

VICE SPEAKER BENJAMIN J.F. CRUZ  
Committee on Appropriations and Adjudication  
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*I Mina'trentai Tres na Liheslaturan Guåhan*  
**THE 33RD GUAM LEGISLATURE**  
155 Hesler Place, Suite 107, Hagåtña, Guam 96910  
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MAY 21 2015

The Honorable Judith T. Won Pat  
Speaker  
*I Mina'trentai Tres na Liheslaturan Guåhan*  
33<sup>rd</sup> Guam Legislature  
155 Hesler Place  
Hagåtña, Guam 96910

VIA: The Honorable Rory J. Respicio  
Chairperson, Committee on Rules

**RE: Committee Report on Bill No. 70-33 (COR), As Substituted by the Committee**

Dear Speaker Won Pat:

Transmitted herewith is the Report of the Committee on Appropriations and Adjudication on Bill No. 70-33 (COR), As Substituted by the Committee - N.B. Underwood, Ph.D. / R.J. Respicio - "An act to *amend* § 41105 of Chapter 41, Article 1 of Title 17 of the Guam Code Annotated; and to *add* to a *new* § 72109 of Chapter 72, Title 10 of the Guam Code Annotated; relative to the creation of an emergency registry for individuals with special needs."

Committee votes are as follows:

- TO DO PASS  
 TO NOT PASS  
 TO REPORT OUT ONLY  
 TO ABSTAIN  
 TO PLACE IN INACTIVE FILE

Sincerely,

  
BENJAMIN J.F. CRUZ  
Chairman

2015 MAY 22 PM 3:05  
RJC



## COMMITTEE REPORT

### **Bill No. 70-33 (COR), As Substituted by the Committee**

***“An act to amend § 41105 of Chapter 41, Article 1 of Title 17 of the Guam Code Annotated; and to add to a new § 72109 of Chapter 72, Title 10 of the Guam Code Annotated; relative to the creation of an emergency registry for individuals with special needs.”***

**VICE SPEAKER BENJAMIN J.F. CRUZ**

Committee on Appropriations and Adjudication  
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*I Mina'trentai Tres na Liheslaturan Guåhan*

**THE 33RD GUAM LEGISLATURE**

155 Hesler Place, Suite 107, Hagåtña, Guam 96910

T: (671) 477-2520/1 | F: (671) 477-2522

**MAY 21 2015**

**MEMORANDUM**

**TO:** All Members  
**FROM:** Vice Speaker Benjamin J.F. Cruz  
*Chairman, Committee on Appropriations and Adjudication*

**SUBJECT:** Committee Report on Bill No. 70-33 (COR), As Substituted by the Committee

Transmitted herewith for your consideration is the Committee Report on Bill No. 70-33 (COR), As Substituted by the Committee - N.B. Underwood, Ph.D. / R.J. Respicio - "An act to amend § 41105 of Chapter 41, Article 1 of Title 17 of the Guam Code Annotated; and to add to a new § 72109 of Chapter 72, Title 10 of the Guam Code Annotated; relative to the creation of an emergency registry for individuals with special needs."

This report includes the following:

- Committee Vote Sheet
- Committee Report Digest
- Bill No. 70-33 (COR), As Introduced
- Bill No. 70-33 (COR), As Substituted by the Committee
- Public Hearing Sign-in Sheet
- Copies of Submitted Testimony & Supporting Documents
- COR Referral of Bill No. 70-33 (COR)
- Fiscal Note Requirement
- Notices of Public Hearing
- Public Hearing Agenda
- Related News Reports

Please take the appropriate action on the attached voting sheet. Your attention to this matter is greatly appreciated. Should you have any questions or concerns, please do not hesitate to contact me.

Sincerely,

  
BENJAMIN J.F. CRUZ

Chairman

**SENATOR BENJAMIN J.F. CRUZ, VICE SPEAKER**

Committee on Appropriations and Adjudication  
 senator@senatorbjcruz.com | www.senatorbjcruz.com



*I Mina'trentai Tres na Liheslaturan Guahan*  
**THE THIRTY-THIRD GUAM LEGISLATURE**

155 Hesler Place, Suite 107, Hagåtña, Guam 96910  
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**COMMITTEE VOTING SHEET**

**Bill No. 70-33 (COR), As Substituted by the Committee - N.B. Underwood, Ph.D. / R.J. Respicio - "An act to amend § 41105 of Chapter 41, Article 1 of Title 17 of the Guam Code Annotated; and to add to a new § 72109 of Chapter 72, Title 10 of the Guam Code Annotated; relative to the creation of an emergency registry for individuals with special needs."**

COMMITTEE MEMBERS	SIGNATURE	TO DO PASS	TO NOT PASS	TO REPORT OUT ONLY	TO ABSTAIN	TO PLACE IN INACTIVE FILE
CRUZ, BENJAMIN J.F. Chairperson		✓				
AGUON, Jr., FRANK B. Vice Chairperson						
WON PAT, Ed.D., JUDITH T. Speaker and Ex-Officio Member		✓ 5/21/15				
MUÑA BARNES, TINA ROSE Member		✓				
RODRIGUEZ, Jr., DENNIS G. Member						
SAN NICOLAS, MICHAEL, F.Q. Member		✓ 5/21/15				
UNDERWOOD, Ph.D., NERISSA B. Member		✓ 5/21/15				
ADA, V. ANTHONY Member		✓				
MORRISON, THOMAS A. Member		✓				
TORRES, MARY C. Member				✓ 5/21/15		



## COMMITTEE REPORT DIGEST

**Bill No. 70-33 (COR), As Substituted by the Committee** - N.B. Underwood, Ph.D. / R.J. Respicio - "An act to *amend* § 41105 of Chapter 41, Article 1 of Title 17 of the Guam Code Annotated; and to add to a *new* § 72109 of Chapter 72, Title 10 of the Guam Code Annotated; relative to the creation of an emergency registry for individuals with special needs."

### **I. OVERVIEW**

**Bill No. 70-33 (COR)**, "An act to amend Section 41105 of Chapter 41, Article 1 of 17 Guam Code Annotated, relative to the creation of a registry for individuals with disabilities," was introduced by Senators Nerissa B. Underwood and Rory J. Respicio on April 3, 2015, and subsequently referred to the **Committee on Appropriations and Adjudication** on April 4, 2015.

The **Committee on Appropriations and Adjudication** convened a public hearing on **Thursday, April 16, 2015**, beginning at 10:00AM in the Guam Legislature Public Hearing Room. The hearing for **Bill No. 70-33 (COR)** began at **10:59AM** and ended at **11:19AM**.

#### Public Notice Requirements

All legal requirements for public notices were met, with requests for publication sent to all media and all Senators on April 9, 2015, and April 14, 2015, via email. Copies of the hearing notices are appended to the report.

#### Senators Present

**Vice Speaker Benjamin J.F. Cruz**, *Chairperson*

**Senator Rory J. Respicio**, *Member*

**Senator V. Anthony Ada**, *Member*

**Senator Mary C. Torres**, *Member*

**Senator Thomas A. Morrison**, *Member*

**Senator Brant T. McCreadie**

#### Appeared Before the Committee

**Mr. Benito S. Servino**, *Director, Department of Integrated Services for Individuals with Disabilities*

**Mrs. Roseanne S. Ada**, *Executive Director, Guam Developmental Disabilities Council*

**Lt. Scott Wade**, *Guam Police Department*

**Mr. Angel Sablan**, *Mayors' Council of Guam*

**Ms. Cynthia Mesa**

**Mr. Sam Ilesugam**, *Guma Mami, Inc.*

**Ms. Mary Therese**

**Submitted Written Testimonies**

**Mr. Benito S. Servino**, Director, Department of Integrated Services for Individuals with Disabilities

**Mrs. Roseanne S. Ada**, Executive Director, Guam Developmental Disabilities Council

**Dr. Heidi E. San Nicolas, Ph.D.**, Director, Guam Center for Excellence in Developmental Disabilities Education, Research, and Service

**Ms. Cynthia Mesa**

**Ms. Carol Darlow**, Chairperson, Guam Statewide Independent Living Council

**II. TESTIMONY & DISCUSSION**

**Chairman Benjamin J.F. Cruz** announced Bill No. 70-33 (COR), and allowed the co-sponsor of the legislation to give a few remarks.

**Senator Rory J. Respicio** thanked Chairman Cruz and proceeded to provide his statement:

“Mr. Chairman, this bill—Bill No. 70-33 (COR)—it’s an act to amend Section 41105 of Chapter 41, Article 1 of 17 Guam Code Annotated, relative to the registry for individuals with disabilities. As you know and as we all know, Senator [Nerissa B.] Underwood is not on island; she’s off-island at the moment attending to family needs and she did submit to us a sponsor statement, which lists eleven (11) key points in this bill. And I know she’s been working very closely with [the Department of Integrated Services for Individuals with Disabilities] (DISID). The director of DISID is here. Instead of reading all of these eleven (11) key points, I’m sure that these points will be brought up during the course of the public hearing on this particular bill. But of course, I want to submit her written testimony for the record, most if not all of which will be discussed as the panel makes its way to provide testimony on this legislation. Thank you, Mr. Chairman.”

**Chairman Cruz** noted that Senator Underwood’s sponsor statement (*appended to this report*) will be highlighted during the hearing and called on the first panel of individuals to provide testimony.

**Mrs. Roseanne S. Ada**, thanked Chairman Cruz and read her testimony in her capacity as Executive Director of Guam Developmental Disabilities Council (GDCC) (*appended to this report*) in support of the legislation, wherein she recommends the inclusion of the definition of developmental disabilities per the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402).

**Chairman Cruz** thanked Mrs. Ada.

**Mr. Benito S. Servino** read his testimony in his capacity as Director of Department of Integrated Services for Individuals with Disabilities (*appended to this report*) in support of the legislation, wherein he stated that DISID had initially established a federally funded on-line registry ([www.guamgetcare.org](http://www.guamgetcare.org)) but the funding and administration was transferred to the Guam Behavioral Health and Wellness Center (GBHWC) and the grant expired in September 2014. Additionally, his letter states that the legislation's appropriation of One Hundred Fifty Thousand Dollars (\$150,000) is sufficient to cover the cost of a full-time limited-term program staff, a multimedia marketing outreach campaign, supplies and computer equipment, printing costs, request for proposal (RFP) for design, and training and registry maintenance. He also stated that the annual funding requirements for subsequent years would be Eighty-Three Thousand Dollars (\$83,000).

**Lt. Scott Wade** introduced himself as an officer with the Guam Police Department (GPD) Auxiliary Services Division, and stated that he was providing testimony on behalf of the Chief of Police and that GPD is ready to work with DISID in implementing the bill.

**Chairman Cruz** thanked Lieutenant Wade.

**Mr. Angel Sablan** began his testimony:

*"Manana si Yu'us.* It's always nice to see the faces that support the Mayors' Council of Guam (MCOG). I want to take this opportunity to thank you for always giving your support. I come this morning to support the passage of Bill No. 70-33 (COR) to implement the registry for persons with disabilities. You know, the MCOG has many registries, including a fragmented registry of person's with disabilities and these come to us with mayor's verification for residency. Right now we get our list from Catholic Social Services, we get our list from the Division of Senior Citizens (DSC) from [the Department of Public Health and Social Services] (DPHSS). We get our list from the Benefits Program Division from DPHSS for the [Supplemental Nutrition Assistance Program] (SNAP), from [Guam Department of Education] (GDOE), from DISID, from the Department of Revenue and Taxation (DRT) for people with disabilities as vehicles are concerned. We get lists from the GDDC. These groups of listing are actually very fragmented – it's incomplete; it's double, triple, quadruple listing. It just doesn't serve [the target demographic] well. And us first responders, we are here to let you know when it comes to emergencies like for storms and typhoons, many of the mayors and vice mayors already know where these people are located. But there are some people [whose location] we do not know because they are not on any of our lists. We certainly go out in the community and try to look for them, try to offer them assistance, and try to get them to a safe location if they need to be moved.

“But simply, I applaud the legislation [and I believe] that it’s about time we get one central bank that can have this kind of information. And I believe we don’t have to reinvent the wheel—I believe the MCOG can provide DISID with the information we have [so] that they can purge and [cross reference the multiple databases for redundancies]. So we already have over a thousand people that we have on our list [who] we have complete information on, as far as their needs, their age[s], where they live, and any disabilities they have if they do have disabilities. And so in that sense, we are more than willing that if this is going to come to provision that we provide the information that we have. Unfortunately we are no longer able to access [the on-line registry] Get Care; DSC has already advised us that they, too, are no longer able to fund this database. So as far as the MCOG is concerned, every time a senior citizen or an individual comes up through a mayor’ office or through the DSC office, we just take their information. And as far as senior citizens are concerned, we have the Intake Profile Referral where[by] we get the complete information. And whatever information we get, actually, we provide to Get Care, so Get Care does not provide us with any information. What Get Care has is information we provide to them from all of these entities, so they are just actually a storage database that the users can access. But right now, like I said, they are no longer contracted. So again everyone is on their own, we just get the information that we have and if we need to go to Catholic Social Services or DSC, we can’t all access it through Get Care; we need to do it manually on our own. We fully support this legislation and we stand by ready to support DISID.”

**Chairman Cruz** thanked the panel and yielded to the floor to the legislation’s co-sponsor, Senator Respicio.

**Senator Respicio** thanked Chairman Cruz and thanked the panel on behalf of Senator Underwood. He stated that Senator Underwood initially met with Mr. Servino in the development of the legislation and continued to elaborate:

“The bottom line is that I see this as if the first responders have this information readily available in their database, as all of you have pointed out. If they respond to a home, with let’s say—God forbid—a fire in that home and they know there is an individual with disabilities that specifically is bedridden or immobile and that’s the first thing on their mind: that they are going to go to the rooms in the home to find an individual with that description of that condition. They are going to know that no one is answering the door and there’s a reason why and they would make every effort to break that door down and go and provide those kinds of services. And so, there’s also the eleven (11) points that Senator Underwood has pointed out, and you know the issue that’s lingering in many minds is how is this going to comply with the requirement of [Health Insurance Portability and Accountability Act of 1996] (HIPAA). And the Bill also



addresses that it would be confidential; only those that need the information would get the information.

“Is there anything else you foresee after the discussions of this bill, any of you foresee how this bill would be amended to address any of the concerns that have been raised over the last several weeks?”

**Mr. Servino** said that he met with the Office of Technology staff, Mr. William Castro, at the Department of Administration (DOA) and discussed security. He stressed the importance of secure transfer of medical information, especially with regards to HIPAA. He also mentioned the need for alternative input methods, e.g. biometrics, in order for individuals with severe disabilities to give consent, and other consent issues such as a disclosure lists, and timelines for consent renewal and expiration period.

**Senator Respicio** asked Mr. Servino to elaborate on the steps to be taken should legislation pass.

**Mr. Servino** replied that DISID plans on being proactive with issuing the RFP, complying with HIPAA requirements, and meeting the implementation date of January 1, 2016.

**Senator Respicio** thanked Mr. Servino.

**Mrs. Ada** spoke about the details of the database that Guam Developmental Disabilities Council administered, emphasizing the low setup and maintenance costs, \$2,600 and \$550 respectively, data entry methods and type of information collected.

**Senator Respicio** stated that based on his understanding of the bill the challenge to the creation of the registry will be in the integration of information from numerous sources and the secure access of this data among the various first responders. He asked Mr. Servino to speak more on this issue.

**Mr. Servino** said:

“Thank you, we don’t want to reinvent the wheel. I think what has already been structured—If we could expand on it, and make sure there’s that integration process within the different agencies. In fact, I’ve already met with the [Guam Fire Department] (GFD) to look at their system, and they’ve informed me that their system is actually pretty outdated. There is an RFP that they’re looking at announcing.”

**Senator Respicio** interjected:

“Also incorporated into the E911 —”

**Mr. Servino** continued:

“Right, and that’s what they were trying to incorporate in the E911 so we can integrate into that system. Also, we’re looking into Section 508 (amendment to the Rehabilitation Act, 29 U.S.C. § 794d) requirements for equal access in the information technology and that’s a requirement under the federal law, and the Governor of Guam has signed an assurance that we will comply with 508 standards. I actually went into that registry – [I] started to but it was a little difficult to navigate, and – especially since I didn’t want to put false statements because I am not a person with a developmental disability. It’s mainly restricted for people with more severe and profound disabilities. Just trying to navigate it was a little bit of a challenge for me, but I think we can work the kinks out of it, and try to integrate it with a system that we’re going to put out when they do the RFP and start go into detail when they go into the specifications.”

**Senator Respicio** thanked Mr. Servino:

**Senator Mary C. Torres** posed her question:

“My question was along the practical lines, and Senator Respicio touched upon it. I know that within the Guam Police Department (GPD), I remember having a tour once of a vehicle where you have the capability to access data on there. And I know it is integrated with the courts systems as well, so perhaps this could be the tie-in. There are two things that cross my mind as I’m listening to this, and a practical application of this law and the database for a first responder. One, if they have [identification] (ID) on them then that is a given, and this bill provides for an ID. But short of that, and the person is not at home and [he or she is] not with another responsible person, then how would you ensure that you have ready access because the key is appropriate attention and timeliness?”

**Lieutenant Wade** replied that he is not certain about the particular car Senator Torres referenced and added that GPD vehicles are not equipped with mobile data system.

**Senator Torres** surmised that the system may not be currently implemented as her tour occurred “perhaps two (2) years ago.” She asked if police officers on patrol had mobile access to data, which **Lieutenant Wade** denied, specifically stating that access to data is not available “in a mobile platform within a vehicle.” She noted that she will have to discuss that matter further with the Chief of Police. She continued:

“The other question I had – this is a volunteer system where people come in and register at their own will. And it’s also contemplated that if they have changes to their situations – which I imagine [includes] medical treatments and the like – they will have that registered. Now, what do you have if that information is outdated? Where does the liability stand if the responder is relying on

information that is outdated or is not current or there are other circumstances that developed that the individual or [his or her] family failed to report? [It's a] liability issue."

**Mr. Servino** replied:

"As we look at the timelines, our intent is to give the consent to release for one (1) year. After that year, the following year we really need to follow up with the individual if they want to continue to provide that consent. Maybe at that time, we can get an updated assessment of their condition and that could be included in the registry. So we want to try to again be more proactive and be able to get current and more updated information, and we leave it at a year. That is what we're doing within the Division of Vocational Rehabilitation (DVR); any type of consent we get from the clients we always go back after a year to update their information."

**Mr. Sablan** said:

"Senator, in our case, as far as the senior citizens are concerned, we update our information annually. Every January, we go through our system and through our records to make sure that all that information is still current. As far as the mayor's verification is concerned, it's only updated when the families or heads of household come in and add, delete, [or] remove themselves from that village.

