



# STATE OF CONNECTICUT

OFFICE OF PROTECTION AND ADVOCACY FOR  
PERSONS WITH DISABILITIES  
60B WESTON STREET, HARTFORD, CT 06120-1551

JAMES D. McGAUGHEY  
Executive Director

Phone: 1/860-297-4307  
Confidential Fax: 1/860-297-4305

## **Testimony of the Office of Protection and Advocacy for Persons with Disabilities Before the Appropriations Committee**

Presented by: James D. McGaughey  
Executive Director  
March 8, 2012

Good morning, and thank you for this opportunity to comment H.B. 5016, which proposes to consolidate a number of agencies, including, in Sections 74 through 82, the consolidation of our agency with the Commission on Human Rights and Opportunities. The Bill proposes formation of a new agency to be called the Department of Human Rights, Protection and Advocacy. For a number of reasons I believe this proposal is ill considered, and that it will significantly weaken safeguarding protections for people with disabilities in Connecticut. These reasons are:

- 1. The proposed consolidation misunderstands the fundamentally different roles and identities of the two agencies, and would foster confusion about their respective missions.** OPA and CHRO exist for different reasons, are charged with different duties and perform very different functions. CHRO is primarily a civil rights law enforcement agency. It impartially investigates and adjudicates claims of discrimination based on membership in a variety of protected classes, and it has the authority to impose remedies. It also enforces a variety of legal requirements that apply to state agencies (e.g. affirmative action, minority contracting set-asides, etc.) On the other hand, OPA exists as a safeguard - a vigilant presence capable of actively interceding in situations of abuse and neglect, and where the rights of people with disabilities are at risk. In contrast to CHRO's investigatory neutrality, we are unabashed advocates for the values espoused by the disability rights movement: respect, dignity, inclusion, personal choice, autonomy and empowerment. We were created because, after numerous scandals, disappointments and repeated systems failures, policymakers realized that good intentions and well meaning reform efforts were not sufficient: that the rights of people with disabilities are too often disregarded, that circumstances often conspire to render people with disabilities vulnerable to abuse and neglect, and that even the most altruistic, best led programs and services can and sometimes do fail. We are what is sometimes described as an "intentional safeguard" against the inherent fallibility of complex human systems. Our operational flexibility and wide-ranging authority contribute to our effectiveness, but our clear identity as independent advocates is equally important. Families and people with disabilities need to know that we understand their experience and will faithfully pursue their interests even if doing so brings us into conflict with others. People who report abuse and neglect to us need to know that our investigations will not be compromised by conflicting loyalties. Consolidating us with an entity that is defined around different issues and fulfills very different functions will cloud our identity as independent disability rights advocates and create confusion about the type of responses people can expect from us.

- 2. In addition to fostering confusion, the proposed new agency would also create conflicts of interest.** Not infrequently, OPA represents people with disabilities who pursue complaints of discrimination before the CHRO. I am not sure how the landlords, employers, providers of public accommodations, municipal agencies and others that must respond to those complaints - and against whom sanctions can be imposed by CHRO - are going to feel about having both the “prosecution” and the “judges” all be from the same agency. Nor is it clear what would happen if CHRO dismisses a complaint of disability discrimination brought by one of our clients, but OPA feels obliged to appeal that decision to court. That could put the CHRO part of the proposed new agency in the defendant role, while the OPA part of the agency represents the plaintiff. There are other conflict-of-interest scenarios as well: What if someone wants to file a CHRO complaint against OPA? What if OPA needs to pursue advocacy action against the CHRO side of the new Department in order to secure reasonable accommodations or modifications for a complainant with a disability? Situations like these do actually occur from time to time. So long as we are two separate agencies, we can each do our job. But in a consolidated agency, these scenarios create unavoidable conflicts of interest. And, while trying to figure out what to do about such conflicts would be a real headache, the perception of an internally conflicted agency would be quite damaging to our credibility. At the end of the day, our credibility is one of our most precious assets. People have to trust that we will give them our undivided loyalty and that we will be faithful to our mandate and assigned role as an independent, zealous advocate for their rights.
- 3. Placing OPA into the proposed new Department, or making any other substantial change to the identity and governance structure of OPA risks the loss of critically needed federal P&A funds and the unique safeguarding authority conferred by federal law. It also puts federal funding for other disability programs at risk.** Federal law requires states to designate an entity as its Protection & Advocacy (P&A) system, which must be structurally independent from service agencies and authorized to perform certain enumerated advocacy and safeguarding functions. Once it has designated an entity to serve as its P&A, a state may only designate a different entity for “good cause”. Even when there is “good cause” for redesignation, strict procedural requirements must be followed. There must be clear notice, a 60 day comment period, a public hearing, and reviews by federal oversight agencies. Most importantly, there must be opportunities for deliberation and input from the disability community.

