Hospital (NF/AH) waiver services;

3. In Home Supportive Services (IHSS), Community-Based Adult Services (CBAS, formerly known as Adult Day Health Services or ADHD), home modifications, and meals;

4. Paramedical/nursing services;

5. Physical, speech, and occupational therapies.

Any integration of financing, coordination or delivery of long-term services and supports must be done in a way that ensures that the consumer receives services in the most integrated setting appropriate, preferably at home or in a community-based setting rather than in an institution, as required by the integration mandate of the Americans with Disabilities Act, and the US Supreme Court decision in the *Olmstead* case.

If done well, the integration of financing, coordination or delivery of community and institutional LTSS has the potential of advancing implementation of community integration as required by the *Olmstead* decision. However, if done too quickly and without adequate planning, it has the potential of disrupting the services and lives of persons with disabilities, leading to unnecessary and inappropriate institutionalization.

LTSS integration must build on the organizational strengths of current systems and providers. LTSS integration must include protections to ensure that consumers will not be at risk of institutionalization and that their health and independence will not be jeopardized. There must be adequate oversight of LTSS providers to ensure enforcement of those protections.

LTSS PRINCIPLES

In analyzing any proposal for integration of financing, coordination or delivery of Long-Term Services and Supports (LTSS), we will be guided by the following principles and values:

1. Consumer-Driven Services

LTSS services must be consumer-driven and promote consumer participation.

a. All long-term services and supports must be person centered and consumer driven. This means the consumer has the primary decision-making role in identifying his/her needs, preferences and strengths, and a shared decision-making role in determining the services and supports that are most effective and helpful for the consumer.

b. At all stages of the eligibility determination and planning process, the consumer must be offered the full range of available options so that the consumer can exercise informed choice in determining which services to receive.

c. Services must be provided based on the informed consent of the consumer. The consumer has the right to refuse services including care management or personal services coordination (targeted case management).

d. Managed Care enrollment cannot be passive enrollment; instead consumers must affirmatively select the managed care plan which will best meet their needs.

e. Managed Care enrollment cannot require a lock-in; instead consumers must have the ability to change plans as often as monthly when the plan is not meeting their needs.

2. Consumer-Driven Systems

LTSS service delivery systems must be consumer-driven and promote consumer participation.

a. The LTSS system must use consumer input as a significant factor for planning, development of policies and procedures, development of service delivery systems, evaluation, and the definition and determination of outcomes.

b. Consumers and other stakeholders must have a designated and substantive role in the design, operation, oversight and evaluation of programs.

c. Consumers must not be brought in after decisions have already been made, and must be equal members of decision-making bodies.

3. No Wrong Door / Single Point of Entry

There must be easy access to services and supports through a No Wrong Door / Single Point of Entry (NWD/SPE) system.

a. A preliminary functional and financial assessment (screen) for referral for LTSS financial and service eligibility determinations

must be available from a number of agencies using a simple, uniform screening and referral tool.

b. The agency or program doing the screen must provide information regarding the availability and scope of LTSS, how to apply for LTSS, referral for LTSS financial and service eligibility determinations, and referral for services and supports otherwise available in the community.

c. Screening must not be used for determining or suggesting ineligibility for any program or service; rather, screening must provide relevant information to consumers and links to services for which consumers may be eligible.

d. All screens must be completed in a timely manner with immediate referrals to appropriate agencies for eligibility determinations.

e. Screens must be available from at least the following agencies or programs:

    i. Aging and Disability Resource Centers (ADRCs)

    ii. MSSP providers

    iii. Senior centers

    iv. Independent living centers

    v. Acute care hospitals

    vi. Nursing facilities

    vii. Federally-Qualified Health Centers (FQHCs) Rural Health Clinics (RHCs) and other community clinics

    viii. Community-Based Adult Services (CBAS) providers

    ix. County welfare departments

x. Area Agencies on Aging (AAAs)

xi. IHSS public authorities

xii. 211 information and referral programs

xiii. DHCS web portal

xiv. Statewide 800 number

4. Core Standardized Assessment Process

A core standardized assessment (CSA) process must be used for determining functional eligibility for all LTSS services.

a. The Core Standardized Assessment (CSA) must be a functional eligibility assessment using a uniform, statewide comprehensive instrument or instruments. The CSA must be a person-centered assessment of medical and social functioning and based on individual need and preferences.

