

SEC. 125. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES AND DESIGNATED STATE AGENCIES. [42 USC 15025]

- a. **IN GENERAL.**—Each State that receives assistance under this subtitle shall establish and maintain a Council to undertake advocacy, capacity building, and systemic change activities (consistent with subsections (b) and (c) of section 101) that contribute to a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system of community services, individualized supports, and other forms of assistance that contribute to the achievement of the purpose of this subtitle. The Council shall have the authority to fulfill the responsibilities described in subsection (c).
- b. **COUNCIL MEMBERSHIP.**—
 1. **COUNCIL APPOINTMENTS.**—
 - A. **IN GENERAL.**—The members of the Council of a State shall be appointed by the Governor of the State from among the residents of that State.
 - B. **RECOMMENDATIONS.**—The Governor shall select members of the Council, at the discretion of the Governor, after soliciting recommendations from organizations representing a broad range of individuals with developmental disabilities and individuals interested in individuals with developmental disabilities, including the non-State agency members of the Council. The Council may, at the initiative of the Council, or on the request of the Governor, coordinate Council and public input to the Governor regarding all recommendations.
 - C. **REPRESENTATION.**—The membership of the Council shall be geographically representative of the State and reflect the diversity of the State with respect to race and ethnicity.
 2. **MEMBERSHIP ROTATION.**—The Governor shall make appropriate provisions to rotate the membership of the Council. Such provisions shall allow members to continue to serve on the Council until such members' successors are appointed. The Council shall notify the Governor regarding membership requirements of the Council, and shall notify the Governor when vacancies on the Council remain unfilled for a significant period of time.
 3. **REPRESENTATION OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES.**—Not less than 60 percent of the membership of each Council shall consist of individuals who are—
 - A.
 - i. individuals with developmental disabilities;
 - ii. parents or guardians of children with developmental disabilities; or

- iii. immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves; and
 - B. not employees of a State agency that receives funds or provides services under this subtitle, and who are not managing employees (as defined in section 1126(b) of the Social Security Act (42 U.S.C. 1320a–5(b)) of any other entity that receives funds or provides services under this subtitle.
- 4. REPRESENTATION OF AGENCIES AND ORGANIZATIONS.—
 - A. IN GENERAL.—Each Council shall include—
 - i. representatives of relevant State entities, including—
 - I. State entities that administer funds provided under Federal laws related to individuals with disabilities, including the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.), the Older Americans Act of 1965 (42 U.S.C. 3001 et seq.), and titles V and XIX of the Social Security Act (42 U.S.C. 701 et seq. and 1396 et seq.);
 - II. Centers in the State; and
 - III. the State protection and advocacy system; and
 - ii. representatives, at all times, of local and non-governmental agencies, and private nonprofit groups concerned with services for individuals with developmental disabilities in the State in which such agencies and groups are located.
 - B. AUTHORITY AND LIMITATIONS.—The representatives described in subparagraph (A) shall—
 - i. have sufficient authority to engage in policy planning and implementation on behalf of the department, agency, or program such representatives represent; and
 - ii. recuse themselves from any discussion of grants or contracts for which such representatives' departments, agencies, or programs are grantees, contractors, or applicants and comply with the conflict of interest assurance requirement under section 124(c)(5)(D).
- 5. COMPOSITION OF MEMBERSHIP WITH DEVELOPMENTAL DISABILITIES.—
 - Of the members of the Council described in paragraph (3)—
 - A. 1/3 shall be individuals with developmental disabilities described in paragraph (3)(A)(i);
 - B. 1/3 shall be parents or guardians of children with developmental disabilities described in paragraph (3)(A)(ii), or immediate

relatives or guardians of adults with developmental disabilities described in paragraph (3)(A)(iii); and

- C. 1/3 shall be a combination of individuals described in paragraph (3)(A).

6. INSTITUTIONALIZED INDIVIDUALS.—

- A. IN GENERAL.—Of the members of the Council described in paragraph (5), at least 1 shall be an immediate relative or guardian of an individual with a developmental disability who resides or previously resided in an institution or shall be an individual with a developmental disability who resides or previously resided in an institution.
- B. LIMITATION.—Subparagraph (A) shall not apply with respect to a State if such an individual does not reside in that State.