Combining OPA and CHRO into a new agency would constitute a “re-designation” of the P&A system for Connecticut, particularly because, under the proposal, our governance structure and operational autonomy would change significantly. More specifically, the director of the P&A would be appointed by, and presumably report to the executive director of the new Department. The implementing language in HB 5016 further provides that the P&A director would no longer have independent control over hiring decisions, budgeting processes and expenditures, including contracting and funding for litigation and investigations – key areas of P&A system authority.

These changes in governance and authority present a markedly different picture of the P&A's operating autonomy than has been the case since 1977, when OPA was first established and designated as Connecticut's P&A system.

I have been told that our federal oversight agencies will see this "consolidation" as a re-designation of the Connecticut P&A system. I have also been told that the federal Administration on Developmental Disabilities (ADD) is, or soon will be notifying OPM of its concerns. If ADD finds it to be an illegal re-designation, or if, as a result of a subsequent compliance review, it determines that our Office no longer conforms to the legal requirements for independence and governance established in the federal statutes and regulations that define P&A systems, the State would risk losing OPA's federal funding. That funding – which amounts to almost \$1.5 million per year - supports 11 staff positions in our agency, as well as several contracts with advocacy groups. And, because having a designated, conforming P&A system is a prerequisite for a state's receiving certain other federal funds under the Developmental Disabilities Act, funding for the Connecticut Council on Developmental Disabilities (\$724,000 per year) and UCONN's Center for Excellence in Developmental Disabilities (\$550,000 per year) would also be imperiled.

Just as importantly, Connecticut residents with disabilities could lose the safeguarding and advocacy authority conferred by federal P&A statutes (PADD, PAIMI, PAIR, etc.). If that happens, OPA would no longer be able to conduct abuse/neglect investigations, pursue legal and administrative remedies, educate policy makers and reach out to traditionally underserved populations under the authority conferred by federal P&A statutes – authority that affords us access to people living in institutions and other facilities, and, under certain circumstances, to information that can otherwise be hidden behind a cloak of confidentiality.

I am aware that there has been some discussion of putting OPA into the Office of Governmental Accountability (OGA) as an alternative to combining us with CHRO. However, based on my research, I believe that moving us into OGA would also be seen as a re-designation of the P&A system. The Administration on Developmental Disabilities has not had the specifics of such a proposal put before it, but I have discussed OGA's structure with them. They are aware that the various divisions within OGA retain their original names, missions and, at least for the time being, most of their original operating autonomy. However, they indicated to me that in reaching a judgment on the "re-designation question", they would look to OPA's governance structure, which has not changed since the time of our original designation, and compare it with what is being proposed. OPA was originally recognized as Connecticut's P&A system based on the passage of our enabling statute, now codified at C.G.S. 46a-7 et. seq. It is clear from both the legislative history surrounding passage of that legislation, and from the structure established by the statute itself, that OPA was intentionally created to be an independent agency – one that could stand on equal footing with other executive branch agencies. The General Assembly had considered several other structural options, including the proposal that had been favored by the Governor's Office – to make OPA a division within the Department of Consumer Protection.