"As far as security is concerned, for the Intake Profile Referral that we do, even I cannot access that information. We provide a password to the individual that is responsible to operate that system and only he or she can get that information. During this last storm that we had, we received a listing from DSC that told us that we need to look for these people in the villages because they may need assistance as far as transporting or getting to a safe place. What we find out in the villages is that many of our families don't want the assistance. They would rather have their families come and take them to wherever they need to go or whatever assistance they need. But for the few that do require assistance because no family is there, the stumbling block we face is that the MCOG, the mayor's themselves are not equipped with transport equipment to transfer these people out of their homes and maybe there can be a mandate that any time there is an emergency or storms that these vehicles that are equipped for persons with disabilities, they be allowed to be used during emergencies, not just GovGuam school buses. We just can't put them in there or put them in the back of the pick-up of a mayor's truck. I know the hassle here is that these modes of transport are federally funded and they can't be used for this reason or that, but we've got to find a way.

"What's the use of a list if we can't provide them the assistance because we don't have the equipment or the method to do that? I know Mayor [Melissa B.

Savares] in Dededo calls her people to lift the person and place them in the truck because there is no other way. If we can mandate the agencies that have these modes of transports, [to] make them available during times of emergency.”

**Mrs. Ada** added:

“Senator Torres, how we keep track of our people with disabilities? GDDC has three (3) standing committees so each committee is on the look out in their villages for those who have passed on or for those who need help. We also do look in the obituaries, cut out the clippings of those individuals who have passed on and put them in our files. That has worked out quite well because our council members really call one another to find out what’s going on in their community and they do report to us when they have their council meetings or our standing committee meetings. They really are valuable to us because they do keep us informed. Thank you.”

**Senator Torres** thanked the panel for their input and noted that she was merely inquiring about the practical applications of the registry.

**Senator Thomas A. Morrison** thanked Chairman Cruz, and thanked the panel for their input, and asked Mr. Servino how much of the appropriation is allocated for maintenance.

**Mr. Servino** answered that the cost for maintenance has been computed with the cost for training (*which is quoted at \$12,000 to \$15,000 in his testimony*).

**Senator Morrison** asked Mr. Servino to clarify how the one-time appropriation will cover annual maintenance costs.

**Mr. Servino** clarified that the appropriation is for the initial cost of establishing the registry, and that it will cost \$83,000 annually to maintain the system.

**Senator Morrison** expressed his concern about the long-term maintenance of the registry and asked Mr. Servino if the development of the RFP and the registry itself is done in coordination with the Office of Technology, which **Mr. Servino** confirmed.

**Mr. Servino** stated he wished to stress that the appropriation also funds the costs of training staff and first responders on the strategies and implementation of the system, as well as marketing.

**Senator Morrison** concurred with Mr. Servino and stated that he appreciates the director’s focus on marketing given the voluntary nature of the registry. He also

mentioned that appreciates that one of the goals with the establishment of the registry is integration to the E911 system, which provides comprehensive access.

**Mr. Servino** added that new FCC requirements mandate the incorporation of technology to allow the hearing impaired to use their text telephone to communicate with the E911 system but that has yet to be implemented.

**Senator Morrison** added that a database with global positioning system (GPS) capabilities will facilitate first responders in locating individuals with disabilities, and that he is glad DISID is using a technologically forward approach.

**Chairman Cruz** stated that the referral of this bill to his Committee came as a surprise, and that it was solely based on the appropriation, for which he said he would have to find a source. He asked Mr. Servino how much did DISID received in federal grants last year.

**Mr. Servino** replied that the federal grants DISID has received mainly goes towards DVR and added that his department's local funding is very limited.

**Chairman Cruz** clarified:

"I'm not talking about local funding; I'm talking about the federal grants that you have. Surely there must be something like the Take Care one that they had in previous years. Is there something in the federal grant programs that would have allowed for an application to underwrite the cost of this kind of a program? There was a registry in the past. You guys have had registries. There's grant money for registries. Is there currently federal registry money in any of your—?"

**Mr. Servino** responded:

"Currently, there are no federal grants. As I stated in my testimony, the Aging and Disability Resource Center did receive a federal grant, almost Two Hundred Fifty Thousand Dollars to Three Hundred Thousand Dollars (\$250,000-\$300,000) to look at options counseling, consumer-centered approaches, and that technology—First Lady had shared—that system was quite expensive, and we didn't get the funding for it. Again, under the permanent injunction, that program was taken away from DISID and given to GBHWC. We didn't actually have that grant, for the last two to three (2-3) years; it's actually through GBHWC, but we were using—"

**Chairman Cruz** interjected and asked if the grant was federally funded, which **Mr. Servino** confirmed but stated that it had expired. Chairman Cruz noted his dismay that Guam State Clearinghouse (GSC, Clearinghouse) Director Ms. Kate Baltazar, who was testifying for a previous item on the hearing's agenda, decided to leave and has not

returned to answer questions regarding the bill at hand. He asked Mr. Servino about the nature of the relationship between DISID, GSC and GBHWC.

**Mrs. Ada** proffered:

“Senator, the GDDC, that’s federally funded. We are not a service provider; we only collaborate with the agencies and we try to build capacity by collaborating with them and researching a lot of our data to support what needs to be done because there is a service gap there so we try to educate our council members. Some of our council members are from the government agencies that serve people with disabilities. [Mr. Servino] is a council member, but sixty percent (60%) of our council members are people with disabilities, or parents or any sibling that has someone in the family with developmental disabilities. So sixty percent (60%), and the rest are providers. Our council does not provide services; we advocate and teach our council members to advocate and speak for themselves. We do provide disability-sensitivity training when it’s requested by DOA, and we do have a Power Point presentation and do that whenever DOA says they have five to six (5-6) agencies or employees that have signed up. We do make time for that. It is usually a two- (2-) hour course or longer if they wish for something longer.

**Mr. Servino** added:

“I’d like to add to that. We do collaborate, and I am a member of the GDDC. And I also collaborate with the GBHWC because they had a system under the permanent injunction, where they were required to develop their own system and so we do try to tap on some of the information and not reinvent the wheel. The real challenge is because of the confidentiality of the information, you can’t just be shared randomly without the consent of the individual, and that’s the biggest challenge we find. When we look at all different programs that are federally funded, that requirement is always there; you cannot just pass it on without the consent of the individual giving that information to be released. Even with DVR, a lot of people have been asking, ‘Can I get this information?’ I say [that] I really can’t list unless the client consents to it [and] signs an actual consent. We don’t want to violate the law, because again, it’s under our rehab program. It’s very strict about the release and confidentiality of that information. Each organization maintains [its] own database or registry of [its] clients that have accessed [its] services. We cannot outright share that information; that’s one of the challenges. So with this registry we can at least have them sign that consent so we can have access to that information.”

**Chairman Cruz:**

“Maybe it was prophetic that this bill came to my committee on the same day that Senator Aguon’s bill came to me and to be heard on the same day that the Clearinghouse is saying they want to have monitoring and compliance control. It would seem to me that we have a perfect example of two (2) agencies dealing with the same types of individuals—pretty close. You belong on her board because of the work that you do. I wish that there were more compliance and monitoring from Clearinghouse on the executive agencies that aren’t able to talk to each other. I have nothing further. Thank you very much. You’re excused.”

**Ms. Cynthia Mesa** introduced herself and began her testimony:

“First of all, I am in the (*Inaudible*) system. I have never been informed of anything, any kind of activities. I have to call up sometimes, and feel like I get the push off from people, workers, and consumers. I was in the hospital last month, and I’m trying to get back my Medicaid, and it’s been about a month, and I still have no insurance. I have to see a doctor or to get medicines. I almost passed away at the hospital, so I don’t know what kind of services I’m getting. I keep submitting documents and I’m still waiting for my social worker from GBHWC on how’s it going to work out.

“I’m somebody that a lot of people know as disabled and I get treated differently by a lot of people. They get irritated for no reason; for example, I hear insults here and there. I read the news that veterans get new additions, [and] those are not all disabled. I know one who was in Iraq but she was enlisted in the [U.S. Army] during the Iraq period, and she’s [being seen] at GBHWC. I know of another veteran; he was sort of homeless, but now he’s dead. He was in the [U.S. Marine Corps], homeless and a doctor—believe it or not—and denied housing and employment, and he was unemployed. He’s dead now, but he just died this year. I see so many sad incidences and I hear about them in the news, and then when see all these homeless people, a lot of them are from the department. I hear snide, hateful remarks about them—‘those dirty, poor people.’ I should say, ‘Excuse me, but I know them.’

“I returned back to Guam when I was forty-three (43) [years old]; I’m (fifty-seven) 57 [years old]. I almost want to pack my bags and go back when I see that going on, especially because Guam is such a small island, and it gets too close for comfort sometimes. Do you understand? Okay. That’s what I have to say. I didn’t follow my notes, but I just had to speak from my mind.”

**Chairman Cruz** thanked Ms. Mesa for advocating for herself.

**Mr. Sam Ilesugam** introduced himself and proceeded with his testimony:

“I work at Guma Mami, a non-profit organization that provides different kinds of services to individuals with disabilities. I have been with the organization for a while. I have had the opportunity to serve in different capacities. Looking at this bill and looking at my experience, it gives me different perspectives. This bill has two (2) purposes: one is for crisis management, crisis intervention; another, it is a tool to respond to disaster or emergency situations. For the last few days, I have tried to engage some individuals with disabilities or people I work with or have relationships with to discuss the bill. My good friend here, Cynthia, is one of them. She provided me a written copy of her statement that if it is okay with you, I can share it.”

**Ms. Mesa** said she doesn't know what she wrote in her testimony, to which Mr. Ilesugam told her as an aside that they would discuss it later.

**Mr. Ilesugam:**

“Looking at this bill, it's a management tool for emergency situations. From the management perspective, it has practical use and it is very useful. It is always useful when information is readily available to you during emergency. But then again the discussions I have had with the class that I work with and with my friends gave me a different perspective especially when one of my friends during discussion asked me, 'If you are the individual with the disability, would you want your name on that list?' While working on this bill I guess that is one question I am going to throw at you. When you are working on it, try to put yourself on their shoes. If that [were] you would you put your information where people with whom you have no control over can access your information? Again that is that question I want to ask you. My answer to that question is: No, I will not put my information on that list.

“However, this bill still has practical use for crisis intervention and disaster preparedness and intervention. I did some research and the first thing I wanted to see was if there was any other jurisdiction throughout the nation where the registry for individual with disabilities has been done. Yes, there are different registries and the First Lady mentioned that the first Guma Mami has their own registry, but it was only for internal use. But, we are talking about a registry that is being shared among agencies, and that is going to be used by people that I don't even know. I looked at the Internet and I only saw one; that is city of Chicago. But this bill still has practical use for preparedness and intervention. I know what this bill is trying to do. Based on my quick research there are other models out there. For crisis intervention, there is one that is advocated by the [Substance Abuse and Mental Health Services Administration] (SAMHSA) and there are guidelines here on crisis management and mental health clients. I know our neighbors in the Pacific—for example, Hawaii uses the same thing, according to this report. This is regarding crisis intervention involving law



enforcement [agencies]. In some places they call it crisis intervention team, while others call it crisis response team. I also pulled out Maui that is the closest to us and they have a model that we can look at.

"I went to the National Alliance on Mental Illness (NAMI) and they advocate the same thing. This model involves law enforcement with mental health workers and involves training and resources for the responding agency. According to NAMI, Memphis practices the same model crisis response team. According to them it is one of the best in the nation. Again, these are the models that are known to be comprehensive, and do not really need the use of a registry. Some of the people that I know and I work with are very nervous about this registry. They are aware of our situation here in Guam, and they are aware of how the government of Guam works with confidential information. It is very risky.

"This bill is also a tool for disaster management. There are a lot of places out there that apply different models. One approach is providing more buses to transport, making sure that the right people are working together with the Mayor's office, DISID, and GBHWC. It just needs a lot of collaboration and a lot of training for first responders and police officers. Again those are some of the models I think that we can look at instead of creating this scary registry that a lot of people don't want to be on.

"I just want to share some written notes that were given to me by some of the people that I work with. They don't want to appear in person but they just want me to share their testimonies.

"This one says: 'I would support a training of first responders. Instead of using the money to invest in creating a registry, invest it in training for first responders and on how to work with the individuals with disabilities. I have many reservations with the registry even on a voluntary basis; individual may still be pressured to register in order to get services. Seems to me that service providers should know who and where their clients are located. But they don't even know where their clients are, they don't even know what their plans are, and they don't even know if they are dead or alive. The training must be standard in academies and in training curriculum for the fire and police departments. Providers also need to provide curriculum training for clients and family on what to do and where to go in an emergency situation. It needs to be publicized trainings for the administration and service providers. By the way, as many as these classes are, who is responsible for the registry? Also take a look at Guam health care, hundreds of thousands of dollar went in to that, how is that working out?'

"So that was one. This one is very short and it says: 'What is the purpose of registry? In case of typhoon, will they pick up people? I don't think so. They

(government) can't even take care of their management without the typhoon! Fix the traffic system instead.'

So, these are the comments of the people that I work with. Thank you, Chairman and thank you Senators."

**Chairman Cruz:**

"Thank you Sam. I did some my research too and Chicago is the only one that is doing what we are trying to do. I was concerned about the profiling issue, but I am sure you don't want to say that word. I am also sure that is something you are concerned about and I appreciate the fact that you provided us with a SAMHSA approved reports dealing with individuals with disabilities, so please leave it with my staff so we can make copies and we will give you back your originals. In the ten (10) years that I have been here, that is the most thorough testimony that has been given here in the legislation with research, and documentations. We really appreciate that you came today and shared your testimony. We all appreciate the work that you do. We understand the concerns of the people who work with you in the field. Thank you very much for your advocacy of them. You had another comment, Ms. Mesa before I go to Mary Therese?"

**Ms. Mesa:**

"He mentioned about helping us during the typhoon. I have to help myself during typhoon. I don't even get a ride from my family or friends. I don't get help from the government during a typhoon. I have to fend for me. I am still waiting for my insurance card. They said that it is being processed, but I have been hearing that for the past month."

**Chairman Cruz:**

"Thank you. If you would remain after and provide your name and contact information, I want my staff to follow up with your insurance card. I want my staff to assist you on why you are not getting your Medicaid insurance card."

**Ms. Mesa:**

"They said something about too much money, but I have a medical condition and that is COPD (chronic obstructive pulmonary disease)."

**Chairman Cruz** asked Ms. Mesa to provide her information to his staff so that they can assist her with her concerns.

**Ms. Mary Therese:**

"I am very passionate about this as well. And I am very glad that you are all here. I am very glad Senator BJ for heating this up. You know I came because way back in 2005 I remember having off-island people here and I remember dealing with children's mental health and young adults. I distinctly remember Sue Smith was here and she was talking about a registry within a police department that was done in several precincts in the states—dealing with children, for instance. So when the police were called for an emergency with children, they had a list of kids so that they would know there are children with disabilities and then they would know how to respond to them appropriately. It was not through another source of agency, but it was just done for them immediately on the spot. So it seems that something was working out, but it was working out on the spot. So I can look at and get the details on that if you would like. I know that Sue is a parent and she works with the Federation of Family for Children's Mental Health organization in Georgia. I can get that information for you because to me this is like somebody on the outside. I can see some of the benefits perhaps.

"You know I was part of those meetings for years and years on how to get care and all the money and all the training that was involved. It's gone from DISID to GBHWC now DPHSS has it. I am sixty-five (65) years old now, and I am still going to those meetings and they are still having discussions. Maybe something will happen one day. I remember when that boy from Palau was killed and we had a support group. I remember how adults and parents were afraid to come to the police, but they were going to the fire department instead because the fire department would keep the young adults there for about an hour and talked to them. They have a different approach and different training than the police. So that brought me to the point of training. When that happened with the boy in Palau, Benny and I went to the police, I think Chief Suba has about at least one hundred fifty (150) police over there and Dr. Post was there and he was saying to the police, 'Why don't you don't you come to me? Why don't you come to me and find out and learn?'

"Since 2005 I have been going to training from off island two to three (2-3) times a year for first responders and families for children with mental health disorders. There's been communication across the country, there's been roundtable discussion and there's been people collaborating with the police and you think I have been trying to do that since 2005, and it has gone absolutely nowhere. After that boy from Palau died, Robert Camacho who was then head of airport police, worked with the Department of Mental Health at the time. But the police still did not have training, they were there and they were not trained. You know that was a crisis that put everybody at risk; it was putting the police at risk as well. So he and I went to the parents for three (3) weeks at ten o'clock (10:00) at night

and because I have been involved with all these trainings in the states and different precincts across the county and family organization collaborating with them, he and I would call the precincts and was talking about first responders trainings.

“Well, I got a forty- (40) hour curriculum for first responders from the University of Southern Florida, and they gave it to me for free. I have given it to GPD several times. It is a forty- (40) hour curriculum, one- (1) day training specifically for families and clients. It’s an accredited training program. Guam never got the money for that. I also have another three- (3) hour crisis intervention training that was done through a system of care that was done through Idaho and I have given that to the police and I am happy to give them to you as well. You can have the police training! Also there is another training that I really love and its two- (2) hour training that is done with families and police. It was done in Massachusetts and they have a little police pocketbook that they go through to explain disorders and what needs be done. So, the police have the pocketbooks that they can keep in the car and I have given them that as well. We have not had funding so I’ve given them everything. Also I have given them DVDs about how to respond to children. That is the kind of thing that is needed inside the precinct. You know if they have some downtime at the precinct, and they have the information, so they can watch it and refer to it. These curricula are actually accredited even though they have already gone through the academy. But there’s got to be intensive training for them so that they fully understand the experiences that people with disabilities go through. It would be wonderful if they can have it in the precinct. You know things like (acting): ‘Senator BJ, my name is Mary Therese! I am Officer Mary Therese, put the knife down Senator BJ. Then I would say to Senator BJ, ‘Your mother is crying she called me.’

“This way, they can learn to use the people or the clients’ names over and over again. They can also learn little simple techniques that they could have at the precincts. I am happy to give it to them and to you. I remember when the Governor was getting elected to the office, so people were busy but I remember at the time Benny Pineda was the [Department of Youth Affairs] (DYA) and he responded quickly to me. There are two (2) policemen in England, and I am not from England. There were two policemen from the top was reducing recidivism and these two (2) policemen discovered that they saved their city Eleven Million Dollars (\$11,000,000) a year. There are books, CDs and websites that they used, and these things are available. They are also willing to help. To be honest with you it’s scary to have a registry when the police and the people that are being called are not trained. It’s even scary to think that an outside entity will come but wasn’t trained. So for people that Sam was talking about, we got the curriculum here. These are some of the concerns I have regarding this bill.