b. The consumer must be offered counseling about all available LTSS options so that the consumer will be able to make informed decisions based on complete information about the full range of available options. The counseling must be part of an interactive decision-support process whereby consumers are supported in their deliberations to determine long-term care choices in the context of the consumer's needs, preferences, values and individual circumstances. (Options counseling.)

c. The CSA team must include individuals knowledgeable about community supports and services, and should include medical personnel only when and to the extent that a decision involving medical judgment must be made. Assessment teams must be comprised of individuals who have knowledge of current professional standards, the full range of services the local

community has to offer, and the capacity of community systems to meet even the most complex needs.

d. The CSA must begin with the presumption that most people can live at home if appropriate supports and services are provided, regardless of the level of care needed.

e. The CSA must insure that all possible options for living at home have been fully identified and explored, regardless of the level of care that the consumer needs, and that the consumer has been given a meaningful choice among all options before nursing home or other institutional placement can be authorized. (Community first.)

f. There must be written standards to ensure that the eligibility determination, assessment process, and options counseling proceed in a streamlined and timely manner, not to exceed 30 days, or 3 days if there is an immediate need.

g. The CSA process must be used for initial assessment, reassessment, and for any significant changes in status.

h. The CSA instrument or instruments must be compatible with assessment instruments that are currently required including:

    i. Assessment instruments used for nursing facility residents including the Minimum Data Set (MDS) / Resident Assessment Instrument (RAI) 3.0, and the PASRR Level I and Level II screening instruments.

    ii. Assessment instruments used to determine hours of need under the IHSS program including the IHSS SOC 293 and 293a needs assessment forms.

i. The assessors must have access to all relevant data from all LTSS assessment instruments, including the assessment instruments listed above. This includes information from residents of

institutions who have expressed interest in moving to the community. (MDS 3.0 Section Q.) There must be adequate privacy protections in place.

j. The CSA must identify necessary supports and services for consumers with a diagnosis of severe mental illness. Medi-Cal mental health plans (MHPs) must be required to participate in the assessment process, for consumers eligible for specialty mental health services, to ensure provision of medically necessary specialty mental health services and other community mental health services.

k. There must be written standards, policies and procedures to ensure that consumers can find out the status of eligibility determinations and next steps.

l. The entity responsible for the CSA must have agreements with hospitals and other entities that refer to nursing facilities or other institutions to ensure that CSAs are done before consumers are transferred from the hospital or other entities to a nursing facility or other institution.

5. Individual Service Plan

An individual service plan must be developed with significant consumer direction and involvement following the core standardized assessment.

a. All LTSS services and supports must be provided and/or coordinated through a written individual service plan that identifies the services and supports the consumer will receive, the frequency with which the consumer receives the services, the duration of these services and supports and how all long-terms services and supports must be coordinated.

b. The individual service plan must be developed with significant consumer direction and involvement, and the participation of those providers and other individuals identified by the consumer.

c. The entity that performs the CSA for LTSS must also prepare the individual service plan.

d. The consumer must be offered all LTSS services identified in the individual service plan. The individual service plan must be based only on needs-based criteria (including medical necessity, if appropriate) not on available funding.

e. The service plan must be developed and completed within two weeks, or shorter if there is an immediate need. The plan must be updated regularly, when there is a change in service needs, and when requested by the consumer.

f. The consumer must have the opportunity to review and sign the individual service plan and any amendments to the plan. The consumer must receive a copy of the plan and any amendments to the plan. If there is immediate need, and the consumer agrees, community LTSS services can begin before the plan is signed.

6. Personal Services Coordination (Targeted Case Management)

Effective personal services coordination (targeted case management or TCM) and effective coordination with other resources must be available for beneficiaries who want or need these services.

a. Personal services coordination / TCM must be available for consumers who need and want it. Likewise, it must not be mandated for consumers who do not want it.

b. Personal services coordination / TCM consists of case management services that assist consumers in obtaining services covered under Medi-Cal, such as home health, IHSS, and durable

medical equipment, as well as services available through other public and private providers, such as meals-on-wheels, affordable/accessible housing and assisted living resources, resources for home modifications, utility and phone programs for low-income individuals and individuals with disabilities, legal services, and resources for emergency food and housing. Covered activities also include assessment, service/support planning, and monitoring services and supports to ensure the services and supports are meeting a consumer's needs.

c. Personal services coordination / TCM must be able to immediately authorize additional services in emergency situations (e.g., secure a replacement overnight care provider, or provision of needed supplies).

d. Personal services coordination / TCM must assist the consumer to maintain or obtain, where appropriate, housing, employment, and other services needed to maintain the consumer in the community.