That option was rejected, in part due to testimony offered by disability advocates and by members of a special commission that had been established to study and recommend how best to implement a P&A system in Connecticut. While the ADD staff I have spoken with is understandably reluctant to “shoot from the hip” when there is no actual proposal before them, they were fairly clear that any change in the location and structure described in our enabling statute would be considered a re-designation, and would have to meet the “good cause” and procedural requirements of the Developmental Disabilities Act.

Virtually all standards for disability advocacy organizations that provide individual representation and safeguarding, including the National Disability Rights Network standards for Protection and Advocacy agencies, stress that structural and administrative independence are essential prerequisites for a credible advocacy program. This emphasis on independence derives partly from the history of human services, which is replete with examples of internal watchdog programs that compromised or were cowed in the face of organizational and political pressures. But it also reflects a reality that many people with disabilities and their families face. People seek out assistance from P&A because they are falling through the cracks or are up against some kind of power structure that isn't listening. They may need useful, empowering information, or some more concrete form of help “fighting city hall”. Or they may need to have immediate attention paid to a neglectful or abusive situation. People with disabilities and their families need a P&A system that carries the full authority of federal law, that is free from conflicts of interest, and that sends a clear message about its identity and role as an independent advocate. I believe that we effectively meet that need as we are currently configured, but that we will not if we are consolidated (acquired?) by the proposed new Department.

I also believe that the investment the State makes in funding us is well justified in terms of the systems changes and improvements that result from our efforts. As we discussed with our sub-committee at our working session, I believe we are “turning some curves”. Our annual report also cites examples of how our safeguarding activities have reduced deaths of service system clients due to choking, drowning, poor healthcare coordination and unrecognized medical risks, just as our administrative attention to reducing the risk of repeat victimization to neglect and abuse is, in fact, reducing that risk. All the “back office” functions of both OPA and CHRO have already been consolidated within the Department of Administrative Services, and both agencies have already been stripped of all but the most essential management positions. So there are no savings to be had from this consolidation. But there is a real risk that people with disabilities in Connecticut will lose a precious resource.

Accordingly, I urge you to delete the sections of HB 5016 that refer to this consolidation, and renew our request that you restore funding for OPA to continue as an independent agency. Thank you for your attention. If there are any questions, I will try to answer them.



DEPARTMENT OF HEALTH & HUMAN SERVICES

ADMINISTRATION FOR CHILDREN AND FAMILIES

370 L'Enfant Promenade, S.W.  
Washington, D.C. 20447

March 7, 2012

James McGaughey  
Executive Director  
Office of Protection and Advocacy for Persons with Disabilities  
60-B Weston Street  
Hartford, CT 06120-1551

Dear Mr. McGaughey:

I am writing to follow up on conversations regarding your questions around a potential consolidation and/or restructuring of the Office of Protection and Advocacy (OPA), Connecticut's federally designated Protection and Advocacy System.

OPA is one of 57 State and Territorial Protection and Advocacy Systems authorized under the federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act). OPA receives federal funding from five federal agencies to implement eight protection and advocacy programs. Restructuring or consolidating OPA with other state agencies could constitute a redesignation. This may be a violation of the DD Act, P.L. 106-402, and could jeopardize Connecticut's federal funding for this Agency that ensures that people with disabilities have their rights protected and live free from abuse and neglect.

Section 143(a)(1) and (4)(A) of the DD Act requires that the State have in effect a system to protect and advocate for the rights of individuals with developmental disabilities, and that the agency implementing the system shall not be redesignated unless there is good cause for the redesignation. The law also describes the redesignation process requirements (see attachment A for full reference to the DD Act requirements).

Changes in the Protection and Advocacy System in Connecticut may jeopardize compliance with federal requirements that the System have the independence and authority to perform certain safeguarding functions, including:

- Any change that affects the structural independence, operating autonomy or the identity of OPA as an independent agency can potentially affect its ability to function as a P&A system. For more than thirty years, OPA has been Connecticut's designated Protection and Advocacy system and has been identified in numerous federal and State documents and public statements as a structurally independent agency.
- Critical functions and operating decisions that are currently within the exclusive domain of the Director of the Protection and Advocacy System must be retained. Specifically, the ability to purchase and contract for necessary services including but not limited to legal services and the authority to receive

and spend funding are critical functions, as well as the ability to employ necessary staff and administer the general operations of the P&A office.