"I also remember when Bob Camacho was willing to do training. He used the curriculum, but a doctor said, 'Don't worry about it; I will do it.' But he never did! So people change in the agency. So if you have one person who is enthusiastic the next person maybe not. I have experienced it with juveniles and we have some amazing policemen; they are compassionate, kind, understanding and supportive of family members with disabilities. There needs to be some consistency and persistence across the board that will last no matter who sits in office and no matter who is in the agency. Something needs to be consistent and persistent across the board so that everybody will benefit from it. Without consistency and persistence, it would not be fair to first responders and it would not be fair for the consumers as well. I have seen these huge gaps for years and years."

On account that there were neither additional questions from the Committee nor other individuals present to testify, **Chairman Cruz** considered Bill No. 70-33 (COR) heard.

### III. FINDINGS AND RECOMMENDATIONS

Based on the Committee Record appended hereto and substantive consultation with the measure's main author and other relevant stakeholders, the Committee on Appropriations and Adjudication made the following amendments reflected in Bill No. 81-33 (COR), As Substituted by the Committee:

1. In keeping with GFD's designation as the administering agency under the Act as Substituted, the funding source for the appropriation contained in Section 5 of the measure has been changed from the General Fund to the Fund balance of the E911 Fund.
2. As funds are presently available under Section 5 as Substituted, the effective date has been revised to "immediately upon enactment."

The Committee on Appropriations and Adjudication to which was referred **Bill No. 70-33 (COR) - N.B. Underwood, Ph.D. / R.J. Respicio - "An act to amend § 41105 of Chapter 41, Article 1 of Title 17 of the Guam Code Annotated; and to add to a new § 72109 of Chapter 72, Title 10 of the Guam Code Annotated; relative to the creation of an emergency registry for individuals with special needs"** hereby submits these findings to *I Mina'trentai Tres na Liheslaturan Guåhan* and reports out **Bill No. 70-33 (COR), As Substituted by the Committee**, with a recommendation TO PASS.

I MINA'TRENTAI TRES NA LIHESLATURAN GUÅHAN  
2015 (FIRST) REGULAR SESSION

Bill No. TD-33 (COR)

Introduced by:

N.B. Underwood, Ph.D.  
R.J. Respicio

2015 APR -3 PM 3:01  
RJR

AN ACT TO *AMEND* SECTION 41105 OF CHAPTER 41, ARTICLE 1 OF 17  
GUAM CODE ANNOTATED, RELATIVE TO THE CREATION OF A  
REGISTRY FOR INDIVIDUALS WITH DISABILITIES.

1 BE IT ENACTED BY THE PEOPLE OF GUAM:

2 Section 1. **Legislative Findings and Intent.** *I Liheslaturan Guåhan* finds that  
3 several laws had been enacted to improve services for individuals with disabilities.  
4 These laws including, the establishment of the Department of Integrated Services for  
5 Individuals with Disabilities (DISID) seek to improve the quality of life for  
6 individuals with disabilities regardless of age, gender, race, and income.

7 *I Liheslaturan Guåhan* further finds that there is a need to better enhance the  
8 current systems in place to effectively address the needs of individuals with disabilities  
9 in emergency situations or in situations where immediate action is performed by law  
10 enforcement personnel and first responders. *I Liheslaturan Guåhan* recognizes that  
11 community support for individuals with disabilities includes treatment that is fair,  
12 respectful and mindful of specific needs of these individuals especially during  
13 interactions with law enforcement personnel and first responders. The ability of law  
14 enforcement personnel and first responders to understand certain characteristics and  
15 requirements of these individuals will not only allow them to interact appropriately

1 with individuals with disabilities, but will ensure that access to the critical need(s) of  
2 the individual with the disability are addressed in a timely manner.

3 Therefore, it is the intent of *I Liheslaturan Guahan* to promote communication  
4 between law enforcement personnel, first responders and individuals with disabilities  
5 and their families and to further improve services to individuals with disabilities by  
6 creating a registry managed through the DISID.

7 **Section 2. Section 41105 of Chapter 41, Article 1 of 17 Guam Code**  
8 **Annotated is hereby amended to read as follows:**

9 §41105. Other Programs/Services.

10 (a) DISID will review annually the needs for new systems, or improvement of  
11 existing systems. DISID shall create and advocate for the expansion of programs and  
12 services and other systems as required to implement the services necessary for persons  
13 with disabilities.

14 (b) Individuals with Disability Registry.

15 (1) Definitions

16 (i) "*Confidential Information*" means any and all non-public, medical, financial  
17 and personal information in whatever form (written, oral, visual or electronic)  
18 possessed or obtained by either party. Confidential Information shall include all  
19 information which (i) either party has labeled in writing as confidential, (ii) is  
20 identified at the time of disclosure as confidential, (iii) is commonly regarded as  
21 confidential in the health care industry, or (iv) is Protected Health Information as  
22 defined by Health Insurance Portability Accountability Act.

23 (ii) "*First Responders*" means those individuals who in the early stages of an  
24 incident are responsible for the protection and preservation of life, property, evidence,  
25 and the environment, including emergency response providers as defined in Section 2  
26 of the Homeland Security Act of 2002 (6 U.S.C. 101), as well as emergency

1 management, public health, clinical care, public works, and other skilled support  
2 personnel (such as equipment operators) that provide immediate support services  
3 during prevention, response, and recovery operations. First Responder Homeland  
4 Security Act of 2002 refers to "Emergency response providers", and includes, federal,  
5 state, and local government emergency public safety, law enforcement, emergency  
6 response, emergency medical, and related personnel, agencies, and authorities.

7 (2) DISID *shall* create a program entitled the "Individuals with Disabilities  
8 Registry" herein referred to as "Registry".

9 (i) The Registry *shall* contain confidential information about a registered  
10 individual with a disability to capture information such as full description,  
11 routine/favorite attractions, communication and other special needs as well as  
12 emergency contact information. The confidential information *shall* only be used for  
13 the purposes of the Registry and may only be disclosed to authorized individuals to  
14 maintain the integrity of the information. Any other disclosure may occur at the  
15 authorization by the person filling out the registration;

16 (ii) The Registry *shall* be voluntary and the individual with a disability, parents  
17 of the individual with a disability under the age of eighteen (18) or legal guardian may  
18 file registrations with DISID. An option to attach a picture (face only similar to an ID,  
19 passport, or school picture) may be permitted. The Registry application form may be  
20 available at the office of DISID or on-line for convenience or mailed as requested;

21 (iii) Once the registration has been received and processed, DISID *shall*  
22 officially respond by mail or email no less than seven (7) days from the date of the  
23 submission of the registration. An identification card *shall* be issued which may  
24 accompany the individual with a disability at all times. The individual with a  
25 disability, parents of the individual with a disability under the age of eighteen (18), or  
26 legal guardian when updating information may also use the identification card.



1 (2) Authorization. DISID is hereby authorized to enter into a Memorandum of  
2 Understanding with government agencies and departments who employ *First*  
3 *Responders* to provide information based on the Registry to be used as a method to  
4 assist *First Responders* in emergency situations involving an individual with a  
5 disability and *shall* make the necessary provisions to implement this program to  
6 ensure that vital information is available so that access to the critical needs of the  
7 individual with a disability are immediately addressed.

8 (3) Information Provided. DISID *shall* provide the information based on the  
9 Registry to the government agencies and departments that employ *First Responders*  
10 no later than forty-eight (48) hours after receipt of the registration.

11 **Section 3. Appropriation.** The amount of One Hundred Fifty Thousand  
12 Dollars (\$150,000) is hereby appropriated from the General Fund to the Department  
13 of Integrated Services for Individuals with Disabilities to be used solely for the  
14 creation and implementation of the Individuals with Disabilities Registry.

15 **Section 4. Effective Date.** The effective date of implementation for the  
16 Individuals with Disabilities Registry is January 1, 2016.

17 **Section 5. Severability.** If any provision of this Act or its application to any  
18 person or circumstance is held invalid, the invalidity *shall not* affect other provisions  
19 or applications of this Act which can be given effect without the invalid provision or  
20 application and to this end the provisions of this Act are severable.

*I MINA'TRENTAI TRES NA LIHESLATURAN GUÅHAN*  
2015 (FIRST) REGULAR SESSION

**Bill No. 70-33 (COR)**

**\*As Substituted by the Committee on Appropriations and Adjudication**

**Introduced by:**

**N.B. Underwood, Ph.D.**  
**R.J. Respicio**

**AN ACT TO *AMEND* § 41105 OF CHAPTER 41, ARTICLE 1 OF TITLE 17 OF THE GUAM CODE ANNOTATED, AND TO *ADD A NEW* § 72109 OF CHAPTER 72, TITLE 10 OF THE GUAM CODE ANNOTATED; RELATIVE TO THE CREATION OF AN EMERGENCY REGISTRY FOR INDIVIDUALS WITH SPECIAL NEEDS.**

**1 BE IT ENACTED BY THE PEOPLE OF GUAM:**

**2 Section 1. Legislative Findings and Intent.** *I Liheslaturan Guåhan* finds  
**3** that there is a need to better enhance the current systems in place to effectively  
**4** address the needs of individuals with special needs in emergency situations or in  
**5** situations where immediate action is performed by law enforcement personnel and  
**6** first responders. *I Liheslaturan Guåhan* recognizes that community support for  
**7** individuals with special needs includes treatment that is fair, respectful and  
**8** mindful of specific needs of these individuals especially during interactions with  
**9** law enforcement personnel and first responders. The ability of law enforcement  
**10** personnel and first responders to understand certain characteristics and  
**11** requirements of these individuals will not only allow them to interact appropriately  
**12** with individuals with special needs, but will ensure the critical needs of the  
**13** individual with special needs are addressed in a timely manner.

1 The Guam Department of Education (GDOE) Division of Special Education  
2 reports that in the program school year 2013-2014, approximately one thousand  
3 seven hundred sixty-eight (1,768) students receive numerous services relating to  
4 their disability. According to the U.S. Census, one in five (1 in 5) people suffer  
5 some form of disability or special need. These children and adults would certainly  
6 benefit from some form of registry in the event of an emergency.

7 Therefore, it is the intent of *I Liheslaturan Guåhan* to promote  
8 communication between law enforcement personnel, first responders and  
9 individuals with special needs and their families and to further improve services to  
10 individuals with special needs by creating an Emergency Registry for Individuals  
11 with Special Needs.

12 **Section 2.** Section 41105 of Chapter 41, Article 1 of Title 17 Guam Code  
13 Annotated is hereby *amended* to read as follows:

14 **“§41105. Other Programs/Services.**

15 (a) DISID will review annually the needs for new systems, or  
16 improvement of existing systems. DISID shall create and advocate for  
17 the expansion of programs and services and other systems as required  
18 to implement the services necessary for persons with disabilities.

19 (b) DISID is hereby authorized to enter into a Memorandum of  
20 Understanding with the Guam Fire Department to act as a consultant  
21 and advisor in the establishment and maintenance of an Emergency  
22 Registry for Individuals with Special Needs (Registry) administered  
23 by the Guam Fire Department.”

24 **Section 3.** A new Section 72109 of Chapter 72, Title 10 of the Guam Code  
25 Annotated is hereby *added* to read:

26 **“§ 72109. Emergency Registry for Individuals with Special Needs.**

27 (a) Definitions.

1 (1) “Confidential information” means any and all non-  
2 public, medical, financial and personal information in whatever  
3 form (written, oral, visual or electronic) possessed or obtained  
4 by either party. Confidential information shall include all  
5 information which

6 (A) either party has labeled in writing as  
7 confidential;

8 (B) is identified at the time of disclosure as  
9 confidential;

10 (C) is commonly regarded as confidential in the  
11 health care industry; or

12 (D) is Protected Health Information as defined by  
13 Health Insurance Portability Accountability Act.

14 (2) “First responders” means those individuals who in the  
15 early stages of an incident are responsible for the protection and  
16 preservation of life, property, evidence and the environment,  
17 including emergency response providers as defined in Section 2  
18 of the Homeland Security Act of 2002 (6 U.S.C. 101), as well  
19 as emergency management, public health, clinical care, public  
20 works and other skilled support personnel (such as equipment  
21 operators) that provide immediate support services during  
22 prevention, response and recovery operations.

23 (3) “Special needs” means the phrase used in clinical  
24 diagnosis and functional development to describe individuals  
25 who require assistance for disabilities that may be medical,  
26 mental or psychological; and the needs of such individuals.

27 (b) The Guam Fire Department *shall* create a registry entitled

1 the “Emergency Registry for Individuals with Special Needs”, herein  
2 referred to as “Registry”.

3 (1) The Registry *shall only* contain information  
4 voluntarily disclosed by a registered individual with special  
5 needs, or his or her parent or legal guardian. Such information  
6 may include, but not be limited to, emergency contact  
7 information, relevant medical history, and a description of any  
8 special need deemed relevant by the registrant. All information  
9 within the registry *shall* be deemed confidential information  
10 that *shall* only be used for the purposes of the Registry. Any  
11 other disclosure may occur only upon the written authorization  
12 of the registrant.

13 (2) The Registry *shall* be voluntary and the individual  
14 with special needs, or the parents or legal guardian of the  
15 individual with special needs under the age of eighteen (18)  
16 may register with the Guam Fire Department. An option to  
17 attach a passport-style photo may be permitted. The Registry  
18 application form may be available at the office of the Guam  
19 Fire Department.

20 (3) Once the registration has been received and  
21 processed, the Guam Fire Department or its designated agent  
22 *shall* officially respond by mail or email no less than seven (7)  
23 days from the date of the submission of the registration. An  
24 identification card *shall* be issued which may accompany the  
25 individual with special needs at all times, as deemed  
26 appropriate.

27 (c) Authorization. The Guam Fire Department is hereby

1 authorized to enter into a Memorandum of Understanding with the  
2 Department of Integrated Services for Individuals with Disabilities  
3 and other departments and agencies, as determined by the Guam Fire  
4 Department to seek consultation and advice in the creation and  
5 maintenance of the Registry.

6 (d) The Guam Fire Department and the Department of  
7 Integrated Services for Individuals with Disabilities *shall meet at least*  
8 *quarterly* to report the activities of the registry and *shall* submit a  
9 yearly report beginning January 1, 2017, to *I Maga'lahaen Guåhan and*  
10 *I Liheslaturan Guåhan*, which *shall* include, but not be limited to:

11 (1) number of individuals voluntarily registered;

12 (2) incident reports from first responders when  
13 responding to an emergency with an individual on the Registry;

14 (3) a list of complaints, if any, from the individual on the  
15 registry; and

16 (4) any other strategy effectiveness related to the  
17 Registry.

18 (e) Evaluation. The Guam Fire Department shall conduct a  
19 yearly evaluation of the Registry, which shall include, but not be  
20 limited to:

21 (1) track implementation process to include any planned  
22 and/or unanticipated adaptations to the Registry that may affect  
23 the outcome of the findings;

24 (2) comparative analysis on the number of individuals on  
25 the Registry that benefited from the Registry, their disability  
26 and the delivery of services received;

27 (3) assess the need for any adaptations to the strategy to

1 meet the needs of the target population;

2 (4) input from first responders on their use of the  
3 Registry and its effectiveness;

4 (5) recommendations, if any, to improve the effectiveness  
5 of the Registry.

6 The Guam Fire Department may charge these duties to the  
7 Department of Integrated Services for Individuals with Disabilities as  
8 part of the Memorandum of Understanding as authorized in this  
9 Section.”

10 **Section 4. Participation in National Registry.** *Nothing* herein *shall* be  
11 interpreted to prevent the Guam Fire Department from participating in a national  
12 on-line registry, which meets the requirements set forth in this Act.

13 **Section 5. Appropriation.** The sum of up to One Hundred Fifty Thousand  
14 Dollars (**\$150,000**) is appropriated from the unappropriated fund balance of the  
15 Enhanced 911 Emergency Reporting System Fund to the Guam Fire Department  
16 for the sole purpose of creating, implementing and maintaining the Emergency  
17 Registry for Individuals with Special Needs.

18 **Section 6. Effective Date.** The Emergency Registry for Individuals with  
19 Special Needs *shall* be implemented immediately upon enactment of this Act.

20 **Section 7. Severability.** If any provision of this Act or its application to any  
21 person or circumstance is held invalid, the invalidity *shall not* affect other  
22 provisions or applications of this Act which can be given effect without the invalid  
23 provision or application and to this end the provisions of this Act are severable.

SENATOR BENJAMIN J.F. CRUZ, VICE SPEAKER

Committee on Appropriations and Adjudication  
 senator@senatorbjcruz.com | www.senatorbjcruz.com



I Mina'trentai Tres na Liheslaturan Guahan  
 THE THIRTY-THIRD GUAM LEGISLATURE

155 Hesler Place, Suite 107, Hagåtña, Guam 96910  
 T: (671) 477-2520/1 | F: (671) 477-2522

PUBLIC HEARING SIGN-IN SHEET

Thursday, April 16, 2015 - 10:00AM  
 Guam Legislature Public Hearing Room • Hagåtña, Guam

Bill No. 70-33 (COR) - N.B. Underwood, Ph.D. / R.J. Respicio - "An act to amend Section 41105 of Chapter 41, Article 1 of 17 Guam Code Annotated; relative to the registry for Individuals with Disabilities."

NAME	AGENCY OR ORGANIZATION	POSITION		TESTIMONY		PHONE NO.	EMAIL ADDRESS
		SUPPORT	OPPOSE	WRITTEN	ORAL		
SUN WANG	OPD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>		
Rosanne Ada	GDPC	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	735-9129	
Angel Sablan	MCoB	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	472-6940	angelhet@co.bhamil.com
Sam S. Servino	DISID	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	898-8095	benito.servino@disid.guam
Cynthia Mesa	GUUMOMI	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	472-1434	mesa.Cynthia@guam.net
Sam Ilesuggin	Young Mami	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	777-1881	samueli@guam.net
MARY THEAS GOGOR	GIFTS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	768-7266	
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*I Mina'trentai Tres na Liheslaturan Guahan*

**33<sup>rd</sup> Guam Legislature**

**Senator Nerissa Bretania Underwood, Ph.D.**

Chairperson, Committee on Early Learning, Juvenile Justice,  
Public Education, and First Generation Initiatives

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April 16, 2015

Vice Speaker Benjamin J.F. Cruz  
Chairman  
Committee on Appropriations and Adjudication  
*I Mina'Trentai Tres Na Liheslaturan Guahan*  
155 Hesler Place  
Hagatna, Guam

Author Statement for Bill No. 70-32 (COR)

Hafa Adai Vice Speaker Cruz,

As author for Bill No. 70-32 (COR), An Act to *Amend* Section 41105 o Chapter 41, Article 1 of 17 Guam Code Annotated, Relative to the Creation of a Registry for Individuals with Disabilities, I want to thank you for quickly scheduling a public hearing. Unfortunately I am currently off island and unable to attend today's hearing.