7. Comprehensive LTSS Benefits Package

There must be a comprehensive LTSS benefits package which ensures access to community-based long-term services and supports throughout the state.

a. LTSS benefits must be available throughout the state to all eligible individuals and must be sufficient in amount, duration and scope to ensure that all consumers can receive services in the most integrated setting appropriate.

b. There must be no carve-outs from LTSS based on type of disability, except to the extent consumers receive services through Regional Centers for persons with developmental disabilities, and except to the extent consumers receive services under PACE or the AIDS HCBS waiver. There must be mechanisms for

coordination of services between carved-out providers and other LTSS providers.

c. Mandatory covered benefits must include the full scope of LTSS benefits currently available under the Medi-Cal state plan and Section 1115 Bridge to Reform waiver. The full range of providers currently allowed under the Medi-Cal program must continue to be available, including non-licensed providers for certain services if appropriate and desired by the consumer. As part of this:

    i. The individual provider mode under current law for providing IHSS services must be retained and offered to all eligible individuals. The consumer has the right to choose all IHSS providers and retains the right to employ IHSS providers, including hiring, firing, training and supervision. Training of providers by someone other than the consumer must remain optional.

    ii. The IHSS Nurse Practice Act exception (Welfare and Institutions Code section 12300.1) must be maintained so that a consumer can continue to choose non-medical care and service providers.

    iii. Functions currently performed by IHSS public authorities must continue, such as provider registries, provision of emergency providers, and consumer training.

d. Mandatory covered benefits must also include other services and provider modes that are flexible enough to remove barriers to establishing or maintaining residence in the community. These include the full range of services currently available under Home and Community-Based Services (HCBS) waivers (but without enrollment or payment caps) and services available under Money Follows the Person programs, in addition to other necessary personal care services (PCS), such as short-term PCS to enable consumers to return home from the hospital or PCS that exceed

the scope of services or maximum hours of need available under the current IHSS program.

e. The Medi-Cal program must also include protection of income to enable people to maintain or establish residence in the community. These income protections include:

   i. Consumers who are in nursing facilities or other institutions must be able to use any monthly income to retain their homes in the community rather than paying it towards share of cost in the facility so they can return home when they leave the institution.

   ii. The SSI Temporary Institutionalization (TI) program rules provide for payment at the full community rate, rather than the institutional rate, for consumers who are expected to stay in an institution for less than three months. The TI rules must be extended to the Medi-Cal program so that consumers who are temporarily in institutions will not be deprived of income necessary to retain and maintain their homes.

f. Managed Care organizations must provide or arrange for non-medical transportation required under the Medi-Cal program.

g. The LTSS benefit package must include services for obtaining or maintaining housing and/or employment, where appropriate.

8. Consumer Protections

Adequate consumer protections including availability of a single due process system for all long-term care services and supports regardless of funding source must be provided.

a. Grievance, appeal and fair hearing procedures should generally follow the PACE model:

i. Initial plan coverage determinations must be integrated. The plan will make a single determination of whether a service could have been covered by either Medicare or Medicaid;

ii. A plan's internal appeals process must also make integrated determinations of whether a service could have been covered by either Medicare or Medicaid; and

iii. A consumer pursuing an appeal beyond the plan's internal process must be able to choose whether to use the Medi-Cal or the Medicare appeals process.

b. The following changes must be made to the PACE procedures:

i. Notices of action must be changed to state that aid paid pending an appeal or fair hearing decision is not subject to recoupment—recoupment of aid paid pending is not permitted under Medi-Cal;

ii. Notices that state that the entity making the eligibility determination will help the consumer decide whether to pursue the Medi-Cal or the Medicare appeals process must clarify that accepting the help is voluntary, and that the final choice rests with the consumer;

iii. Consumers should not have to exhaust the managed care plan internal appeal procedure before requesting a Medi-Cal fair hearing; and

iv. Independent medical review (IMR) from the Department of Managed Health Care (DMHC) must not be limited to consumers with Medi-Cal only, but must be available for dual eligible beneficiaries as well.

c. The Independent Medical Review (IMR) process must be expanded:

i. Independent medical review (IMR) from DMHC must not be limited to consumers with Medi-Cal only, but must be available for dual eligible beneficiaries as well.

ii. There must be a process similar to the IMR process for denial of LTSS services by the entity or program doing the functional eligibility assessment for LTSS.