- OPA's federally mandated Advisory Board serves an important role, advising the director of OPA on matters relating to advocacy policy, client service priorities and issues affecting persons with disabilities. The director's authority to independently implement those policies, pursue those priorities, and address those issues must be retained in order to be capable of "advis[ing] the system (emphasis added) on policies and priorities to be carried out in protecting and advocating the rights of individuals with developmental disabilities," as required by the DD Act. In effect, reduction of the independent authority of the Director to govern the P&A system also reduces the effectiveness with which the Advisory Board could impact the way the system goes about the business of protecting and advocating.

We hope to support the Office of Protection and Advocacy for Persons with Disabilities to remain in compliance with federal requirements for the Protection and Advocacy System to protect the legal and human rights of individuals with disabilities. We are happy to answer any further questions or supply any additional technical assistance you may find useful.

Sincerely,



Sharon Lewis  
Commissioner  
Administration on Developmental Disabilities

Attachment: The Developmental Disabilities Assistance and Bill of Rights Act of 2000, Subtitle C

CC: Molly Cole, Director, Connecticut Council on Developmental Disabilities  
Mary Elisabeth Bruder, Director, A.J. Papanikou Center for Excellence in Developmental Disabilities

## **Attachment A**

### **The Developmental Disabilities Assistance and Bill of Rights Act of 2000**

**PUBLIC LAW 106-402--October 30, 2000  
114 STAT. 1677**

#### **SUBTITLE C--PROTECTION AND ADVOCACY OF INDIVIDUAL RIGHTS**

##### **42 USC 15041 SEC. 141. PURPOSE.2**

The purpose of this subtitle is to provide for allotments to support a protection and advocacy system (referred to in this subtitle as a "system") in each State to protect the legal and human rights of individuals with developmental disabilities in accordance with this subtitle.

##### **42 USC 15042 SEC. 142. ALLOTMENTS AND PAYMENTS.**

###### **(a) ALLOTMENTS.-**

(1) **IN GENERAL.** -To assist States in meeting the requirements of section 143(a), the Secretary shall allot to the States the amounts appropriated under section 145 and not reserved under paragraph (6). Allotments and reallootments of such sums shall be made on the same basis as the allotments

and reallootments are made under subsections (a)(1)(A) and (e) of section 122, except as provided in paragraph (2).

###### **(2) MINIMUM ALLOTMENTS.** -In any case in which-

(A) the total amount appropriated under section 145 for a fiscal year is not less than \$20,000,000, the allotment under paragraph (1) for such fiscal year-

(i) to each of American Samoa, Guam, the United States Virgin Islands, and the Commonwealth of the Northern Mariana Islands may not be less than \$107,000; and

(ii) to any State not described in clause (i) may not be less than \$200,000;  
or

(B) the total amount appropriated under section 145 for a fiscal year is less than \$20,000,000, the allotment under paragraph (1) for such fiscal year-

(i) to each of American Samoa, Guam, the United States Virgin Islands, and the Commonwealth of the Northern Mariana Islands may not be less than \$80,000; and

(ii) to any State not described in clause (i) may not be less than \$150,000.

(3) REDUCTION OF ALLOTMENT. -Notwithstanding paragraphs (1) and (2), if the aggregate of the amounts to be allotted to the States pursuant to such paragraphs for any fiscal year exceeds the total amount appropriated for such allotments under section 145 for such fiscal year, the amount to be allotted to each State for such fiscal year shall be proportionately reduced.