The critical component of Bill 70 is to create an Individuals with Disability Registry (Registry). The Registry will be composed of information of an individual with a disability to improve communications between the individual and a first responder in the event of an emergency. Currently, there is no effective mechanism in place to ensure that the crucial needs of an individual with disability are addressed in a timely manner.

Other key points in the bill are:

- An additional program/service is to be provided by the Department of Integrated Services for Individuals with Disabilities (DISID)---the "Individuals with Disabilities Registry";
- Registry administered by DISID includes information voluntarily registered and provided by the individual with disability, parents, grandparents or legal guardians;
- Information that is registered should include full description of disability, routine/favorite attractions, communication and other special needs, and emergency contact information. Picture ID may be included with registered information;

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- DISID to process registration and issue ID card to individual with disability within seven (7) days of registration application;
- Individual encouraged to carry DISID issued-ID card at all times
- All information regarding the individual with disability remains confidential and protected, and follows the Health Insurance Portability Accountability Act (HIPAA);
- First responders defined to include those federal, state and local personnel responsible for protection and preservation of life;
- DISID authorized to enter Memorandum of Understanding (MOU) with government agencies and departments who employ first responders to ensure that Registry program is implemented appropriately;
- Registry information obtained by DISID to be provided to government agencies and departments that employ first responders within forty-eight (48) hours of receipt of registration;
- Appropriation of \$150,000 to DISID for the creation and implementation of the Registry;
- Effective date of Registry: January 1, 2016.

I welcome the comments and concerns shared at the today's hearing and look forward to working with the Committee and members of the community to create and implement the Registry, which I believe will enhance the services provided to individuals with disabilities.

Sincerely,



Nerissa Bretania Underwood, Ph.D.  
Senator



Benito "Ben" Servino  
DIRECTOR

# Department of Integrated Services for Individuals with Disabilities

Dipattamenton Programa Para I Maninutet  
Government of Guam

*Division of Support Services for Individuals with Disabilities*



Eddie Baza Calvo  
GOVERNOR

Ray Tenorio LIEUTENANT  
GOVERNOR

April 16, 2015

*DISID Ref. No. 1504-1351*

**Honorable Senator/Vice-Speaker Benjamin J.F. Cruz**  
Chairman, Committee on Appropriations and Adjudication  
33rd Guam Legislature  
155 Hesler Place, Suite 107  
Hagåtña, Guam 96910

**Subject: Testimony on Bill No. 70-33 (COR) – N.B Underwood, Ph.D., R.J. Respicio**

## **AN ACT TO AMEND SECTION 41105 OF CHAPTER 41, ARTICLE 1 OF 17 GUAM CODE ANNOTATED, RELATIVE TO THE CREATION OF A REGISTRY FOR INDIVIDUALS WITH DISABILITIES..**

*Buenas yan Hafa Adai* Senator/Vice Speaker Cruz and Members of the Committee on  
Appropriations and Adjudication

For the record, my name is Ben S. Servino, and I currently serve as the Director for the  
Department of Integrated Services for Individuals with Disabilities (DISID).

Our Department has had an opportunity to review Bill 70-33 (COR) and I wish to express our  
support for the bill.

The creation of this bill allows for the registry to act as part of a system-wide access to allow our  
emergency personnel and first responders to be better equipped to handle certain situations  
placed upon them during the call of duty. This registry will allow for Individuals with  
Disabilities and their families to know that "help is on the way". This is priority in certain  
situations when the individual themselves or their families feel helpless.

Allowing individuals with disabilities to provide important information on themselves that will  
ultimately assist them during times of distress, is moving in the right direction. DISID was  
created to become the single point of entry for Individuals with Disabilities and this bill would  
help to build the capacity for DISID to address such a need.

If an individual with a disability voluntarily agrees to participate and be included in the registry  
important information regarding their disability could be accessed by first responders so that  
effective communication strategies could be utilized and first responders could be better prepared  
to provide the necessary accommodations and medical equipment to assist the individual.

Another benefit for individuals with disabilities is that they would be able to receive valuable  
information regarding local legislative bills that have been introduced such as Bill 70-33 or

federal laws that have recently been passed such as the Achieving a Better Life Experience (ABLE) Act which provides a tax deferred savings account for individuals with disabilities.

Individuals with disabilities would be able to also receive information regarding community calendar of events or available grants such as the Individualized Budgeting Program (IBP) that provides funding resources to address the critical needs of a qualified applicant with a disability.

There are a number of agencies and organizations that have established their own registry database of individuals that have accessed their program services including DOE's Head Start and Special Education Programs, DISID's Division of Vocational Rehabilitation (DVR) and Division of Support Services (DSS) Programs, Dept. of Public Health and Social Services/Division of Senior Citizens Program, Guam Regional Transit Authority (GRTA) Para-transit services, and the Guam Behavioral Health and Wellness Center (GBHWC) program services, to mention a few.

For your information, DISID had initially established an on-line registry ([www.guamgetcare.org](http://www.guamgetcare.org)) that set up a client's profile and tracked the services that were provided by the participating agency partners. The on-line resource site was federally funded and administered through DISID's Aging and Disability Resource Center (ADRC). Regrettably, funding and administration for the program was transferred to the GBHWC under the Permanent Injunction process and the grant expired last September 2014. The DPHSS Division of Senior Citizens had actively utilized this website resource and continues to maintain the site to address their Client's needs.

We are collaboratively working with DSC on a new twelve month planning grant process for a three year implementation grant through the Administration on Community Living (ACL) and the Centers for Medicare and Medicaid Services (CMS) that focuses on Long Term Services and Supports and is entitled the "No Wrong Door" system. An on-line comprehensive database registry and tracking system similar to the one used by ADRC is also being considered as part of this initiative and incorporates Person-Centered Counseling and Streamlined Access to Public Program components.

The Guam Developmental Disabilities Council (GDCC) has also established an online registry which is limited to data regarding their constituents with developmental disabilities and does not include a comprehensive approach to collecting data on other disabilities.

DISID's registry would be more comprehensive to include all individuals with various types of disabilities from birth to senior age. It would collect accurate and unduplicated data of the predominance of disabilities on our island which would be very beneficial when applying for federal grants.

Bill No. 70-33 appropriates \$150,000 from the General Fund to DISID to be used solely for the creation and implementation of the Individuals with Disabilities Registry. This funding amount is sufficient to carry-out the intent of Bill No. 70-33 and would be utilized to cover the cost of a Full Time Limited-Term Program Staff (\$35-40,000) which would be hopefully hired under the 2% law to manage and oversee the implementation of the registry. Other funding categories would include the cost for developing an aggressive multi-media (Newspaper, TV, Radio, Mall, Theater) marketing outreach campaign (\$40-50,000) to let the public know about the purpose

and the benefits that can be gained as a participant of the registry, Supplies and computer equipment (\$10,000), Printing costs (\$10-15,000) and lastly, for the development of an RFP for the design (one time cost of \$15 - \$20,000), training and maintenance of the registry (\$12,000-\$15,000).

Proposed funding requirements for subsequent years to maintain the registry would include costs for Program Staff at \$40,000/yr, for Multi-media Marketing Outreach at \$20,000/yr, for Printing costs at \$8,000/year, and Training and Maintenance of the registry at \$15,000/yr, at a total cost of \$83,000/year.

As part of the marketing incentives, DISID plans to solicit discounts from private businesses so that it can be provided to individuals that voluntarily sign up in the registry.

The intent of the Registry is limited to providing demographic information and the special accommodation needs of the individual with a disability to first responders. However, the individual with a disability may voluntarily opt to provide other information that they wish to provide.

DISID will also ensure that the privacy and confidentiality of the information that is provided by the Registry Participant is protected and in compliance with the ADA and HIPPA requirements and that a consent to release of information form is signed by the individual with a disability to include a timeline for this consent provision.

DISID has already initiated discussions on Bill 70-33 (COR) with some the agencies that are to be involved in the implementation of this important initiative and hope that the sustainability of the registry will be supported in future budget allocations. This is a major strategic effort in the identification of a population that almost always goes underserved. This bill will open doors not just for individuals with disabilities but in the ability for our community to assist everyone in years to come.

I "Thank You" for allowing me the opportunity to provide input in support of Bill 70-33 (COR) and I look forward to the continued support of the Legislature and in the passage of this important bill.

Respectfully,



**BENITO S. SERVINO**  
Director, DISID



GOVERNMENT OF GUAHAN



GUAM DEVELOPMENTAL DISABILITIES COUNCIL  
*Konsehelon Guåhan para i Taotao ni' Maninutet desde ki Manhoben*  
130 University Drive Suite 17, Mangilao, Guam 96913

EDDIE B. CALVO  
Governor

RAYMOND TENORIO  
Lieutenant Governor

Guam Developmental  
Disabilities Council

ROSANNE S. ADA  
Executive Director

ERLINDA TYDINGCO  
Chairperson

Vice Speaker Benjamin Cruz  
33<sup>rd</sup> Guam Legislature  
Hagatna, Guam

Dear Honorable B.J. Cruz,

Hafa Adai!

Thank you for inviting me to provide testimony on the following important matter: - "An Act to Amend Section 41105 of Chapter 41, Article 1 of 17 GCA, Relative to the registry for Individuals with Disabilities."

I agree with the intent of the registry "to promote communication between law enforcement personnel, first responders and individuals with disabilities and their families and to further improve services to individuals with disabilities by creating a registry.

DISID Support Services Division had a Guam GetCare System funded by the Aging and Disability Resources Program more than 10 years ago. This was a Registry of programs and services that can be accessed by individuals with disabilities online. It was transferred to the Department of Mental Health and Substance Agency. Funding by the federal agency ended last September 30, 2014.

The System was simple, but expensive. Contractual services to run the system cost \$300,000. Personnel, equipment, and supplies not included. It was managed by a Program Coordinator 1V.

The Program assisted the Division of Senior Citizens in the submission of their State Program Report, the NAPIS, National Aging Program Information System.

At the end of the Project period, DISID must sustain it with funding from the Government of Guam.

DISID has no program staff capable of running the Guam GetCare system. Almost all programs in DISID were transferred to the current Department of Guam Behavioral Health and Wellness Center.

There are programs funded federally to implement a Registry for Individuals with Disabilities.

DVR has the SILC (State Independent Living Council) whose mandate is to establish a Registry of Individuals with Disabilities.

The Guam Developmental Disabilities Council (GDDC) has in its five year State Plan to implement a Registry for Individuals with Developmental Disabilities. (Please see Registry: Attachment 1)

The goal is to access immediate care in the event of a disaster.

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The objective is to facilitate the development and maintenance of a Special Needs Registry to help identify people with developmental disabilities who may need assistance during an emergency.

The Registry is online and can be used to register only. It was developed last year and we are now in the process of keying in all the forms. This registry is only for emergency responders.

The GDDC will begin planning its five year state plan for 2017-2021. The Registry may not be included for the next five years depending on the pressing and current needs of the Developmental Disabilities Community.

To designate DISID in the management of the Registry for Individuals with Disabilities, it is necessary to include the population of individuals with developmental disabilities as defined in the federal mandate of P.L. 106-402 Developmental Disabilities Assistance and Bill of Rights Act of 2000 also known as the DD Act. (Please see Attachment 2 DD Act) Under this Act, Developmental Disabilities are defined as severe, chronic disabilities that:

- Are caused by a mental or physical impairment or a combination of the two
- Are evident before the person is 22 years old
- Are likely to continue indefinitely
- Result in substantial functional limitations in three (3) or more of the following major life activities:
  1. Self Care
  2. Receptive and expressive language
  3. Learning
  4. Mobility
  5. Self-Direction
  6. Capacity for independent living, and
  7. Economic self-sufficiency, and
- Require individually planned and coordinated supports and assistance of a lifelong or extended duration.

Individuals with developmental disabilities are almost always ineligible for vocational rehabilitation services due to the severity of their disabilities. They are the most underserved individuals in our community and in the government service system.

It is recommended to include the aforementioned definition of developmental disabilities in the proposed creation of a Registry for Individuals with Disabilities.

If there are any questions please call our Office at 735-9128 or 735-9129.

Thank you for the opportunity to respond to this proposed Act.

Sincerely yours,



Rosanne S. Ada

Attachments:

- DD Act of 2000
- IIDD Registry Form





GOVERNMENT OF GUAHAN



GUAM DEVELOPMENTAL DISABILITIES COUNCIL
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130 University Drive Suite 17, Mangilao, Guam 96913

Guam Developmental Disabilities Council

Intellectual and Developmental Disabilities Registry

According to the Developmental Disabilities Act, Section 102(8), the term "developmental disability" means a severe, chronic disability of an individual that: is attributed to an intellectual or physical impairment or combination of intellectual and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in 3 or more of the following areas of major life activity: Self-care, Receptive and expressive language, Learning, Mobility, Self-direction, Capacity for independent living, and Economic self-sufficiency; and reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

I. INDIVIDUAL WITH AN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Name: \_\_\_\_\_

(Last, First, Middle Initial)

Gender:

- Male
Female

Date of Birth: \_\_\_\_\_ Place of Birth: \_\_\_\_\_

Home Address: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

II. PARENT/GUARDIAN INFORMATION

Name: \_\_\_\_\_

(Last, First, Middle Initial)

Home Address: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

III. DISABILITY INFORMATION

Type of Disability: \_\_\_\_\_

How old was the individual when this disability was diagnosed: Age: \_\_\_ years \_\_\_ months

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Email: guamddc2@teleguam.net



#### IV. SCHOOL/EMPLOYMENT INFORMATION

For individuals from Birth to 18 years of age.

Name of School: \_\_\_\_\_

An IEP or (Individualized Education Program) is a detailed description of a child's educational program that is used in a public school setting. Children who have an IEP receive at least some special education services:

Does the individual have an IEP at their school?

- Yes
- No
- I don't know

For individuals 18 years of age and older.

What does the individual do? (Check all that apply)

- Is employed full time, with no supports
- Is employed full time, with supports
- Is employed part time, with no supports
- Is employed part time, with supports
- Is not employed
- Attends College/University/other higher education
- Is in public school transitional services (for adults 18-21)
- Volunteer work
- I don't know
- Other (please specify) \_\_\_\_\_

How or where does the individual live?

- Independently, with no assistance
- Independently, but with some assistance
- With a parent(s), guardian (s), or sibling (s)
- In a Group Home(name) \_\_\_\_\_
- In a higher education dormitory
- Other (please specify) \_\_\_\_\_

Please sign and date this form. Thank You!

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Public Law 106-402  
106th Congress

An Act

To improve service systems for individuals with developmental disabilities, and for other purposes.

Oct. 30, 2000  
[S. 1809]

*Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*

Developmental  
Disabilities  
Assistance and  
Bill of Rights Act  
of 2000.  
42 USC 15001  
note.

**SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

(a) **SHORT TITLE.**—This Act may be cited as the “Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(b) **TABLE OF CONTENTS.**—The table of contents of this Act is as follows:

Sec. 1. Short title; table of contents.

**TITLE I—PROGRAMS FOR INDIVIDUALS WITH DEVELOPMENTAL  
DISABILITIES**

**Subtitle A—General Provisions**

- Sec. 101. Findings, purposes, and policy.
- Sec. 102. Definitions.
- Sec. 103. Records and audits.
- Sec. 104. Responsibilities of the Secretary.
- Sec. 105. Reports of the Secretary.
- Sec. 106. State control of operations.
- Sec. 107. Employment of individuals with disabilities.
- Sec. 108. Construction.
- Sec. 109. Rights of individuals with developmental disabilities.

**Subtitle B—Federal Assistance to State Councils on Developmental Disabilities**

- Sec. 121. Purpose.
- Sec. 122. State allotments.
- Sec. 123. Payments to the States for planning, administration, and services.
- Sec. 124. State plan.
- Sec. 125. State Councils on Developmental Disabilities and designated State agencies.
- Sec. 126. Federal and non-Federal share.
- Sec. 127. Withholding of payments for planning, administration, and services.
- Sec. 128. Appeals by States.
- Sec. 129. Authorization of appropriations.

**Subtitle C—Protection and Advocacy of Individual Rights**

- Sec. 141. Purpose.
- Sec. 142. Allotments and payments.
- Sec. 143. System required.
- Sec. 144. Administration.
- Sec. 145. Authorization of appropriations.

**Subtitle D—National Network of University Centers for Excellence in  
Developmental Disabilities Education, Research, and Service**

- Sec. 151. Grant authority.
- Sec. 152. Grant awards.
- Sec. 153. Purpose and scope of activities.
- Sec. 154. Applications.

- Sec. 155. Definition.  
 Sec. 156. Authorization of appropriations.

Subtitle E—Projects of National Significance

- Sec. 161. Purpose.  
 Sec. 162. Grant authority.  
 Sec. 163. Authorization of appropriations.

TITLE II—FAMILY SUPPORT

- Sec. 201. Short title.  
 Sec. 202. Findings, purposes, and policy.  
 Sec. 203. Definitions and special rule.  
 Sec. 204. Grants to States.  
 Sec. 205. Application.  
 Sec. 206. Designation of the lead entity.  
 Sec. 207. Authorized activities.  
 Sec. 208. Reporting.  
 Sec. 209. Technical assistance.  
 Sec. 210. Evaluation.  
 Sec. 211. Projects of national significance.  
 Sec. 212. Authorization of appropriations.

TITLE III—PROGRAM FOR DIRECT SUPPORT WORKERS WHO ASSIST  
 INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

- Sec. 301. Findings.  
 Sec. 302. Definitions.  
 Sec. 303. Reaching up scholarship program.  
 Sec. 304. Staff development curriculum authorization.  
 Sec. 305. Authorization of appropriations.

TITLE IV—REPEAL

- Sec. 401. Repeal.

