







Disability Rights Education & Defense Fund

Advocacy Principles for Dual Eligible Integration Policy Initiatives

The principles below apply broadly to individuals of all ages who are dually eligible for Medicare and Medicaid, including people with disabilities and chronic conditions. The term "community-based long term supportive services" (CBLTSS) encompasses the full gamut of medical and functional assistance services needed by individuals to live safely, live well, and with maximum independence in their communities throughout their lifetimes.

1. CHOICE

Individuals have the right to choose where, how, and from whom they receive health care. The opportunity to live independently in an apartment or home, to be employed, to be engaged in the community with family and friends, to pursue personal activities, and to set one's own schedule is not to be determined by an individual's physical or mental health status or functional capacity.

2. COMMUNITY-BASED LONG TERM SUPPORTS AND SERVICES Individuals have a right to community-based long term supportive services (CBLTSS) that are readily available, consumer-directed to the maximum extent, and of sufficient scope to support independent living in the community. Policy initiatives must address how they will enhance the development and availability of CBLTSS, while also preserving the best features of a state's existing CBLTSS systems.

3. DO NO HARM

Individuals cannot be forced to bear such possible consequences as the short or long-term interruption of needed provider relations, reduced or lost services and benefits, CBLTSS coverage that is inadequate in both scope and levels, and the constant fear of unknown disruptions to critical healthcare services as states attempt to integrate highly complex and historically discrete Medicaid and Medicare funding and service streams. Existing Medicare and state Medicaid packages must not be weakened in the name of achieving unproven future benefits.

4. INDIVIDUAL AT CENTER

The individual's needs and experiences are core to every aspect of policy initiative design, from stakeholder outreach and process to integrated service delivery, from beneficiary assessment to establishing provider reimbursement rates, from implementation to monitoring and enforcement. In particular, care coordination strategies and CBLTSS must consistently inform and build upon individuals'

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desires and capacity for self-directed care and independent living within their chosen communities.

5. MEANINGFUL COMMUNICATION AND INPUT

Individuals have a right to effective communication of all outreach information, general enrollee and beneficiary communications, and individual notices concerning either their health or policy initiatives and procedures that could affect their health care services. This principle applies whether information is intended for distribution by mail, in person, electronically, or through any other technological process. Stakeholder processes are not complete without beneficiary input and feedback. Once enrolled in new programs, beneficiaries must have meaningful avenues to provide ongoing input into program governance, policy and direction.

6. PRESERVING ESTABLISHED PROVIDER RELATIONS

Individuals have a right to continue to see the experienced providers with whom they have established relationships. Various options for preserving individual continuity of care with providers must be made available at several levels and during key periods of time, such as during enrollment, during an extended transition period, and throughout treatment for a complex chronic or temporary condition.

7. NON-DISCRIMINATION

Individuals have a right to receive non-discriminatory and effective healthcare that fully complies with applicable federal and state law, which includes physical and programmatic accessibility, cultural and linguistic capacity, and appropriate specialist expertise in all aspects and levels of service delivery.

8. CONSUMER PROTECTION

Individuals have a right to consumer protections including strong state and federal administrative complaint mechanisms and recourse to state and federal anti-discrimination law without the need for administrative exhaustion, as well as requirements directed at such critical components as network adequacy, cultural and linguistic competence, stakeholder input, strong oversight and enforcement mechanisms, and the continual collection and development of real time and beneficiary-oriented data measures that track successful health outcomes and the maintenance of independent living in the community.

9. FINANCING AND PAYMENT

Initiative financing and payment structures must be transparent and cannot give providers an incentive for denying or minimizing the services and care needed by individuals, or give states the opportunity to use federal financing to supplement a state's Medicaid budget. The accrual of short and long-term savings from integration must be reinvested in the expansion of CBLTSS and a broad range of alternative services that further independent living in the community.

10. ENROLLMENT

Individuals must be allowed to actively opt in to new initiatives rather than being passively or mandatorily enrolled.