(4) INCREASE IN ALLOTMENTS. -In any year in which the total amount appropriated under section 145 for a fiscal year exceeds the total amount appropriated under such section (or a corresponding provision) for the preceding fiscal year by a percentage greater than the most recent percentage change in the Consumer Price Index published by the Secretary of Labor under section 100(c)(1) of the Rehabilitation Act of 1973 (29 U.S.C. 720(c)(1)) (if the percentage change indicates an increase), the Secretary shall increase each of the minimum allotments described in subparagraphs (A) and (B) of paragraph (2). The Secretary shall increase each minimum allotment by an amount that bears the same ratio to the amount of such minimum allotment (including any increases in such minimum allotment under this paragraph (or a corresponding provision) for prior fiscal years) as the amount that is equal to the difference between-

(A) the total amount appropriated under section 145 for the fiscal year for which the increase in the minimum allotment is being made; minus

(B) the total amount appropriated under section 145 (or a corresponding provision) for the immediately preceding fiscal year, bears to the total amount appropriated under section 145 (or a corresponding provision) for such preceding fiscal year.

(5) MONITORING THE ADMINISTRATION OF THE SYSTEM. -In a State in which the system is housed in a State agency, the State may use not more than 5 percent of any allotment under this subsection for the costs of monitoring the administration of the system required under section 143(a).

(6) TECHNICAL ASSISTANCE AND AMERICAN INDIAN CONSORTIUM. -In any case in which the total amount appropriated under section 145 for a fiscal year is more than \$24,500,000, the Secretary shall-

(A) use not more than 2 percent of the amount appropriated to provide technical assistance to eligible systems with respect to activities carried out under this subtitle (consistent with requests by such systems for such assistance for the year); and

**114 STAT. 1714 PUBLIC LAW 106-402-OCT. 30, 2000**

(B) provide a grant in accordance with section 143(b), and in an amount described in paragraph (2)(A)(i), to an American Indian consortium to provide protection and advocacy services.

(b) PAYMENT TO SYSTEMS. -Notwithstanding any other provision of law, the Secretary shall pay directly to any system in a State that complies with the provisions of this subtitle the amount of the allotment made for the State under this section, unless the system specifies otherwise.

(c) UNOBLIGATED FUNDS. -Any amount paid to a system under this subtitle for a fiscal year and remaining unobligated at the end of such year shall remain available to such system for the next fiscal year, for the purposes for which such amount was paid.

**42 USC 15043 SEC. 143. SYSTEM REQUIRED.**

(a) SYSTEM REQUIRED. -In order for a State to receive an allotment under subtitle B or this subtitle-

(1) the State shall have in effect a system to protect and advocate the rights of individuals with developmental disabilities;

(2) such system shall-

(A) have the authority to-

(i) pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of such individuals within the State who are or who may be eligible for treatment, services, or habilitation, or who are being considered for a change in living arrangements, with particular attention to members of ethnic and racial minority groups; and

(ii) provide information on and referral to programs and services addressing the needs of individuals with developmental disabilities;

(B) have the authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred;

(C) on an annual basis, develop, submit to the Secretary, and take action with regard to goals (each of which is related to 1 or more areas of emphasis) and priorities, developed through data driven strategic planning, for the system's activities;

(D) on an annual basis, provide to the public, including individuals with developmental disabilities attributable to either physical impairment, mental impairment, or a combination of physical and mental impairment, and their representatives, and as appropriate, non-State agency representatives of the State Councils on Developmental Disabilities, and Centers, in the State, an opportunity to comment on-

(i) the goals and priorities established by the system and the rationale for the establishment of such goals; and

(ii) the activities of the system, including the coordination of services with the entities carrying out advocacy programs under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the Older Americans

**PUBLIC LAW 106-402-OCT. 30, 2000 114 STAT. 1715**

Act of 1965 (42 U.S.C. 3001 et seq.), and the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (42 U.S.C. 10801 et seq.), and with entities carrying out other related programs, including the parent training and information centers funded under the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.), and activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012);

(E) establish a grievance procedure for clients or prospective clients of the system to ensure that individuals with developmental disabilities have full access to services of the system;

(F) not be administered by the State Council on Developmental Disabilities;

(G) be independent of any agency that provides treatment, services, or habilitation to individuals with developmental disabilities;

(H) have access at reasonable times to any individual with a developmental disability in a location in which services, supports, and other assistance are provided to such an individual, in order to carry out the purpose of this subtitle;