**TITLE I—PROGRAMS FOR INDIVIDUALS  
 WITH DEVELOPMENTAL DISABILITIES**

**Subtitle A—General Provisions**

42 USC 15001.

**SEC. 101. FINDINGS, PURPOSES, AND POLICY.**

(a) FINDINGS.—Congress finds that—

(1) disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society;

(2) in 1999, there were between 3,200,000 and 4,500,000 individuals with developmental disabilities in the United States, and recent studies indicate that individuals with developmental disabilities comprise between 1.2 and 1.65 percent of the United States population;

(3) individuals whose disabilities occur during their developmental period frequently have severe disabilities that are likely to continue indefinitely;

(4) individuals with developmental disabilities often encounter discrimination in the provision of critical services, such as services in the areas of emphasis (as defined in section 102);

(5) individuals with developmental disabilities are at greater risk than the general population of abuse, neglect,

financial and sexual exploitation, and the violation of their legal and human rights;

(6) a substantial portion of individuals with developmental disabilities and their families do not have access to appropriate support and services, including access to assistive technology, from generic and specialized service systems, and remain unserved or underserved;

(7) individuals with developmental disabilities often require lifelong community services, individualized supports, and other forms of assistance, that are most effective when provided in a coordinated manner;

(8) there is a need to ensure that services, supports, and other assistance are provided in a culturally competent manner, that ensures that individuals from racial and ethnic minority backgrounds are fully included in all activities provided under this title;

(9) family members, friends, and members of the community can play an important role in enhancing the lives of individuals with developmental disabilities, especially when the family members, friends, and community members are provided with the necessary community services, individualized supports, and other forms of assistance;

(10) current research indicates that 88 percent of individuals with developmental disabilities live with their families or in their own households;

(11) many service delivery systems and communities are not prepared to meet the impending needs of the 479,862 adults with developmental disabilities who are living at home with parents who are 60 years old or older and who serve as the primary caregivers of the adults;

(12) in almost every State, individuals with developmental disabilities are waiting for appropriate services in their communities, in the areas of emphasis;

(13) the public needs to be made more aware of the capabilities and competencies of individuals with developmental disabilities, particularly in cases in which the individuals are provided with necessary services, supports, and other assistance;

(14) as increasing numbers of individuals with developmental disabilities are living, learning, working, and participating in all aspects of community life, there is an increasing need for a well trained workforce that is able to provide the services, supports, and other forms of direct assistance required to enable the individuals to carry out those activities;

(15) there needs to be greater effort to recruit individuals from minority backgrounds into professions serving individuals with developmental disabilities and their families;

(16) the goals of the Nation properly include a goal of providing individuals with developmental disabilities with the information, skills, opportunities, and support to—

(A) make informed choices and decisions about their lives;

(B) live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens;

(C) pursue meaningful and productive lives;

(D) contribute to their families, communities, and States, and the Nation;

(E) have interdependent friendships and relationships with other persons;

(F) live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights; and

(G) achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual; and

(17) as the Nation, States, and communities maintain and expand community living options for individuals with developmental disabilities, there is a need to evaluate the access to those options by individuals with developmental disabilities and the effects of those options on individuals with developmental disabilities.

(b) PURPOSE.—The purpose of this title is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under this title, including specifically—

(1) State Councils on Developmental Disabilities in each State to engage in advocacy, capacity building, and systemic change activities that—

(A) are consistent with the purpose described in this subsection and the policy described in subsection (c); and

(B) contribute to a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families;

(2) protection and advocacy systems in each State to protect the legal and human rights of individuals with developmental disabilities;

(3) University Centers for Excellence in Developmental Disabilities Education, Research, and Service—

(A) to provide interdisciplinary pre-service preparation and continuing education of students and fellows, which may include the preparation and continuing education of leadership, direct service, clinical, or other personnel to strengthen and increase the capacity of States and communities to achieve the purpose of this title;

(B) to provide community services—

(i) that provide training and technical assistance for individuals with developmental disabilities, their families, professionals, paraprofessionals, policy-makers, students, and other members of the community; and

(ii) that may provide services, supports, and assistance for the persons described in clause (i) through demonstration and model activities;

(C) to conduct research, which may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively

or negatively, individuals with developmental disabilities and their families; and

(D) to disseminate information related to activities undertaken to address the purpose of this title, especially dissemination of information that demonstrates that the network authorized under this subtitle is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances; and

(4) funding for—

(A) national initiatives to collect necessary data on issues that are directly or indirectly relevant to the lives of individuals with developmental disabilities;

(B) technical assistance to entities who engage in or intend to engage in activities consistent with the purpose described in this subsection or the policy described in subsection (c); and

(C) other nationally significant activities.

(c) POLICY.—It is the policy of the United States that all programs, projects, and activities receiving assistance under this title shall be carried out in a manner consistent with the principles that—

(1) individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of self-determination, independence, productivity, and integration and inclusion in all facets of community life, but often require the provision of community services, individualized supports, and other forms of assistance;

(2) individuals with developmental disabilities and their families have competencies, capabilities, and personal goals that should be recognized, supported, and encouraged, and any assistance to such individuals should be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individuals;

(3) individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families;

(4) services, supports, and other assistance should be provided in a manner that demonstrates respect for individual dignity, personal preferences, and cultural differences;

(5) specific efforts must be made to ensure that individuals with developmental disabilities from racial and ethnic minority backgrounds and their families enjoy increased and meaningful opportunities to access and use community services, individualized supports, and other forms of assistance available to other individuals with developmental disabilities and their families;

(6) recruitment efforts in disciplines related to developmental disabilities relating to pre-service training, community training, practice, administration, and policymaking must focus on bringing larger numbers of racial and ethnic minorities



into the disciplines in order to provide appropriate skills, knowledge, role models, and sufficient personnel to address the growing needs of an increasingly diverse population;

(7) with education and support, communities can be accessible to and responsive to the needs of individuals with developmental disabilities and their families and are enriched by full and active participation in community activities, and contributions, by individuals with developmental disabilities and their families;

(8) individuals with developmental disabilities have access to opportunities and the necessary support to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, communities, and States, and the Nation;

(9) efforts undertaken to maintain or expand community-based living options for individuals with disabilities should be monitored in order to determine and report to appropriate individuals and entities the extent of access by individuals with developmental disabilities to those options and the extent of compliance by entities providing those options with quality assurance standards;

(10) families of children with developmental disabilities need to have access to and use of safe and appropriate child care and before-school and after-school programs, in the most integrated settings, in order to enrich the participation of the children in community life;

(11) individuals with developmental disabilities need to have access to and use of public transportation, in order to be independent and directly contribute to and participate in all facets of community life; and

(12) individuals with developmental disabilities need to have access to and use of recreational, leisure, and social opportunities in the most integrated settings, in order to enrich their participation in community life.

42 USC 15002.

**SEC. 102. DEFINITIONS.**

In this title:

(1) **AMERICAN INDIAN CONSORTIUM.**—The term “American Indian Consortium” means any confederation of 2 or more recognized American Indian tribes, created through the official action of each participating tribe, that has a combined total resident population of 150,000 enrolled tribal members and a contiguous territory of Indian lands in 2 or more States.

(2) **AREAS OF EMPHASIS.**—The term “areas of emphasis” means the areas related to quality assurance activities, education activities and early intervention activities, child care-related activities, health-related activities, employment-related activities, housing-related activities, transportation-related activities, recreation-related activities, and other services available or offered to individuals in a community, including formal and informal community supports, that affect their quality of life.

(3) **ASSISTIVE TECHNOLOGY DEVICE.**—The term “assistive technology device” means any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improve

functional capabilities of individuals with developmental disabilities.

(4) **ASSISTIVE TECHNOLOGY SERVICE.**—The term “assistive technology service” means any service that directly assists an individual with a developmental disability in the selection, acquisition, or use of an assistive technology device. Such term includes—

(A) conducting an evaluation of the needs of an individual with a developmental disability, including a functional evaluation of the individual in the individual’s customary environment;

(B) purchasing, leasing, or otherwise providing for the acquisition of an assistive technology device by an individual with a developmental disability;

(C) selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing or replacing an assistive technology device;

(D) coordinating and using another therapy, intervention, or service with an assistive technology device, such as a therapy, intervention, or service associated with an education or rehabilitation plan or program;

(E) providing training or technical assistance for an individual with a developmental disability, or, where appropriate, a family member, guardian, advocate, or authorized representative of an individual with a developmental disability; and

(F) providing training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of, an individual with developmental disabilities.

(5) **CENTER.**—The term “Center” means a University Center for Excellence in Developmental Disabilities Education, Research, and Service established under subtitle D.

(6) **CHILD CARE-RELATED ACTIVITIES.**—The term “child care-related activities” means advocacy, capacity building, and systemic change activities that result in families of children with developmental disabilities having access to and use of child care services, including before-school, after-school, and out-of-school services, in their communities.

(7) **CULTURALLY COMPETENT.**—The term “culturally competent”, used with respect to services, supports, or other assistance, means services, supports, or other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.

(8) **DEVELOPMENTAL DISABILITY.**—

(A) **IN GENERAL.**—The term “developmental disability” means a severe, chronic disability of an individual that—

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;



(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.

(II) Receptive and expressive language.

(III) Learning.

(IV) Mobility.

(V) Self-direction.

(VI) Capacity for independent living.

(VII) Economic self-sufficiency; and

(v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) INFANTS AND YOUNG CHILDREN.—An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.

(9) EARLY INTERVENTION ACTIVITIES.—The term “early intervention activities” means advocacy, capacity building, and systemic change activities provided to individuals described in paragraph (8)(B) and their families to enhance—

(A) the development of the individuals to maximize their potential; and

(B) the capacity of families to meet the special needs of the individuals.

(10) EDUCATION ACTIVITIES.—The term “education activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities being able to access appropriate supports and modifications when necessary, to maximize their educational potential, to benefit from lifelong educational activities, and to be integrated and included in all facets of student life.

(11) EMPLOYMENT-RELATED ACTIVITIES.—The term “employment-related activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities acquiring, retaining, or advancing in paid employment, including supported employment or self-employment, in integrated settings in a community.

(12) FAMILY SUPPORT SERVICES.—

(A) IN GENERAL.—The term “family support services” means services, supports, and other assistance, provided to families with members who have developmental disabilities, that are designed to—

(i) strengthen the family's role as primary caregiver;

(ii) prevent inappropriate out-of-the-home placement of the members and maintain family unity; and

(iii) reunite families with members who have been placed out of the home whenever possible.

(B) **SPECIFIC SERVICES.**—Such term includes respite care, provision of rehabilitation technology and assistive technology, personal assistance services, parent training and counseling, support for families headed by aging caregivers, vehicular and home modifications, and assistance with extraordinary expenses, associated with the needs of individuals with developmental disabilities.

(13) **HEALTH-RELATED ACTIVITIES.**—The term “health-related activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of coordinated health, dental, mental health, and other human and social services, including prevention activities, in their communities.

(14) **HOUSING-RELATED ACTIVITIES.**—The term “housing-related activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of housing and housing supports and services in their communities, including assistance related to renting, owning, or modifying an apartment or home.

(15) **INCLUSION.**—The term “inclusion”, used with respect to individuals with developmental disabilities, means the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enables individuals with developmental disabilities to—

(A) have friendships and relationships with individuals and families of their own choice;

(B) live in homes close to community resources, with regular contact with individuals without disabilities in their communities;

(C) enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and

(D) take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.

(16) **INDIVIDUALIZED SUPPORTS.**—The term “individualized supports” means supports that—

(A) enable an individual with a developmental disability to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life;

(B) are designed to—

(i) enable such individual to control such individual's environment, permitting the most independent life possible;

(ii) prevent placement into a more restrictive living arrangement than is necessary; and

(iii) enable such individual to live, learn, work, and enjoy life in the community; and

(C) include—

(i) early intervention services;

(ii) respite care;

(iii) personal assistance services;

- (iv) family support services;
- (v) supported employment services;
- (vi) support services for families headed by aging caregivers of individuals with developmental disabilities; and
- (vii) provision of rehabilitation technology and assistive technology, and assistive technology services.

(17) **INTEGRATION.**—The term “integration”, used with respect to individuals with developmental disabilities, means exercising the equal right of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals.

(18) **NOT-FOR-PROFIT.**—The term “not-for-profit”, used with respect to an agency, institution, or organization, means an agency, institution, or organization that is owned or operated by 1 or more corporations or associations, no part of the net earnings of which inures, or may lawfully inure, to the benefit of any private shareholder or individual.

(19) **PERSONAL ASSISTANCE SERVICES.**—The term “personal assistance services” means a range of services, provided by 1 or more individuals, designed to assist an individual with a disability to perform daily activities, including activities on or off a job that such individual would typically perform if such individual did not have a disability. Such services shall be designed to increase such individual’s control in life and ability to perform everyday activities, including activities on or off a job.

(20) **PREVENTION ACTIVITIES.**—The term “prevention activities” means activities that address the causes of developmental disabilities and the exacerbation of functional limitation, such as activities that—

(A) eliminate or reduce the factors that cause or predispose individuals to developmental disabilities or that increase the prevalence of developmental disabilities;

(B) increase the early identification of problems to eliminate circumstances that create or increase functional limitations; and

(C) mitigate against the effects of developmental disabilities throughout the lifespan of an individual.

(21) **PRODUCTIVITY.**—The term “productivity” means—

(A) engagement in income-producing work that is measured by increased income, improved employment status, or job advancement; or

(B) engagement in work that contributes to a household or community.

(22) **PROTECTION AND ADVOCACY SYSTEM.**—The term “protection and advocacy system” means a protection and advocacy system established in accordance with section 143.

(23) **QUALITY ASSURANCE ACTIVITIES.**—The term “quality assurance activities” means advocacy, capacity building, and systemic change activities that result in improved consumer- and family-centered quality assurance and that result in systems of quality assurance and consumer protection that—

(A) include monitoring of services, supports, and assistance provided to an individual with developmental disabilities that ensures that the individual—

(i) will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and

(ii) will not be subject to the inappropriate use of restraints or seclusion;

(B) include training in leadership, self-advocacy, and self-determination for individuals with developmental disabilities, their families, and their guardians to ensure that those individuals—

(i) will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and

(ii) will not be subject to the inappropriate use of restraints or seclusion; or

(C) include activities related to interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-determination, independence, productivity, and integration and inclusion in all facets of community life, of individuals with developmental disabilities.

(24) RECREATION-RELATED ACTIVITIES.—The term “recreation-related activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of recreational, leisure, and social activities, in their communities.

(25) REHABILITATION TECHNOLOGY.—The term “rehabilitation technology” means the systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of, and address the barriers confronted by, individuals with developmental disabilities in areas that include education, rehabilitation, employment, transportation, independent living, and recreation. Such term includes rehabilitation engineering, and the provision of assistive technology devices and assistive technology services.

(26) SECRETARY.—The term “Secretary” means the Secretary of Health and Human Services.

(27) SELF-DETERMINATION ACTIVITIES.—The term “self-determination activities” means activities that result in individuals with developmental disabilities, with appropriate assistance, having—

(A) the ability and opportunity to communicate and make personal decisions;

(B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;

(C) the authority to control resources to obtain needed services, supports, and other assistance;

(D) opportunities to participate in, and contribute to, their communities; and

(E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

(28) STATE.—The term “State”, except as otherwise provided, includes, in addition to each of the several States of the United States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

(29) STATE COUNCIL ON DEVELOPMENTAL DISABILITIES.—The term “State Council on Developmental Disabilities” means a Council established under section 125.

(30) SUPPORTED EMPLOYMENT SERVICES.—The term “supported employment services” means services that enable individuals with developmental disabilities to perform competitive work in integrated work settings, in the case of individuals with developmental disabilities—

(A)(i) for whom competitive employment has not traditionally occurred; or

(ii) for whom competitive employment has been interrupted or intermittent as a result of significant disabilities; and

(B) who, because of the nature and severity of their disabilities, need intensive supported employment services or extended services in order to perform such work.

(31) TRANSPORTATION-RELATED ACTIVITIES.—The term “transportation-related activities” means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of transportation.

(32) UNSERVED AND UNDERSERVED.—The term “unserved and underserved” includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in and contribute to community life.

42 USC 15003.

**SEC. 103. RECORDS AND AUDITS.**

(a) RECORDS.—Each recipient of assistance under this title shall keep such records as the Secretary shall prescribe, including—

(1) records that fully disclose—

(A) the amount and disposition by such recipient of the assistance;

(B) the total cost of the project or undertaking in connection with which such assistance is given or used; and

(C) the amount of that portion of the cost of the project or undertaking that is supplied by other sources; and

(2) such other records as will facilitate an effective audit.

(b) ACCESS.—The Secretary and the Comptroller General of the United States, or any of their duly authorized representatives, shall have access for the purpose of audit and examination to any books, documents, papers, and records of the recipients of assistance under this title that are pertinent to such assistance.

42 USC 15004.

**SEC. 104. RESPONSIBILITIES OF THE SECRETARY.**

(a) PROGRAM ACCOUNTABILITY.—

(1) **IN GENERAL.**—In order to monitor entities that received funds under this Act to carry out activities under subtitles B, C, and D and determine the extent to which the entities have been responsive to the purpose of this title and have taken actions consistent with the policy described in section 101(c), the Secretary shall develop and implement an accountability process as described in this subsection, with respect to activities conducted after October 1, 2001.

(2) **AREAS OF EMPHASIS.**—The Secretary shall develop a process for identifying and reporting (pursuant to section 105) on progress achieved through advocacy, capacity building, and systemic change activities, undertaken by the entities described in paragraph (1), that resulted in individuals with developmental disabilities and their families participating in the design of and having access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life. Specifically, the Secretary shall develop a process for identifying and reporting on progress achieved, through advocacy, capacity building, and systemic change activities, by the entities in the areas of emphasis.

(3) **INDICATORS OF PROGRESS.**—

(A) **IN GENERAL.**—In identifying progress made by the entities described in paragraph (1) in the areas of emphasis, the Secretary, in consultation with the Commissioner of the Administration on Developmental Disabilities and the entities, shall develop indicators for each area of emphasis.

(B) **PROPOSED INDICATORS.**—Not later than 180 days after the date of enactment of this Act, the Secretary shall develop and publish in the Federal Register for public comment proposed indicators of progress for monitoring how entities described in paragraph (1) have addressed the areas of emphasis described in paragraph (2) in a manner that is responsive to the purpose of this title and consistent with the policy described in section 101(c).

Deadline.  
Federal Register,  
publication.

(C) **FINAL INDICATORS.**—Not later than October 1, 2001, the Secretary shall revise the proposed indicators of progress, to the extent necessary based on public comment, and publish final indicators of progress in the Federal Register.

Deadline.  
Federal Register,  
publication.

(D) **SPECIFIC MEASURES.**—At a minimum, the indicators of progress shall be used to describe and measure—

(i) the satisfaction of individuals with developmental disabilities with the advocacy, capacity building, and systemic change activities provided under subtitles B, C, and D;

(ii) the extent to which the advocacy, capacity building, and systemic change activities provided through subtitles B, C, and D result in improvements in—

(I) the ability of individuals with developmental disabilities to make choices and exert control over the type, intensity, and timing of services, supports, and assistance that the individuals have used;

(II) the ability of individuals with developmental disabilities to participate in the full range of community life with persons of the individuals' choice; and

(III) the ability of individuals with developmental disabilities to access services, supports, and assistance in a manner that ensures that such an individual is free from abuse, neglect, sexual and financial exploitation, violation of legal and human rights, and the inappropriate use of restraints and seclusion; and

(iii) the extent to which the entities described in paragraph (1) collaborate with each other to achieve the purpose of this title and the policy described in section 101(c).