iii. The IMR process for LTSS must include an evaluation of psychosocial factors and needs of the consumer. It must not be a strictly medical review.

iv. The entity conducting the LTSS IMR must demonstrate experience, expertise and/or specialized training in evaluating LTSS needs.

d. There must be a right to access records including core standardized assessment records and individual service plans, documents and information used in preparing core standardized assessments and individual service plans, records related to services provided, and records related to decisions to deny, defer, approve at a lesser amount than requested, suspend, reduce, or terminate services. The records must be provided without charge.

e. Timely and adequate individualized written notice must be provided to the consumer including:

i. Notices informing the consumer when a request for a service has been denied, deferred, approved at a lesser amount than requested, suspended, reduced or terminated.

ii. Notice for determinations of eligibility or ineligibility for LTSS, including notice of LTSS services that may be available or considered but not ultimately recommended by the provider or assessment team.

iii. Notice provided before there is any change in current services or treatment regimes.

iv. Notice in the language the consumer understands. This includes using "plain English" i.e. using terms that are easily understood, translated into the primary language of the consumer (different from requirements that plans translate materials into threshold languages, *i.e.,* languages spoken by a certain percentage of the population) and in alternative formats that are accessible to individuals with disabilities.

f. There must be a right to appeal the following determinations:

i. Eligibility for or enrollment in a particular managed care plan.

ii. Assignment to a particular provider or care team, including denial of the right to decline personal services coordination, case management or care management.

iii. Service decisions including denial, deferral, approval at a lesser amount than requested, suspension, reduction or termination, or provision/non provision of any service, or any other element of the individual service plan.

g. Aid paid pending

i. Aid paid pending the outcome of an appeal or hearing challenging a denial, reduction, suspension or termination of services must be preserved.

ii. Aid paid pending the outcome of an appeal or hearing must be allowed for an appeal or hearing request made:

1. before the end of a period of time for which a service has previously been authorized:

a. when a new request for authorization to continue the service has been deferred or denied, or

b. when the service has been approved at a lesser amount or for a shorter period of time than requested and currently authorized;

2. before the scheduled effective date of any suspension, reduction or termination of a service; or

3. when a currently-authorized service is suspended, reduced or terminated and timely or adequate notice has not been provided.

iii. The obligation of the managed care plan to provide aid paid pending must be specified in the managed care provider's contract with the state.

iv. The obligation to provide aid paid pending must extend to all benefits and services provided by the plan including ones that would traditionally be covered by both Medicare and Medi-Cal, or by Medicare alone.

h. Participation in internal appeals processes and external hearings

i. There must be a right to participate in the plan level appeal process in-person or via video conference or teleconference or at home at the choice of the consumer, as with Medi-Cal fair hearings.

ii. Current rights to participate in Medi-Cal fair hearings and Medicare Administrative Law Judge hearings must be preserved.

i. Timelines

i. The consumer must have at least 60 days from the date of receiving written notice of the most recent determination to file an appeal with the managed care plan.

ii. Plans must make internal decisions on appeals within 30 days for most services and within 72 hours for prescription drug appeals.

iii. Plans must provide expedited appeals processes. Expedited decisions must be made within 72 hours for most services and within 24 hours for prescription drugs.

iv. An expedited appeal must be granted when failing do so will seriously jeopardize the life or health of the enrollee or the enrollee's ability to regain, attain or maintain maximum function.

v. Timelines for external appeals must follow current Medicare and Medi-Cal rules.

9. Access to Independent (Conflict-of-Interest-Free) Ombudsman/Advocate

The Ombudsman/Advocate must be independent of the service delivery system (free from conflicts of interest), and have the funding and capacity to provide information and education on consumer rights; investigate complaints; assist clients in filing grievances, complaints and appeals; assist clients in administrative hearings and in court; and have the capacity to address systemic issues with MCOs and DHCS.

10. Financial Incentives

Financial incentives must be designed to maximize provision of home and community-based services and non-institutional care.

a. Managed care plan capitation rates and incentives must encourage provision of community services. This includes a blended capitation rate in which the same rate is paid for consumers receiving LTSS, whether in the community or in an institution. Blended rates must contain assumptions based on the state's previous year's data regarding the numbers of consumers receiving LTSS both in the community and in institutions.

b. Contracts with Managed Care Organizations must ensure that the medical loss ratio is at least 85% for services.

c. There must be no risk corridors that require payment by the state for institutional care over and above a certain monetary threshold. Capitation rates must be adjusted to reward plans that serve more consumers in the community than was expected and to penalize plans that transition too few consumers from institutions into the community.

d. Managed care plans must have responsibility for institutional LTSS if there is responsibility for community LTSS.

e. Full funding must be available for LTSS services as defined in consumers' individual service plans.

f. Budgets for community-based and institutional care must be integrated (i.e., no carve out or pass-through for institutional payments regardless of the length of stay in the institution).

g. Incentives must be given to encourage and reward provision of community LTSS based on reduced institutional frequency and duration.

h. There must be procedures in place to insure that services are not assessed at less than the actual hours of need.