(I) have access to all records of-

(i) any individual with a developmental disability who is a client of the system if such individual, or the legal guardian, conservator, or other legal representative of such individual, has authorized the system to have such access;

(ii) any individual with a developmental disability, in a situation in which-

(I) the individual, by reason of such individual's mental or physical condition, is unable to authorize the system to have such access;

(II) the individual does not have a legal guardian, conservator, or other legal representative, or the legal guardian of the individual is the State; and

(III) a complaint has been received by the system about the individual with regard to the status or treatment of the individual or, as a result of monitoring or other activities, there is probable cause to believe that such individual has been subject to abuse or neglect; and

(iii) any individual with a developmental disability, in a situation in which-

(I) the individual has a legal guardian, conservator, or other legal representative;

(II) a complaint has been received by the system about the individual with regard to the status or treatment of the individual or, as a result of monitoring or other activities, there is probable cause to believe that such individual has been subject to abuse or neglect;

(III) such representative has been contacted by such system, upon receipt of the name and address of such representative;

**114 STAT. 1716 PUBLIC LAW 106-402-OCT. 30, 2000**

(IV) such system has offered assistance to such representative to resolve the situation; and

(V) such representative has failed or refused to act on behalf of the individual;

(J)

(i) have access to the records of individuals described in subparagraphs (B) and (I), and other records that are relevant to conducting an investigation, under the circumstances described in those subparagraphs, not later than 3 business days after the system makes a written request for the records involved; and

(ii) have immediate access, not later than 24 hours after the system makes such a request, to the records without consent from another party, in a situation in which services, supports, and other assistance are provided to an individual with a developmental disability-

(I) if the system determines there is probable cause to believe that the health or safety of the individual is in serious and immediate jeopardy; or

(II) in any case of death of an individual with a developmental disability;

(K) hire and maintain sufficient numbers and types of staff (qualified by training and experience) to carry out such system's functions, except that the State involved shall not apply hiring freezes, reductions in force, prohibitions on travel, or other policies to the staff of the system, to the extent that such policies would impact the staff or functions of the system funded with Federal funds or would prevent the system from carrying out the functions of the system under this subtitle;

(L) have the authority to educate policymakers; and

(M) provide assurances to the Secretary that funds allotted to the State under section 142 will be used to supplement, and not supplant, the non-Federal funds that would otherwise be made available for the purposes for which the allotted funds are provided;

(3) to the extent that information is available, the State shall provide to the system-

(A) a copy of each independent review, pursuant to section 1902(a)(30)(C) of the Social Security Act (42 U.S.C. 1396a(a)(30)(C)), of an Intermediate Care Facility (Mental Retardation) within the State, not later than 30 days after the availability of such a review; and

(B) information about the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are served through home and community-based waivers (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c))) receive; and

(4) the agency implementing the system shall not be redesignated unless-

(A) there is good cause for the redesignation;

(B) the State has given the agency notice of the intention to make such redesignation, including notice regarding the good cause for such redesignation, and given the agency an opportunity to respond to the assertion that good cause has been shown;

**114 STAT. 1717 PUBLIC LAW 106-402-OCT. 30, 2000**

(C) the State has given timely notice and an opportunity for public comment in an accessible format to individuals with developmental disabilities or their representatives; and

(D) the system has an opportunity to appeal the redesignation to the Secretary, on the basis that the redesignation was not for good cause.

(b) AMERICAN INDIAN CONSORTIUM.-Upon application to the Secretary, an American Indian consortium established to provide protection and advocacy services under this subtitle, shall receive funding pursuant to section 142(a)(6) to provide the services. Such consortium shall be considered to be a system for purposes of this subtitle and shall coordinate the services with other systems serving the same geographic area. The tribal council that designates the consortium shall carry out the responsibilities and exercise the authorities specified for a State in this subtitle, with regard to the consortium.