(4) **TIME LINE FOR COMPLIANCE WITH INDICATORS OF PROGRESS.**—The Secretary shall require entities described in paragraph (1) to meet the indicators of progress described in paragraph (3). For fiscal year 2002 and each year thereafter, the Secretary shall apply the indicators in monitoring entities described in paragraph (1), with respect to activities conducted after October 1, 2001.

Deadline.

(b) **TIME LINE FOR REGULATIONS.**—Except as otherwise expressly provided in this title, the Secretary, not later than 1 year after the date of enactment of this Act, shall promulgate such regulations as may be required for the implementation of this title.

(c) **INTERAGENCY COMMITTEE.**—

(1) **IN GENERAL.**—The Secretary shall maintain the interagency committee authorized in section 108 of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6007) as in effect on the day before the date of enactment of this Act, except as otherwise provided in this subsection.

(2) **COMPOSITION.**—The interagency committee shall be composed of representatives of—

(A) the Administration on Developmental Disabilities, the Administration on Children, Youth, and Families, the Administration on Aging, and the Health Resources and Services Administration, of the Department of Health and Human Services; and

(B) such other Federal departments and agencies as the Secretary of Health and Human Services considers to be appropriate.

(3) **DUTIES.**—Such interagency committee shall meet regularly to coordinate and plan activities conducted by Federal departments and agencies for individuals with developmental disabilities.

(4) **MEETINGS.**—Each meeting of the interagency committee (except for any meetings of any subcommittees of the committee) shall be open to the public. Notice of each meeting, and a statement of the agenda for the meeting, shall be published in the Federal Register not later than 14 days before the date on which the meeting is to occur.

Federal Register,  
publication.  
Deadline.

42 USC 15005.

**SEC. 105. REPORTS OF THE SECRETARY.**

At least once every 2 years, the Secretary, using information submitted in the reports and information required under subtitles

B, C, D, and E, shall prepare and submit to the President, Congress, and the National Council on Disability, a report that describes the goals and outcomes of programs supported under subtitles B, C, D, and E. In preparing the report, the Secretary shall provide—

(1) meaningful examples of how the councils, protection and advocacy systems, centers, and entities funded under subtitles B, C, D, and E, respectively—

(A) have undertaken coordinated activities with each other;

(B) have enhanced the ability of individuals with developmental disabilities and their families to participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life;

(C) have brought about advocacy, capacity building, and systemic change activities (including policy reform), and other actions on behalf of individuals with developmental disabilities and their families, including individuals who are traditionally unserved or underserved, particularly individuals who are members of ethnic and racial minority groups and individuals from underserved geographic areas; and

(D) have brought about advocacy, capacity building, and systemic change activities that affect individuals with disabilities other than individuals with developmental disabilities;

(2) information on the extent to which programs authorized under this title have addressed—

(A) protecting individuals with developmental disabilities from abuse, neglect, sexual and financial exploitation, and violations of legal and human rights, so that those individuals are at no greater risk of harm than other persons in the general population; and

(B) reports of deaths of and serious injuries to individuals with developmental disabilities; and

(3) a summary of any incidents of noncompliance of the programs authorized under this title with the provisions of this title, and corrections made or actions taken to obtain compliance.

**SEC. 106. STATE CONTROL OF OPERATIONS.**

42 USC 15006.

Except as otherwise specifically provided, nothing in this title shall be construed as conferring on any Federal officer or employee the right to exercise any supervision or control over the administration, personnel, maintenance, or operation of any programs, services, and supports for individuals with developmental disabilities with respect to which any funds have been or may be expended under this title.

**SEC. 107. EMPLOYMENT OF INDIVIDUALS WITH DISABILITIES.**

42 USC 15007.

As a condition of providing assistance under this title, the Secretary shall require that each recipient of such assistance take affirmative action to employ and advance in employment qualified individuals with disabilities on the same terms and conditions required with respect to the employment of such individuals under the provisions of title V of the Rehabilitation Act of 1973 (29



U.S.C. 791 et seq.) and the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), that govern employment.

42 USC 15008.

**SEC. 108. CONSTRUCTION.**

Nothing in this title shall be construed to preclude an entity funded under this title from engaging in advocacy, capacity building, and systemic change activities for individuals with developmental disabilities that may also have a positive impact on individuals with other disabilities.

42 USC 15009.

**SEC. 109. RIGHTS OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES.**

(a) **IN GENERAL.**—Congress makes the following findings respecting the rights of individuals with developmental disabilities:

(1) Individuals with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities, consistent with section 101(c).

(2) The treatment, services, and habilitation for an individual with developmental disabilities should be designed to maximize the potential of the individual and should be provided in the setting that is least restrictive of the individual's personal liberty.

(3) The Federal Government and the States both have an obligation to ensure that public funds are provided only to institutional programs, residential programs, and other community programs, including educational programs in which individuals with developmental disabilities participate, that—

(A) provide treatment, services, and habilitation that are appropriate to the needs of such individuals; and

(B) meet minimum standards relating to—

(i) provision of care that is free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights and that subjects individuals with developmental disabilities to no greater risk of harm than others in the general population;

(ii) provision to such individuals of appropriate and sufficient medical and dental services;

(iii) prohibition of the use of physical restraint and seclusion for such an individual unless absolutely necessary to ensure the immediate physical safety of the individual or others, and prohibition of the use of such restraint and seclusion as a punishment or as a substitute for a habilitation program;

(iv) prohibition of the excessive use of chemical restraints on such individuals and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment, or habilitation for such individuals; and

(v) provision for close relatives or guardians of such individuals to visit the individuals without prior notice.

(4) All programs for individuals with developmental disabilities should meet standards—

(A) that are designed to assure the most favorable possible outcome for those served; and

(B)(i) in the case of residential programs serving individuals in need of comprehensive health-related,

habilitative, assistive technology or rehabilitative services, that are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded, promulgated in regulations of the Secretary on June 3, 1988, as appropriate, taking into account the size of the institutions and the service delivery arrangements of the facilities of the programs;

(ii) in the case of other residential programs for individuals with developmental disabilities, that assure that—

(I) care is appropriate to the needs of the individuals being served by such programs;

(II) the individuals admitted to facilities of such programs are individuals whose needs can be met through services provided by such facilities; and

(III) the facilities of such programs provide for the humane care of the residents of the facilities, are sanitary, and protect their rights; and

(iii) in the case of nonresidential programs, that assure that the care provided by such programs is appropriate to the individuals served by the programs.

(b) CLARIFICATION.—The rights of individuals with developmental disabilities described in findings made in this section shall be considered to be in addition to any constitutional or other rights otherwise afforded to all individuals.

## Subtitle B—Federal Assistance to State Councils on Developmental Disabilities

### SEC. 121. PURPOSE.

42 USC 15021.

The purpose of this subtitle is to provide for allotments to support State Councils on Developmental Disabilities (referred to individually in this subtitle as a “Council”) in each State to—

(1) engage in advocacy, capacity building, and systemic change activities that are consistent with the purpose described in section 101(b) and the policy described in section 101(c); and

(2) 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 enable individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life.

### SEC. 122. STATE ALLOTMENTS.

42 USC 15022.

(a) ALLOTMENTS.—

(1) IN GENERAL.—

(A) AUTHORITY.—For each fiscal year, the Secretary shall, in accordance with regulations and this paragraph, allot the sums appropriated for such year under section 129 among the States on the basis of—

(i) the population;

(ii) the extent of need for services for individuals with developmental disabilities; and

(iii) the financial need,

of the respective States.

(B) USE OF FUNDS.—Sums allotted to the States under this section shall be used to pay for the Federal share of the cost of carrying out projects in accordance with State plans approved under section 124 for the provision under such plans of services for individuals with developmental disabilities.

(2) ADJUSTMENTS.—The Secretary may make adjustments in the amounts of State allotments based on clauses (i), (ii), and (iii) of paragraph (1)(A) not more often than annually. The Secretary shall notify each State of any adjustment made under this paragraph and the percentage of the total sums appropriated under section 129 that the adjusted allotment represents not later than 6 months before the beginning of the fiscal year in which such adjustment is to take effect.

Deadline.

(3) MINIMUM ALLOTMENT FOR APPROPRIATIONS LESS THAN OR EQUAL TO \$70,000,000.—

(A) IN GENERAL.—Except as provided in paragraph (4), for any fiscal year the allotment under this section—

(i) to each of American Samoa, Guam, the United States Virgin Islands, or the Commonwealth of the Northern Mariana Islands may not be less than \$210,000; and

(ii) to any State not described in clause (i) may not be less than \$400,000.

(B) REDUCTION OF ALLOTMENT.—Notwithstanding subparagraph (A), if the aggregate of the amounts to be allotted to the States pursuant to subparagraph (A) for any fiscal year exceeds the total amount appropriated under section 129 for such fiscal year, the amount to be allotted to each State for such fiscal year shall be proportionately reduced.

(4) MINIMUM ALLOTMENT FOR APPROPRIATIONS IN EXCESS OF \$70,000,000.—

(A) IN GENERAL.—In any case in which the total amount appropriated under section 129 for a fiscal year is more than \$70,000,000, the allotment under this section for such fiscal year—

(i) to each of American Samoa, Guam, the United States Virgin Islands, or the Commonwealth of the Northern Mariana Islands may not be less than \$220,000; and

(ii) to any State not described in clause (i) may not be less than \$450,000.

(B) REDUCTION OF ALLOTMENT.—The requirements of paragraph (3)(B) shall apply with respect to amounts to be allotted to States under subparagraph (A), in the same manner and to the same extent as such requirements apply with respect to amounts to be allotted to States under paragraph (3)(A).

(5) STATE SUPPORTS, SERVICES, AND OTHER ACTIVITIES.—In determining, for purposes of paragraph (1)(A)(ii), the extent of need in any State for services for individuals with developmental disabilities, the Secretary shall take into account the scope and extent of the services, supports, and assistance described, pursuant to section 124(c)(3)(A), in the State plan of the State.

(6) INCREASE IN ALLOTMENTS.—In any year in which the total amount appropriated under section 129 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 paragraphs (3) and (4). 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 129 for the fiscal year for which the increase in the minimum allotment is being made; minus

(B) the total amount appropriated under section 129 (or a corresponding provision) for the immediately preceding fiscal year,

bears to the total amount appropriated under section 129 (or a corresponding provision) for such preceding fiscal year.

(b) UNOBLIGATED FUNDS.—Any amount paid to a State for a fiscal year and remaining unobligated at the end of such year shall remain available to such State for the next fiscal year for the purposes for which such amount was paid.

(c) OBLIGATION OF FUNDS.—For the purposes of this subtitle, State Interagency Agreements are considered valid obligations for the purpose of obligating Federal funds allotted to the State under this subtitle.

(d) COOPERATIVE EFFORTS BETWEEN STATES.—If a State plan approved in accordance with section 124 provides for cooperative or joint effort between or among States or agencies, public or private, in more than 1 State, portions of funds allotted to 1 or more States described in this subsection may be combined in accordance with the agreements between the States or agencies involved.

(e) REALLOTMENTS.—

(1) IN GENERAL.—If the Secretary determines that an amount of an allotment to a State for a period (of a fiscal year or longer) will not be required by the State during the period for the purpose for which the allotment was made, the Secretary may reallocate the amount.

(2) TIMING.—The Secretary may make such a reallocation from time to time, on such date as the Secretary may fix, but not earlier than 30 days after the Secretary has published notice of the intention of the Secretary to make the reallocation in the Federal Register.

(3) AMOUNTS.—The Secretary shall reallocate the amount to other States with respect to which the Secretary has not made that determination. The Secretary shall reallocate the amount in proportion to the original allotments of the other States for such fiscal year, but shall reduce such proportionate amount for any of the other States to the extent the proportionate amount exceeds the sum that the Secretary estimates the State needs and will be able to use during such period.

(4) REALLOTMENT OF REDUCTIONS.—The Secretary shall similarly reallocate the total of the reductions among the States whose proportionate amounts were not so reduced.

(5) TREATMENT.—Any amount reallocated to a State under this subsection for a fiscal year shall be deemed to be a part of the allotment of the State under subsection (a) for such fiscal year.

42 USC 15023.

**SEC. 123. PAYMENTS TO THE STATES FOR PLANNING, ADMINISTRATION, AND SERVICES.**

(a) STATE PLAN EXPENDITURES.—From each State's allotments for a fiscal year under section 122, the Secretary shall pay to the State the Federal share of the cost, other than the cost for construction, incurred during such year for activities carried out under the State plan approved under section 124. The Secretary shall make such payments from time to time in advance on the basis of estimates by the Secretary of the sums the State will expend for the cost under the State plan. The Secretary shall make such adjustments as may be necessary to the payments on account of previously made underpayments or overpayments under this section.

(b) DESIGNATED STATE AGENCY EXPENDITURES.—The Secretary may make payments to a State for the portion described in section 124(c)(5)(B)(vi) in advance or by way of reimbursement, and in such installments as the Secretary may determine.

42 USC 15024.

**SEC. 124. STATE PLAN.**

(a) IN GENERAL.—Any State desiring to receive assistance under this subtitle shall submit to the Secretary, and obtain approval of, a 5-year strategic State plan under this section.

(b) PLANNING CYCLE.—The plan described in subsection (a) shall be updated as appropriate during the 5-year period.

(c) STATE PLAN REQUIREMENTS.—In order to be approved by the Secretary under this section, a State plan shall meet each of the following requirements:

(1) STATE COUNCIL.—The plan shall provide for the establishment and maintenance of a Council in accordance with section 125 and describe the membership of such Council.

(2) DESIGNATED STATE AGENCY.—The plan shall identify the agency or office within the State designated to support the Council in accordance with this section and section 125(d) (referred to in this subtitle as a "designated State agency").

(3) COMPREHENSIVE REVIEW AND ANALYSIS.—The plan shall describe the results of a comprehensive review and analysis of the extent to which services, supports, and other assistance are available to individuals with developmental disabilities and their families, and the extent of unmet needs for services, supports, and other assistance for those individuals and their families, in the State. The results of the comprehensive review and analysis shall include—

(A) a description of the services, supports, and other assistance being provided to individuals with developmental disabilities and their families under other federally assisted State programs, plans, and policies under which the State operates and in which individuals with developmental disabilities are or may be eligible to participate, including particularly programs relating to the areas of emphasis, including—

(i) medical assistance, maternal and child health care, services for children with special health care needs, children's mental health services, comprehensive health and mental health services, and institutional care options;

(ii) job training, job placement, worksite accommodation, and vocational rehabilitation, and other work assistance programs; and

(iii) social, child welfare, aging, independent living, and rehabilitation and assistive technology services, and such other services as the Secretary may specify;

(B) a description of the extent to which agencies operating such other federally assisted State programs, including activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012), pursue interagency initiatives to improve and enhance community services, individualized supports, and other forms of assistance for individuals with developmental disabilities;

(C) an analysis of the extent to which community services and opportunities related to the areas of emphasis directly benefit individuals with developmental disabilities, especially with regard to their ability to access and use services provided in their communities, to participate in opportunities, activities, and events offered in their communities, and to contribute to community life, identifying particularly—

(i) the degree of support for individuals with developmental disabilities that are attributable to either physical impairment, mental impairment, or a combination of physical and mental impairments;

(ii) criteria for eligibility for services, including specialized services and special adaptation of generic services provided by agencies within the State, that may exclude individuals with developmental disabilities from receiving services described in this clause;

(iii) the barriers that impede full participation of members of unserved and underserved groups of individuals with developmental disabilities and their families;

(iv) the availability of assistive technology, assistive technology services, or rehabilitation technology, or information about assistive technology, assistive technology services, or rehabilitation technology to individuals with developmental disabilities;

(v) the numbers of individuals with developmental disabilities on waiting lists for services described in this subparagraph;

(vi) a description of the adequacy of current resources and projected availability of future resources to fund services described in this subparagraph;

(vii) a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive (based in part on 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, which the State shall provide to the Council not later than 30 days after the availability of the review); and

(viii) to the extent that information is available, a description of 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;

(D) a description of how entities funded under subtitles C and D, through interagency agreements or other mechanisms, collaborated with the entity funded under this subtitle in the State, each other, and other entities to contribute to the achievement of the purpose of this subtitle; and

(E) the rationale for the goals related to advocacy, capacity building, and systemic change to be undertaken by the Council to contribute to the achievement of the purpose of this subtitle.

(4) PLAN GOALS.—The plan shall focus on Council efforts to bring about the purpose of this subtitle, by—

(A) specifying 5-year goals, as developed through data driven strategic planning, for advocacy, capacity building, and systemic change related to the areas of emphasis, to be undertaken by the Council, that—

(i) are derived from the unmet needs of individuals with developmental disabilities and their families identified under paragraph (3); and

(ii) include a goal, for each year of the grant, to—

(I) establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities;

(II) support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders; and

(III) support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions; and

(B) for each year of the grant, describing—

(i) the goals to be achieved through the grant, which, beginning in fiscal year 2002, shall be consistent with applicable indicators of progress described in section 104(a)(3);

(ii) the strategies to be used in achieving each goal; and

(iii) the method to be used to determine if each goal has been achieved.

(5) ASSURANCES.—

(A) IN GENERAL.—The plan shall contain or be supported by assurances and information described in subparagraphs (B) through (N) that are satisfactory to the Secretary.

(B) USE OF FUNDS.—With respect to the funds paid to the State under section 122, the plan shall provide assurances that—

(i) not less than 70 percent of such funds will be expended for activities related to the goals described in paragraph (4);

(ii) such funds will contribute to the achievement of the purpose of this subtitle in various political subdivisions of the State;

(iii) such funds will be used to supplement, and not supplant, the non-Federal funds that would otherwise be made available for the purposes for which the funds paid under section 122 are provided;

(iv) such funds will be used to complement and augment rather than duplicate or replace services for individuals with developmental disabilities and their families who are eligible for Federal assistance under other State programs;

(v) part of such funds will be made available by the State to public or private entities;

(vi) at the request of any State, a portion of such funds provided to such State under this subtitle for any fiscal year shall be available to pay up to  $\frac{1}{2}$  (or the entire amount if the Council is the designated State agency) of the expenditures found to be necessary by the Secretary for the proper and efficient exercise of the functions of the designated State agency, except that not more than 5 percent of such funds provided to such State for any fiscal year, or \$50,000, whichever is less, shall be made available for total expenditures for such purpose by the designated State agency; and

(vii) not more than 20 percent of such funds will be allocated to the designated State agency for service demonstrations by such agency that—

(I) contribute to the achievement of the purpose of this subtitle; and

(II) are explicitly authorized by the Council.

(C) STATE FINANCIAL PARTICIPATION.—The plan shall provide assurances that there will be reasonable State financial participation in the cost of carrying out the plan.