c. COUNCIL RESPONSIBILITIES.—

- 1. IN GENERAL.—A Council, through Council members, staff, consultants, contractors, or subgrantees, shall have the responsibilities described in paragraphs (2) through (10).
- 2. ADVOCACY, CAPACITY BUILDING, AND SYSTEMIC CHANGE ACTIVITIES.—The Council shall serve as an advocate for individuals with developmental disabilities and conduct or support programs, projects, and activities that carry out the purpose of this subtitle.
- 3. EXAMINATION OF GOALS.—At the end of each grant year, each Council shall—
 - A. determine the extent to which each goal of the Council was achieved for that year;
 - B. determine to the extent that each goal was not achieved, the factors that impeded the achievement;
 - C. determine needs that require amendment of the 5-year strategic State plan required under section 124;
 - D. separately determine the information on the self-advocacy goal described in section 124(c)(4)(A)(ii); and
 - E. determine customer satisfaction with Council supported or conducted activities.
- 4. STATE PLAN DEVELOPMENT.—The Council shall develop the State plan and submit the State plan to the Secretary after consultation with the designated State agency under the State plan. Such consultation shall be solely for the purposes of obtaining State assurances and ensuring consistency of the plan with State law.
- 5. STATE PLAN IMPLEMENTATION.—
 - A. IN GENERAL.—The Council shall implement the State plan by conducting and supporting advocacy, capacity building, and systemic change activities such as those described in subparagraphs (B) through (L).

- B. OUTREACH.—The Council may support and conduct outreach activities to identify individuals with developmental disabilities and their families who otherwise might not come to the attention of the Council and assist and enable the individuals and families to obtain services, individualized supports, and other forms of assistance, including access to special adaptation of generic community services or specialized services.
- C. TRAINING.—The Council may support and conduct training for persons who are individuals with developmental disabilities, their families, and personnel (including professionals, paraprofessionals, students, volunteers, and other community members) to enable such persons to obtain access to, or to provide, community services, individualized supports, and other forms of assistance, including special adaptation of generic community services or specialized services for individuals with developmental disabilities and their families. To the extent that the Council supports or conducts training activities under this subparagraph, such activities shall contribute to the achievement of the purpose of this subtitle.
- D. TECHNICAL ASSISTANCE.—The Council may support and conduct technical assistance activities to assist public and private entities to contribute to the achievement of the purpose of this subtitle.
- E. SUPPORTING AND EDUCATING COMMUNITIES.—The Council may support and conduct activities to assist neighborhoods and communities to respond positively to individuals with developmental disabilities and their families—
 - i. by encouraging local networks to provide informal and formal supports;
 - ii. through education; and
 - iii. by enabling neighborhoods and communities to offer such individuals and their families access to and use of services, resources, and opportunities.
- F. INTERAGENCY COLLABORATION AND COORDINATION.—The Council may support and conduct activities to promote interagency collaboration and coordination to better serve, support, assist, or advocate for individuals with developmental disabilities and their families.
- G. COORDINATION WITH RELATED COUNCILS, COMMITTEES, AND PROGRAMS.—The Council may support and conduct activities to enhance coordination of services with—
 - i. other councils, entities, or committees, authorized by Federal or State law, concerning individuals with disabilities (such as the State interagency coordinating council established under subtitle C of the Individuals

with Disabilities Education Act (20 U.S.C. 1431 et seq.), the State Rehabilitation Council and the Statewide Independent Living Council established under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the State mental health planning council established under subtitle B of title XIX of the Public Health Service Act (42 U.S.C. 300x-1 et seq.), and the activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012), and

- ii. entities carrying out other similar councils, entities, or committees);
 - iii. parent training and information centers under part D of the Individuals with Disabilities Education Act (20 U.S.C. 1451 et seq.) and other entities carrying out federally funded projects that assist parents of children with disabilities; and
 - iv. other groups interested in advocacy, capacity building, and systemic change activities to benefit individuals with disabilities.
- H. BARRIER ELIMINATION, SYSTEMS DESIGN AND REDESIGN.—The Council may support and conduct activities to eliminate barriers to access and use of community services by individuals with developmental disabilities, enhance systems design and redesign, and enhance citizen participation to address issues identified in the State plan.
- I. COALITION DEVELOPMENT AND CITIZEN PARTICIPATION.—The Council may support and conduct activities to educate the public about the capabilities, preferences, and needs of individuals with developmental disabilities and their families and to develop and support coalitions that support the policy agenda of the Council, including training in self-advocacy, education of policymakers, and citizen leadership skills.
- J. INFORMING POLICYMAKERS.—The Council may support and conduct activities to provide information to policymakers by supporting and conducting studies and analyses, gathering information, and developing and disseminating model policies and procedures, information, approaches, strategies, findings, conclusions, and recommendations. The Council may provide the information directly to Federal, State, and local policymakers, including Congress, the Federal executive branch, the Governors, State legislatures, and State agencies, in order to increase the ability of such policymakers to offer opportunities and to enhance or adapt generic services to meet the needs of, or provide specialized services to, individuals with developmental disabilities and their families.