(c) RECORD. -In this section, the term "record" includes-

(1) a report prepared or received by any staff at any location at which services, supports, or other assistance is provided to individuals with developmental disabilities;

(2) a report prepared by an agency or staff person charged with investigating reports of incidents of abuse or neglect, injury, or death occurring at such location, that describes such incidents and the steps taken to investigate such incidents; and

(3) a discharge planning record.

**SEC. 144. ADMINISTRATION. 42 USC 15044**

(a) GOVERNING BOARD. -In a State in which the system described in section 143 is organized as a private nonprofit entity with a multimember governing board, or a public system with a multimember governing board, such governing board shall be selected according to the policies and procedures of the system, except that-

(1)

(A) the governing board shall be composed of members who broadly represent or are knowledgeable about the needs of the individuals served by the system;

(B) a majority of the members of the board shall be-

(i) individuals with disabilities, including individuals with developmental disabilities, who are eligible for services, or have received or are receiving services through the system; or

(ii) parents, family members, guardians, advocates, or authorized representatives of individuals referred to in clause (i); and

(C) the board may include a representative of the State Council on Developmental Disabilities, the Centers in the State, and the self-advocacy organization described in section 124(c)(4)(A)(ii)(I);

(2) not more than 1 /3 of the members of the governing board may be appointed by the chief executive officer of the State involved, in the case of any State in which such officer has the authority to appoint members of the board;

(3) the membership of the governing board shall be subject to term limits set by the system to ensure rotating membership;

**114 STAT. 1718 PUBLIC LAW 106-402-OCT. 30, 2000**

(4) any vacancy in the board shall be filled not later than 60 days after the date on which the vacancy occurs; and

(5) in a State in which the system is organized as a public system without a multimember governing or advisory board, the system shall establish an advisory council-

(A) that shall advise the system on policies and priorities to be carried out in protecting and advocating the rights of individuals with developmental disabilities; and

(B) on which a majority of the members shall be-

(i) individuals with developmental disabilities who are eligible for services, or have received or are receiving services, through the system; or

(ii) parents, family members, guardians, advocates, or authorized representatives of individuals referred to in clause (i).

(b) LEGAL ACTION. -

(1) IN GENERAL. -Nothing in this title shall preclude a system from bringing a suit on behalf of individuals with developmental disabilities against a State, or an agency or instrumentality of a State.

(2) USE OF AMOUNTS FROM JUDGMENT.-An amount received pursuant to a suit described in paragraph (1) through a court judgment may only be used

by the system to further the purpose of this subtitle and shall not be used to augment payments to legal contractors or to award personal bonuses.

(3) **LIMITATION.** -The system shall use assistance provided under this subtitle in a manner consistent with section 5 of the Assisted Suicide Funding Restriction Act of 1997 (42 U.S.C. 14404).

(c) **DISCLOSURE OF INFORMATION.** -For purposes of any periodic audit, report, or evaluation required under this subtitle, the Secretary shall not require an entity carrying out a program to disclose the identity of, or any other personally identifiable information related to, any individual requesting assistance under such program.

(d) **PUBLIC NOTICE OF FEDERAL ONSITE REVIEW.** -The Secretary shall provide advance public notice of any Federal programmatic or administrative onsite review of a system conducted under this subtitle and solicit public comment on the system through such notice. The Secretary shall prepare an onsite visit report containing the results of such review, which shall be distributed to the Governor of the State and to other interested public and private parties. The comments received in response to the public comment solicitation notice shall be included in the onsite visit report.

(e) **REPORTS.** -Beginning in fiscal year 2002, each system established in a State pursuant to this subtitle shall annually prepare and transmit to the Secretary a report that describes the activities, accomplishments, and expenditures of the system during the preceding fiscal year, including a description of the system's goals, the extent to which the goals were achieved, barriers to their achievement, the process used to obtain public input, the nature of such input, and how such input was used.

#### **42 USC 15045 SEC. 145. AUTHORIZATION OF APPROPRIATIONS.**

For allotments under section 142, there are authorized to be appropriated \$32,000,000 for fiscal year 2001 and such sums as may be necessary for each of fiscal years 2002 through 2007.