(D) CONFLICT OF INTEREST.—The plan shall provide an assurance that no member of such Council will cast a vote on any matter that would provide direct financial benefit to the member or otherwise give the appearance of a conflict of interest.

(E) URBAN AND RURAL POVERTY AREAS.—The plan shall provide assurances that special financial and technical assistance will be given to organizations that provide community services, individualized supports, and other forms of assistance to individuals with developmental disabilities who live in areas designated as urban or rural poverty areas.



(F) PROGRAM ACCESSIBILITY STANDARDS.—The plan shall provide assurances that programs, projects, and activities funded under the plan, and the buildings in which such programs, projects, and activities are operated, will meet standards prescribed by the Secretary in regulations and all applicable Federal and State accessibility standards, including accessibility requirements of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), section 508 of the Rehabilitation Act of 1973 (29 U.S.C. 794d), and the Fair Housing Act (42 U.S.C. 3601 et seq.).

(G) INDIVIDUALIZED SERVICES.—The plan shall provide assurances that any direct services provided to individuals with developmental disabilities and funded under the plan will be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individual.

(H) HUMAN RIGHTS.—The plan shall provide assurances that the human rights of the individuals with developmental disabilities (especially individuals without familial protection) who are receiving services under programs assisted under this subtitle will be protected consistent with section 109 (relating to rights of individuals with developmental disabilities).

(I) MINORITY PARTICIPATION.—The plan shall provide assurances that the State has taken affirmative steps to assure that participation in programs funded under this subtitle is geographically representative of the State, and reflects the diversity of the State with respect to race and ethnicity.

(J) EMPLOYEE PROTECTIONS.—The plan shall provide assurances that fair and equitable arrangements (as determined by the Secretary after consultation with the Secretary of Labor) will be provided to protect the interests of employees affected by actions taken under the plan to provide community living activities, including arrangements designed to preserve employee rights and benefits and provide training and retraining of such employees where necessary, and arrangements under which maximum efforts will be made to guarantee the employment of such employees.

(K) STAFF ASSIGNMENTS.—The plan shall provide assurances that the staff and other personnel of the Council, while working for the Council, will be responsible solely for assisting the Council in carrying out the duties of the Council under this subtitle and will not be assigned duties by the designated State agency, or any other agency, office, or entity of the State.

(L) NONINTERFERENCE.—The plan shall provide assurances that the designated State agency, and any other agency, office, or entity of the State, will not interfere with the advocacy, capacity building, and systemic change activities, budget, personnel, State plan development, or plan implementation of the Council, except that the designated State agency shall have the authority necessary to carry out the responsibilities described in section 125(d)(3).

(M) STATE QUALITY ASSURANCE.—The plan shall provide assurances that the Council will participate in the planning, design or redesign, and monitoring of State quality assurance systems that affect individuals with developmental disabilities.

(N) OTHER ASSURANCES.—The plan shall contain such additional information and assurances as the Secretary may find necessary to carry out the provisions (including the purpose) of this subtitle.

(d) PUBLIC INPUT AND REVIEW, SUBMISSION, AND APPROVAL.—

(1) PUBLIC INPUT AND REVIEW.—The plan shall be based on public input. The Council shall make the plan available for public review and comment, after providing appropriate and sufficient notice in accessible formats of the opportunity for such review and comment. The Council shall revise the plan to take into account and respond to significant comments.

(2) CONSULTATION WITH THE DESIGNATED STATE AGENCY.—Before the plan is submitted to the Secretary, the Council shall consult with the designated State agency to ensure that the State plan is consistent with State law and to obtain appropriate State plan assurances.

(3) PLAN APPROVAL.—The Secretary shall approve any State plan and, as appropriate, amendments of such plan that comply with the provisions of subsections (a), (b), and (c) and this subsection. The Secretary may take final action to disapprove a State plan after providing reasonable notice and an opportunity for a hearing to the State.

**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)  $\frac{1}{3}$  shall be individuals with developmental disabilities described in paragraph (3)(A)(i);

(B)  $\frac{1}{3}$  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)  $\frac{1}{3}$  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 entities carrying out other similar councils, entities, or committees);

(ii) 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

(iii) 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.).

(d) DESIGNATED STATE AGENCY.—

(1) IN GENERAL.—Each State that receives assistance under this subtitle shall designate a State agency that shall, on behalf of the State, provide support to the Council. After the date of enactment of the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994 (Public Law 103-230), any designation of a State agency under this paragraph shall be made in accordance with the requirements of this subsection.

(2) DESIGNATION.—

(A) TYPE OF AGENCY.—Except as provided in this subsection, the designated State agency shall be—

- (i) the Council if such Council may be the designated State agency under the laws of the State;
- (ii) a State agency that does not provide or pay for services for individuals with developmental disabilities; or
- (iii) a State office, including the immediate office of the Governor of the State or a State planning office.

(B) CONDITIONS FOR CONTINUATION OF STATE SERVICE AGENCY DESIGNATION.—

(i) DESIGNATION BEFORE ENACTMENT.—If a State agency that provides or pays for services for individuals with developmental disabilities was a designated State agency for purposes of part B of the Developmental Disabilities Assistance and Bill of Rights Act on the date of enactment of the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994, and the Governor of the State (or the legislature, where appropriate and in accordance with State law) determines prior to June 30, 1994, not to change the designation of such agency, such agency may continue to be a designated State agency for purposes of this subtitle.

(ii) CRITERIA FOR CONTINUED DESIGNATION.—The determination, at the discretion of the Governor (or the legislature, as the case may be), shall be made after—

(I) the Governor has considered the comments and recommendations of the general public and a majority of the non-State agency members of the Council with respect to the designation of such State agency; and

(II) the Governor (or the legislature, as the case may be) has made an independent assessment that the designation of such agency will not interfere with the budget, personnel, priorities, or other action of the Council, and the ability of the Council to serve as an independent advocate for individuals with developmental disabilities.

(C) REVIEW OF DESIGNATION.—The Council may request a review of and change in the designation of the designated State agency by the Governor (or the legislature, as the case may be). The Council shall provide documentation

concerning the reason the Council desires a change to be made and make a recommendation to the Governor (or the legislature, as the case may be) regarding a preferred designated State agency.

(D) APPEAL OF DESIGNATION.—After the review is completed under subparagraph (C), a majority of the non-State agency members of the Council may appeal to the Secretary for a review of and change in the designation of the designated State agency if the ability of the Council to serve as an independent advocate is not assured because of the actions or inactions of the designated State agency.

(3) RESPONSIBILITIES.—

(A) IN GENERAL.—The designated State agency shall, on behalf of the State, have the responsibilities described in subparagraphs (B) through (G).

(B) SUPPORT SERVICES.—The designated State agency shall provide required assurances and support services as requested by and negotiated with the Council.

(C) FISCAL RESPONSIBILITIES.—The designated State agency shall—

(i) receive, account for, and disburse funds under this subtitle based on the State plan required in section 124; and

(ii) provide for such fiscal control and fund accounting procedures as may be necessary to assure the proper disbursement of, and accounting for, funds paid to the State under this subtitle.

(D) RECORDS, ACCESS, AND FINANCIAL REPORTS.—The designated State agency shall keep and provide access to such records as the Secretary and the Council may determine to be necessary. The designated State agency, if other than the Council, shall provide timely financial reports at the request of the Council regarding the status of expenditures, obligations, and liquidation by the agency or the Council, and the use of the Federal and non-Federal shares described in section 126, by the agency or the Council.

(E) NON-FEDERAL SHARE.—The designated State agency, if other than the Council, shall provide the required non-Federal share described in section 126(c).

(F) ASSURANCES.—The designated State agency shall assist the Council in obtaining the appropriate State plan assurances and in ensuring that the plan is consistent with State law.

(G) MEMORANDUM OF UNDERSTANDING.—On the request of the Council, the designated State agency shall enter into a memorandum of understanding with the Council delineating the roles and responsibilities of the designated State agency.

(4) USE OF FUNDS FOR DESIGNATED STATE AGENCY RESPONSIBILITIES.—

(A) CONDITION FOR FEDERAL FUNDING.—

(i) IN GENERAL.—The Secretary shall provide amounts to a State under section 124(c)(5)(B)(vi) for a fiscal year only if the State expends an amount from State sources for carrying out the responsibilities of the designated State agency under paragraph (3)

for the fiscal year that is not less than the total amount the State expended from such sources for carrying out similar responsibilities for the previous fiscal year.

(ii) EXCEPTION.—Clause (i) shall not apply in a year in which the Council is the designated State agency.

(B) SUPPORT SERVICES PROVIDED BY OTHER AGENCIES.—

With the agreement of the designated State agency, the Council may use or contract with agencies other than the designated State agency to perform the functions of the designated State agency.

42 USC 15026.

**SEC. 126. FEDERAL AND NON-FEDERAL SHARE.**

(a) AGGREGATE COST.—

(1) IN GENERAL.—Except as provided in paragraphs (2) and (3), the Federal share of the cost of all projects in a State supported by an allotment to the State under this subtitle may not be more than 75 percent of the aggregate necessary cost of such projects, as determined by the Secretary.

(2) URBAN OR RURAL POVERTY AREAS.—In the case of projects whose activities or products target individuals with developmental disabilities who live in urban or rural poverty areas, as determined by the Secretary, the Federal share of the cost of all such projects may not be more than 90 percent of the aggregate necessary cost of such projects, as determined by the Secretary.

(3) STATE PLAN ACTIVITIES.—In the case of projects undertaken by the Council or Council staff to implement State plan activities, the Federal share of the cost of all such projects may be not more than 100 percent of the aggregate necessary cost of such activities.

(b) NONDUPLICATION.—In determining the amount of any State's Federal share of the cost of such projects incurred by such State under a State plan approved under section 124, the Secretary shall not consider—

(1) any portion of such cost that is financed by Federal funds provided under any provision of law other than section 122; and

(2) the amount of any non-Federal funds required to be expended as a condition of receipt of the Federal funds described in paragraph (1).

(c) NON-FEDERAL SHARE.—

(1) IN-KIND CONTRIBUTIONS.—The non-Federal share of the cost of any project supported by an allotment under this subtitle may be provided in cash or in kind, fairly evaluated, including plant, equipment, or services.

(2) CONTRIBUTIONS OF POLITICAL SUBDIVISIONS AND PUBLIC OR PRIVATE ENTITIES.—

(A) IN GENERAL.—Contributions to projects by a political subdivision of a State or by a public or private entity under an agreement with the State shall, subject to such limitations and conditions as the Secretary may by regulation prescribe under section 104(b), be considered to be contributions by such State, in the case of a project supported under this subtitle.

(B) STATE CONTRIBUTIONS.—State contributions, including contributions by the designated State agency to

provide support services to the Council pursuant to section 125(d)(4), may be counted as part of such State's non-Federal share of the cost of projects supported under this subtitle.

(3) VARIATIONS OF THE NON-FEDERAL SHARE.—The non-Federal share required of each recipient of a grant from a Council under this subtitle may vary.

**SEC. 127. WITHHOLDING OF PAYMENTS FOR PLANNING, ADMINISTRATION, AND SERVICES.** 42 USC 15027.

Whenever the Secretary, after providing reasonable notice and an opportunity for a hearing to the Council and the designated State agency, finds that—

(1) the Council or agency has failed to comply substantially with any of the provisions required by section 124 to be included in the State plan, particularly provisions required by paragraphs (4)(A) and (5)(B)(vii) of section 124(c), or with any of the provisions required by section 125(b)(3); or

(2) the Council or agency has failed to comply substantially with any regulations of the Secretary that are applicable to this subtitle,

the Secretary shall notify such Council and agency that the Secretary will not make further payments to the State under section 122 (or, in the discretion of the Secretary, that further payments to the State under section 122 for activities for which there is such failure), until the Secretary is satisfied that there will no longer be such failure. Until the Secretary is so satisfied, the Secretary shall make no further payments to the State under section 122, or shall limit further payments under section 122 to such State to activities for which there is no such failure.

**SEC. 128. APPEALS BY STATES.**

42 USC 15028.

(a) APPEAL.—If any State is dissatisfied with the Secretary's action under section 124(d)(3) or 127, such State may appeal to the United States court of appeals for the circuit in which such State is located, by filing a petition with such court not later than 60 days after such action.

(b) FILING.—The clerk of the court shall transmit promptly a copy of the petition to the Secretary, or any officer designated by the Secretary for that purpose. The Secretary shall file promptly with the court the record of the proceedings on which the Secretary based the action, as provided in section 2112 of title 28, United States Code.

(c) JURISDICTION.—Upon the filing of the petition, the court shall have jurisdiction to affirm the action of the Secretary or to set the action aside, in whole or in part, temporarily or permanently. Until the filing of the record, the Secretary may modify or set aside the order of the Secretary relating to the action.

(d) FINDINGS AND REMAND.—The findings of the Secretary about the facts, if supported by substantial evidence, shall be conclusive, but the court, for good cause shown, may remand the case involved to the Secretary for further proceedings to take further evidence. On remand, the Secretary may make new or modified findings of fact and may modify the previous action of the Secretary, and shall file with the court the record of the further proceedings. Such new or modified findings of fact shall likewise be conclusive if supported by substantial evidence.

(e) **FINALITY.**—The judgment of the court affirming or setting aside, in whole or in part, any action of the Secretary shall be final, subject to review by the Supreme Court of the United States upon certiorari or certification as provided in section 1254 of title 28, United States Code.

(f) **EFFECT.**—The commencement of proceedings under this section shall not, unless so specifically ordered by a court, operate as a stay of the Secretary's action.

42 USC 15029.

**SEC. 129. AUTHORIZATION OF APPROPRIATIONS.**

(a) **FUNDING FOR STATE ALLOTMENTS.**—Except as described in subsection (b), there are authorized to be appropriated for allotments under section 122 \$76,000,000 for fiscal year 2001 and such sums as may be necessary for each of fiscal years 2002 through 2007.

(b) **RESERVATION FOR TECHNICAL ASSISTANCE.**—

(1) **LOWER APPROPRIATION YEARS.**—For any fiscal year for which the amount appropriated under subsection (a) is less than \$76,000,000, the Secretary shall reserve funds in accordance with section 163(e) to provide technical assistance to entities funded under this subtitle.

(2) **HIGHER APPROPRIATION YEARS.**—For any fiscal year for which the amount appropriated under subsection (a) is not less than \$76,000,000, the Secretary shall reserve not less than \$300,000 and not more than 1 percent of the amount appropriated under subsection (a) to provide technical assistance to entities funded under this subtitle.

## Subtitle C—Protection and Advocacy of Individual Rights

42 USC 15041.

**SEC. 141. PURPOSE.**

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 reallocations of such sums shall be made on the same basis as the allotments and reallocations 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

(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

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;



(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;

(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  $\frac{1}{3}$  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;

(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.

## Subtitle D—National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service

### SEC. 151. GRANT AUTHORITY.

42 USC 15061.

(a) NATIONAL NETWORK.—From appropriations authorized under section 156(a)(1), the Secretary shall make 5-year grants to entities in each State designated as University Centers for Excellence in Developmental Disabilities Education, Research, and Service to carry out activities described in section 153(a).

(b) NATIONAL TRAINING INITIATIVES.—From appropriations authorized under section 156(a)(1) and reserved under section 156(a)(2), the Secretary shall make grants to Centers to carry out activities described in section 153(b).

(c) TECHNICAL ASSISTANCE.—From appropriations authorized under section 156(a)(1) and reserved under section 156(a)(3) (or from funds reserved under section 163, as appropriate), the Secretary shall enter into 1 or more cooperative agreements or contracts for the purpose of providing technical assistance described in section 153(c).

### SEC. 152. GRANT AWARDS.

42 USC 15062.

#### (a) EXISTING CENTERS.—

(1) IN GENERAL.—In awarding and distributing grant funds under section 151(a) for a fiscal year, the Secretary, subject to the availability of appropriations and the condition specified in subsection (d), shall award and distribute grant funds in equal amounts of \$500,000 (adjusted in accordance with subsection (b)), to each Center that existed during the preceding fiscal year and that meets the requirements of this subtitle, prior to making grants under subsection (c) or (d).

(2) REDUCTION OF AWARD.—Notwithstanding paragraph (1), if the aggregate of the funds to be awarded to the Centers pursuant to paragraph (1) for any fiscal year exceeds the total amount appropriated under section 156 for such fiscal year, the amount to be awarded to each Center for such fiscal year shall be proportionately reduced.

(b) ADJUSTMENTS.—Subject to the availability of appropriations, for any fiscal year following a year in which each Center described in subsection (a) received a grant award of not less than \$500,000 under subsection (a) (adjusted in accordance with this subsection), the Secretary shall adjust the awards to take into account 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), prior to making grants under subsection (c) or (d).

(c) NATIONAL TRAINING INITIATIVES ON CRITICAL AND EMERGING NEEDS.—Subject to the availability of appropriations, for any fiscal year in which each Center described in subsection (a) receives a grant award of not less than \$500,000, under subsection (a) (adjusted in accordance with subsection (b)), after making the grant awards, the Secretary shall make grants under section 151(b) to

Centers to pay for the Federal share of the cost of training initiatives related to the unmet needs of individuals with developmental disabilities and their families, as described in section 153(b).

(d) **ADDITIONAL GRANTS.**—For any fiscal year in which each Center described in subsection (a) receives a grant award of not less than \$500,000 under subsection (a) (adjusted in accordance with subsection (b)), after making the grant awards, the Secretary may make grants under section 151(a) for activities described in section 153(a) to additional Centers, or additional grants to Centers, for States or populations that are unserved or underserved by Centers due to such factors as—

- (1) population;
- (2) a high concentration of rural or urban areas; or
- (3) a high concentration of unserved or underserved populations.

42 USC 15063.

**SEC. 153. PURPOSE AND SCOPE OF ACTIVITIES.**

(a) **NATIONAL NETWORK OF UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE.**—

(1) **IN GENERAL.**—In order to provide leadership in, advise Federal, State, and community policymakers about, and promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life, the Secretary shall award grants to eligible entities designated as Centers in each State to pay for the Federal share of the cost of the administration and operation of the Centers. The Centers shall be interdisciplinary education, research, and public service units of universities (as defined by the Secretary) or public or not-for-profit entities associated with universities that engage in core functions, described in paragraph (2), addressing, directly or indirectly, 1 or more of the areas of emphasis.

(2) **CORE FUNCTIONS.**—The core functions referred to in paragraph (1) shall include the following:

(A) Provision of interdisciplinary pre-service preparation and continuing education of students and fellows, which may include the preparation and continuing education of leadership, direct service, clinical, or other personnel to strengthen and increase the capacity of States and communities to achieve the purpose of this title.