- K. DEMONSTRATION OF NEW APPROACHES TO SERVICES AND SUPPORTS.—
 - i. IN GENERAL.—The Council may support and conduct, on a time-limited basis, activities to demonstrate new approaches to serving individuals with developmental disabilities that are a part of an overall strategy for systemic change. The strategy may involve the education of policymakers and the public about how to deliver effectively, to individuals with developmental disabilities and their families, services, supports, and assistance that contribute to the achievement of the purpose of this subtitle.
 - ii. SOURCES OF FUNDING.—The Council may carry out this subparagraph by supporting and conducting demonstration activities through sources of funding other than funding provided under this subtitle, and by assisting entities conducting demonstration activities to develop strategies for securing funding from other sources.
 - L. OTHER ACTIVITIES.—The Council may support and conduct other advocacy, capacity building, and systemic change activities to promote the development of a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system of community services, individualized supports, and other forms of assistance that contribute to the achievement of the purpose of this subtitle.
6. REVIEW OF DESIGNATED STATE AGENCY.—The Council shall periodically review the designated State agency and activities carried out under this subtitle by the designated State agency and make any recommendations for change to the Governor.
7. REPORTS.—Beginning in fiscal year 2002, the Council shall annually prepare and transmit to the Secretary a report. Each report shall be in a form prescribed by the Secretary by regulation under section 104(b). Each report shall contain information about the progress made by the Council in achieving the goals of the Council (as specified in section 124(c)(4)), including—
- A. a description of the extent to which the goals were achieved;
 - B. a description of the strategies that contributed to achieving the goals;
 - C. to the extent to which the goals were not achieved, a description of factors that impeded the achievement;
 - D. separate information on the self-advocacy goal described in section 124(c)(4)(A)(ii);
 - E.

- i. as appropriate, an update on the results of the comprehensive review and analysis described in section 124(c)(3); and
 - ii. information on consumer satisfaction with Council supported or conducted activities;
 - F.
 - i. a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities in Intermediate Care Facilities (Mental Retardation) receive; and
 - ii. a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities served through home and community-based waivers (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c)) receive;
 - G. an accounting of the manner in which funds paid to the State under this subtitle for a fiscal year were expended;
 - H. a description of—
 - i. resources made available to carry out activities to assist individuals with developmental disabilities that are directly attributable to Council actions; and
 - ii. resources made available for such activities that are undertaken by the Council in collaboration with other entities; and
 - I. a description of the method by which the Council will widely disseminate the annual report to affected constituencies and the general public and will assure that the report is available in accessible formats.
- 8. BUDGET.—Each Council shall prepare, approve, and implement a budget using amounts paid to the State under this subtitle to fund and implement all programs, projects, and activities carried out under this subtitle, including—
 - A.
 - i. conducting such hearings and forums as the Council may determine to be necessary to carry out the duties of the Council; and
 - ii. as determined in Council policy—
 - I. reimbursing members of the Council for reasonable and necessary expenses (including expenses for child care and personal assistance services) for attending Council meetings and performing Council duties;

- II. paying a stipend to a member of the Council, if such member is not employed or must forfeit wages from other employment, to attend Council meetings and perform other Council duties;
 - III. supporting Council member and staff travel to authorized training and technical assistance activities including in-service training and leadership development activities; and
 - IV. carrying out appropriate subcontracting activities;
 - B. hiring and maintaining such numbers and types of staff (qualified by training and experience) and obtaining the services of such professional, consulting, technical, and clerical staff (qualified by training and experience), consistent with State law, as the Council determines to be necessary to carry out the functions of the Council under this subtitle, except that such State shall not apply hiring freezes, reductions in force, prohibitions on travel, or other policies to the staff of the Council, to the extent that such policies would impact the staff or functions funded with Federal funds, or would prevent the Council from carrying out the functions of the Council under this subtitle; and
 - C. directing the expenditure of funds for grants, contracts, interagency agreements that are binding contracts, and other activities authorized by the State plan approved under section 124.
- 9. STAFF HIRING AND SUPERVISION.—The Council shall, consistent with State law, recruit and hire a Director of the Council, should the position of Director become vacant, and supervise and annually evaluate the Director. The Director shall hire, supervise, and annually evaluate the staff of the Council. Council recruitment, hiring, and dismissal of staff shall be conducted in a manner consistent with Federal and State nondiscrimination laws. Dismissal of personnel shall be conducted in a manner consistent with State law and personnel policies.
- 10. STAFF ASSIGNMENTS.—The staff of the Council, while working for the Council, shall be responsible solely for assisting the Council in carrying out the duties of the Council under this subtitle and shall not be assigned duties by the designated State agency or any other agency or entity of the State.
- 11. CONSTRUCTION.—Nothing in this title shall be construed to authorize a Council to direct, control, or exercise any policymaking authority or administrative authority over any program assisted under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.) or the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.).