11. Administration

Administration of LTSS programs must be done in a manner that protects consumers' rights at all stages of the process, improves access to services, and promotes delivery of quality services.

a. To mitigate any explicit or implicit conflicts of interest, the individual or entity performing the CSA or providing personal services coordination must not be influenced by variations in available funding, either locally or from the state. Payment for evaluation or assessment, or qualifications to do evaluation or assessment, cannot be based on the cost of the resulting independent service plans.

b. The State must ensure the independence of persons performing CSAs and developing individual service plans. Written conflict-of-interest-free case management ensures, at a minimum, that persons performing these functions are not:

    i. related by blood or marriage to the consumer,

    ii. related by blood or marriage to any paid caregiver of the consumer,

    iii. financially responsible for the consumer,

    iv. empowered to make financial or health-related decisions on behalf of the consumer,

    v. providers of LTSS for the individual, or those who have interest in or are employed by a provider of LTSS.

c. There must be written standards specifying how screens will be conducted, how CSAs will be conducted, what must be in the individual service plan and how the plan will be implemented, and specifying all other requirements for LTSS eligibility determinations and provision of LTSS services.

d. Implementation of integrated LTSS systems must ensure realistic timelines for implementation of programs and pilot projects for untried or unproven models.

e. Managed Care enrollment and changes to the long-term care system must not disrupt care and services.

f. There must be adequate readiness standards for new programs, e.g., sufficient capacity, accessibility, governance, and fiscal stability.

g. There must be procedures for stopping enrollment pending correction of enrollment problems.

h. Provider contracts must ensure that contractor and subcontractor reimbursement is sufficient to enable provision of quality services.

i. Plans must be required to contract with high quality providers who meet meaningful quality standards, and must be prohibited from contracting with substandard providers. For example, the California Healthcare Foundation at www.calqualitycare.org rates nursing facilities, and plans must be required to contract with providers who have an average or above average rating.

12. Robust State Monitoring and Data Collection

The State must establish standards for, and monitor, quality measures that assess the impact of current programs and new service delivery innovations.

a. The State shall ensure provision of LTSS through state contract provisions, use of data collection, enforcement activities, and corrective action plans.

b. Quality measures must not be limited to clinical outcomes but must also measure whether the consumer is receiving all of the outcomes desired by the consumer.

c. Annual quality improvement reports performed by independent Quality Improvement Organizations (QIOs) must be required for evaluation of the performance of managed care plans and entities that perform core standardized assessments (CSAs) and prepare individual service plans.

d. All information and services, including provider sites, medical diagnostic equipment, and informing materials, must be accessible to persons with disabilities.

e. All providers must be required to have policies and procedures for providing reasonable accommodations and program modifications to people with disabilities upon request.

f. All LTSS service providers must provide adequate data for monitoring need and outcome and the state must establish a single LTSS database that includes:

    i. Annual data on the number of individuals who are assessed (including demographic information on age, race, gender, eligibility group), assessment data (on the number of ADLs and IADL limitations, cognitive limitations, disability conditions), utilization data by service (including all waiver services and IHSS), and expenditure data by services.

    ii. All data obtained as part of the core standardized assessment process (CSA).

    iii. All data obtained through use of assessment instruments for residents of institutions. (Minimum Data Set (MDS) / Resident Assessment Instrument (RAI) 3.0, and the PASRR Level I and Level II screening instruments.)

    iv. All data used to determine IHSS hours of need. (All data collected through the IHSS SOC 293 instrument.)

v. Data on authorization and provision of each service which exceeds the scope of services available under the current Medi-Cal program, including the IHSS program.

vi. Data on LTSS services that are unavailable or could not be provided, and the reason for unavailability or failure to provide.

g. Information regarding performance by providers of LTSS, including Managed Care plans, shall be collected and publicly available so that adjustments can be made and consumers, family members, and advocates can make informed choices.

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