(B) Provision of community services—

(i) that provide training or technical assistance for individuals with developmental disabilities, their families, professionals, paraprofessionals, policymakers, students, and other members of the community; and

(ii) that may provide services, supports, and assistance for the persons described in clause (i) through demonstration and model activities.

(C) Conduct of research, which may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families.

(D) Dissemination of information related to activities undertaken to address the purpose of this title, especially dissemination of information that demonstrates that the network authorized under this subtitle is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances.

(b) NATIONAL TRAINING INITIATIVES ON CRITICAL AND EMERGING NEEDS.—

(1) SUPPLEMENTAL GRANTS.—After consultation with relevant, informed sources, including individuals with developmental disabilities and their families, the Secretary shall award, under section 151(b), supplemental grants to Centers to pay for the Federal share of the cost of training initiatives related to the unmet needs of individuals with developmental disabilities and their families. The Secretary shall make the grants on a competitive basis, and for periods of not more than 5 years.

(2) ESTABLISHMENT OF CONSULTATION PROCESS BY THE SECRETARY.—Not later than 1 year after the date of enactment of this Act, the Secretary shall establish a consultation process that, on an ongoing basis, allows the Secretary to identify and address, through supplemental grants authorized under paragraph (1), training initiatives related to the unmet needs of individuals with developmental disabilities and their families.

(c) TECHNICAL ASSISTANCE.—In order to strengthen and support the national network of Centers, the Secretary may enter into 1 or more cooperative agreements or contracts to—

(1) assist in national and international dissemination of specific information from multiple Centers and, in appropriate cases, other entities whose work affects the lives of individuals with developmental disabilities;

(2) compile, analyze, and disseminate state-of-the-art training, research, and demonstration results policies, and practices from multiple Centers and, in appropriate cases, other entities whose work affects the lives of persons with developmental disabilities;

(3) convene experts from multiple Centers to discuss and make recommendations with regard to national emerging needs of individuals with developmental disabilities;

(4)(A) develop portals that link users with every Center's website; and

(B) facilitate electronic information sharing using state-of-the-art Internet technologies such as real-time online discussions, multipoint video conferencing, and web-based audio/video broadcasts, on emerging topics that impact individuals with disabilities and their families;

(5) serve as a research-based resource for Federal and State policymakers on information concerning and issues impacting individuals with developmental disabilities and entities that assist or serve those individuals; or

(6) undertake any other functions that the Secretary determines to be appropriate;

to promote the viability and use of the resources and expertise of the Centers nationally and internationally.

**SEC. 154. APPLICATIONS.****(a) APPLICATIONS FOR CORE CENTER GRANTS.—**

(1) **IN GENERAL.**—To be eligible to receive a grant under section 151(a) for a Center, an entity shall submit to the Secretary, and obtain approval of, an application at such time, in such manner, and containing such information, as the Secretary may require.

(2) **APPLICATION CONTENTS.**—Each application described in paragraph (1) shall describe a 5-year plan, including a projected goal related to 1 or more areas of emphasis for each of the core functions described in section 153(a).

(3) **ASSURANCES.**—The application shall be approved by the Secretary only if the application contains or is supported by reasonable assurances that the entity designated as the Center will—

(A) meet regulatory standards as established by the Secretary for Centers;

(B) address the projected goals, and carry out goal-related activities, based on data driven strategic planning and in a manner consistent with the objectives of this subtitle, that—

(i) are developed in collaboration with the consumer advisory committee established pursuant to subparagraph (E);

(ii) are consistent with, and to the extent feasible complement and further, the Council goals contained in the State plan submitted under section 124 and the system goals established under section 143; and

(iii) will be reviewed and revised annually as necessary to address emerging trends and needs;

(C) use the funds made available through the grant to supplement, and not supplant, the funds that would otherwise be made available for activities described in section 153(a);

(D) protect, consistent with the policy specified in section 101(c) (relating to rights of individuals with developmental disabilities), the legal and human rights of all individuals with developmental disabilities (especially those individuals under State guardianship) who are involved in activities carried out under programs assisted under this subtitle;

(E) establish a consumer advisory committee—

(i) of which a majority of the members shall be individuals with developmental disabilities and family members of such individuals;

(ii) that is comprised of—

(I) individuals with developmental disabilities and related disabilities;

(II) family members of individuals with developmental disabilities;

(III) a representative of the State protection and advocacy system;

(IV) a representative of the State Council on Developmental Disabilities;

(V) a representative of a self-advocacy organization described in section 124(c)(4)(A)(ii)(I); and

(VI) representatives of organizations that may include parent training and information centers assisted under section 682 or 683 of the Individuals with Disabilities Education Act (20 U.S.C. 1482, 1483), entities carrying out activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012), relevant State agencies, and other community groups concerned with the welfare of individuals with developmental disabilities and their families;

(iii) that reflects the racial and ethnic diversity of the State; and

(iv) that shall—

(I) consult with the Director of the Center regarding the development of the 5-year plan, and shall participate in an annual review of, and comment on, the progress of the Center in meeting the projected goals contained in the plan, and shall make recommendations to the Director of the Center regarding any proposed revisions of the plan that might be necessary; and

(II) meet as often as necessary to carry out the role of the committee, but at a minimum twice during each grant year;

(F) to the extent possible, utilize the infrastructure and resources obtained through funds made available under the grant to leverage additional public and private funds to successfully achieve the projected goals developed in the 5-year plan;

(G)(i) have a director with appropriate academic credentials, demonstrated leadership, expertise regarding developmental disabilities, significant experience in managing grants and contracts, and the ability to leverage public and private funds; and

(ii) allocate adequate staff time to carry out activities related to each of the core functions described in section 153(a); and

(H) educate, and disseminate information related to the purpose of this title to, the legislature of the State in which the Center is located, and to Members of Congress from such State.

(b) SUPPLEMENTAL GRANT APPLICATIONS PERTAINING TO NATIONAL TRAINING INITIATIVES IN CRITICAL AND EMERGING NEEDS.—To be eligible to receive a supplemental grant under section 151(b), a Center may submit a supplemental application to the Secretary at such time, in such manner, and containing such information as the Secretary may require, pursuant to the terms and conditions set by the Secretary consistent with section 153(b).

(c) PEER REVIEW.—

(1) IN GENERAL.—The Secretary shall require that all applications submitted under this subtitle be subject to technical and qualitative review by peer review groups established under paragraph (2). The Secretary may approve an application under this subtitle only if such application has been recommended by a peer review group that has conducted the peer review required under this paragraph. In conducting the



review, the group may conduct onsite visits or inspections of related activities as necessary.

(2) ESTABLISHMENT OF PEER REVIEW GROUPS.—

(A) IN GENERAL.—The Secretary, acting through the Commissioner of the Administration on Developmental Disabilities, may, notwithstanding—

(i) the provisions of title 5, United States Code, concerning appointments to the competitive service; and

(ii) the provisions of chapter 51, and subchapter III of chapter 53 of title 5, United States Code, concerning classification and General Schedule pay rates; establish such peer review groups and appoint and set the rates of pay of members of such groups.

(B) COMPOSITION.—Each peer review group shall include such individuals with disabilities and parents, guardians, or advocates of or for individuals with developmental disabilities, as are necessary to carry out this subsection.

(3) WAIVERS OF APPROVAL.—The Secretary may waive the provisions of paragraph (1) with respect to review and approval of an application if the Secretary determines that exceptional circumstances warrant such a waiver.

(d) FEDERAL SHARE.—

(1) IN GENERAL.—The Federal share of the cost of administration or operation of a Center, or the cost of carrying out a training initiative, supported by a grant made under this subtitle may not be more than 75 percent of the necessary cost of such project, as determined by the Secretary.

(2) URBAN OR RURAL POVERTY AREAS.—In the case of a project whose activities or products target individuals with developmental disabilities who live in an urban or rural poverty area, as determined by the Secretary, the Federal share of the cost of the project may not be more than 90 percent of the necessary costs of the project, as determined by the Secretary.

(3) GRANT EXPENDITURES.—For the purpose of determining the Federal share with respect to the project, expenditures on that project by a political subdivision of a State or by a public or private entity shall, subject to such limitations and conditions as the Secretary may by regulation prescribe under section 104(b), be considered to be expenditures made by a Center under this subtitle.

(e) ANNUAL REPORT.—Each Center shall annually prepare and transmit to the Secretary a report containing—

(1) information on progress made in achieving the projected goals of the Center for the previous year, including—

(A) 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; and

(D) an accounting of the manner in which funds paid to the Center under this subtitle for a fiscal year were expended;

(2) information on proposed revisions to the goals; and

(3) a description of successful efforts to leverage funds, other than funds made available under this subtitle, to pursue goals consistent with this subtitle.

**SEC. 155. DEFINITION.**

42 USC 15065.

In this subtitle, the term “State” means each of the several States of the United States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, and Guam.

**SEC. 156. AUTHORIZATION OF APPROPRIATIONS.**

42 USC 15066.

**(a) AUTHORIZATION AND RESERVATIONS.—**

(1) **AUTHORIZATION.**—There are authorized to be appropriated to carry out this subtitle (other than section 153(c)(4)) \$30,000,000 for fiscal year 2001 and such sums as may be necessary for each of fiscal years 2002 through 2007.

(2) **RESERVATION FOR TRAINING INITIATIVES.**—From any amount appropriated for a fiscal year under paragraph (1) and remaining after each Center described in section 152(a) has received a grant award of not less than \$500,000, as described in section 152, the Secretary shall reserve funds for the training initiatives authorized under section 153(b).

**(3) RESERVATION FOR TECHNICAL ASSISTANCE.—**

(A) **YEARS BEFORE APPROPRIATION TRIGGER.**—For any covered year, the Secretary shall reserve funds in accordance with section 163(c) to fund technical assistance activities under section 153(c) (other than section 153(c)(4)).

(B) **YEARS AFTER APPROPRIATION TRIGGER.**—For any fiscal year that is not a covered year, the Secretary shall reserve not less than \$300,000 and not more than 2 percent of the amount appropriated under paragraph (1) to fund technical assistance activities under section 153(c) (other than section 153(c)(4)).

(C) **COVERED YEAR.**—In this paragraph, the term “covered year” means a fiscal year prior to the first fiscal year for which the amount appropriated under paragraph (1) is not less than \$20,000,000.

(b) **LIMITATION.**—The Secretary may not use, for peer review or other activities directly related to peer review conducted under this subtitle—

(1) for fiscal year 2001, more than \$300,000 of the funds made available under subsection (a); and

(2) for any succeeding fiscal year, more than the amount of funds used for the peer review and related activities in fiscal year 2001, adjusted to take into account 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).

## Subtitle E—Projects of National Significance

**SEC. 161. PURPOSE.**

42 USC 15081.

The purpose of this subtitle is to provide grants, contracts, or cooperative agreements for projects of national significance that—

(1) create opportunities for individuals with developmental disabilities to directly and fully contribute to, and participate in, all facets of community life; and

(2) support the development of national and State policies that reinforce and promote, with the support of families, guardians, advocates, and communities, of individuals with developmental disabilities, the self-determination, independence, productivity, and integration and inclusion in all facets of community life of such individuals through—

(A) family support activities;

(B) data collection and analysis;

(C) technical assistance to entities funded under subtitles B and D, subject to the limitations described in sections 129(b), 156(a)(3), and 163(c); and

(D) other projects of sufficient size and scope that hold promise to expand or improve opportunities for such individuals, including—

(i) projects that provide technical assistance for the development of information and referral systems;

(ii) projects that provide technical assistance to self-advocacy organizations of individuals with developmental disabilities;

(iii) projects that provide education for policy-makers;

(iv) Federal interagency initiatives;

(v) projects that enhance the participation of racial and ethnic minorities in public and private sector initiatives in developmental disabilities;

(vi) projects that provide aid to transition youth with developmental disabilities from school to adult life, especially in finding employment and postsecondary education opportunities and in upgrading and changing any assistive technology devices that may be needed as a youth matures;

(vii) initiatives that address the development of community quality assurance systems and the training related to the development, implementation, and evaluation of such systems, including training of individuals with developmental disabilities and their families;

(viii) initiatives that address the needs of aging individuals with developmental disabilities and aging caregivers of adults with developmental disabilities in the community;

(ix) initiatives that create greater access to and use of generic services systems, community organizations, and associations, and initiatives that assist in community economic development;

(x) initiatives that create access to increased living options;

(xi) initiatives that address the challenging behaviors of individuals with developmental disabilities, including initiatives that promote positive alternatives to the use of restraints and seclusion; and

(xii) initiatives that address other areas of emerging need.

**SEC. 162. GRANT AUTHORITY.**

42 USC 15082.

(a) **IN GENERAL.**—The Secretary shall award grants, contracts, or cooperative agreements to public or private nonprofit entities for projects of national significance relating to individuals with developmental disabilities to carry out activities described in section 161(2).

(b) **FEDERAL INTERAGENCY INITIATIVES.**—

(1) **IN GENERAL.**—

(A) **AUTHORITY.**—The Secretary may—

(i) enter into agreements with Federal agencies to jointly carry out activities described in section 161(2) or to jointly carry out activities of common interest related to the objectives of such section; and

(ii) transfer to such agencies for such purposes funds appropriated under this subtitle, and receive and use funds from such agencies for such purposes.

(B) **RELATION TO PROGRAM PURPOSES.**—Funds transferred or received pursuant to this paragraph shall be used only in accordance with statutes authorizing the appropriation of such funds. Such funds shall be made available through grants, contracts, or cooperative agreements only to recipients eligible to receive such funds under such statutes.

(C) **PROCEDURES AND CRITERIA.**—If the Secretary enters into an agreement under this subsection for the administration of a jointly funded project—

(i) the agreement shall specify which agency's procedures shall be used to award grants, contracts, or cooperative agreements and to administer such awards;

(ii) the participating agencies may develop a single set of criteria for the jointly funded project, and may require applicants to submit a single application for joint review by such agencies; and

(iii) unless the heads of the participating agencies develop joint eligibility requirements, an applicant for an award for the project shall meet the eligibility requirements of each program involved.

(2) **LIMITATION.**—The Secretary may not construe the provisions of this subsection to take precedence over a limitation on joint funding contained in an applicable statute.

**SEC. 163. AUTHORIZATION OF APPROPRIATIONS.**

42 USC 15083.

(a) **IN GENERAL.**—There are authorized to be appropriated to carry out the projects specified in this section \$16,000,000 for fiscal year 2001, and such sums as may be necessary for each of fiscal years 2002 through 2007.

(b) **USE OF FUNDS.**—

(1) **GRANTS, CONTRACTS, AND AGREEMENTS.**—Except as provided in paragraph (2), the amount appropriated under subsection (a) for each fiscal year shall be used to award grants, or enter into contracts, cooperative agreements, or other agreements, under section 162.

(2) **ADMINISTRATIVE COSTS.**—Not more than 1 percent of the amount appropriated under subsection (a) for each fiscal year may be used to provide for the administrative costs (other than compensation of Federal employees) of the Administration

on Developmental Disabilities for administering this subtitle and subtitles B, C, and D, including monitoring the performance of and providing technical assistance to, entities that receive funds under this title.

(c) TECHNICAL ASSISTANCE FOR COUNCILS AND CENTERS.—

(1) IN GENERAL.—For each covered year, the Secretary shall expend, to provide technical assistance for entities funded under subtitle B or D, an amount from funds appropriated under subsection (a) that is not less than the amount the Secretary expended on technical assistance for entities funded under that subtitle (or a corresponding provision) in the previous fiscal year.

(2) COVERED YEAR.—In this subsection, the term “covered year” means—

(A) in the case of an expenditure for entities funded under subtitle B, a fiscal year for which the amount appropriated under section 129(a) is less than \$76,000,000; and

(B) in the case of an expenditure for entities funded under subtitle D, a fiscal year prior to the first fiscal year for which the amount appropriated under section 156(a)(1) is not less than \$20,000,000.

(3) REFERENCES.—References in this subsection to subtitle D shall not be considered to include section 153(c)(4).

(d) TECHNICAL ASSISTANCE ON ELECTRONIC INFORMATION SHARING.—In addition to any funds reserved under subsection (c), the Secretary shall reserve \$100,000 from the amount appropriated under subsection (a) for each fiscal year to carry out section 153(c)(4).

(e) LIMITATION.—For any fiscal year for which the amount appropriated under subsection (a) is not less than \$10,000,000, not more than 50 percent of such amount shall be used for activities carried out under section 161(2)(A).

Families of  
Children With  
Disabilities  
Support Act of  
2000.  
42 USC 15001  
note.

## TITLE II—FAMILY SUPPORT

### SEC. 201. SHORT TITLE.

This title may be cited as the “Families of Children With Disabilities Support Act of 2000”.

### SEC. 202. FINDINGS, PURPOSES, AND POLICY.

(a) FINDINGS.—Congress makes the following findings:

(1) It is in the best interest of our Nation to preserve, strengthen, and maintain the family.

(2) Families of children with disabilities provide support, care, and training to their children that can save States millions of dollars. Without the efforts of family caregivers, many persons with disabilities would receive care through State-supported out-of-home placements.

(3) Most families of children with disabilities, especially families in unserved and underserved populations, do not have access to family-centered and family-directed services to support such families in their efforts to care for such children at home.

(4) Medical advances and improved health care have increased the life span of many people with disabilities, and the combination of the longer life spans and the aging of family

42 USC 15091.

caregivers places a continually increasing demand on the finite service delivery systems of the States.

(5) In 1996, 49 States provided family support initiatives in response to the needs of families of children with disabilities. Such initiatives included the provision of cash subsidies, respite care, and other forms of support. There is a need in each State, however, to strengthen, expand, and coordinate the activities of a system of family support services for families of children with disabilities that is easily accessible, avoids duplication, uses resources efficiently, and prevents gaps in services to families in all areas of the State.

(6) The goals of the Nation properly include the goal of providing to families of children with disabilities the family support services necessary—

(A) to support the family;

(B) to enable families of children with disabilities to nurture and enjoy their children at home;

(C) to enable families of children with disabilities to make informed choices and decisions regarding the nature of supports, resources, services, and other assistance made available to such families; and

(D) to support family caregivers of adults with disabilities.

(b) PURPOSES.—The purposes of this title are—

(1) to promote and strengthen the implementation of comprehensive State systems of family support services, for families with children with disabilities, that are family-centered and family-directed, and that provide families with the greatest possible decisionmaking authority and control regarding the nature and use of services and support;

(2) to promote leadership by families in planning, policy development, implementation, and evaluation of family support services for families of children with disabilities;

(3) to promote and develop interagency coordination and collaboration between agencies responsible for providing the services; and

(4) to increase the availability of, funding for, access to, and provision of family support services for families of children with disabilities.

(c) POLICY.—It is the policy of the United States that all programs, projects, and activities funded under this title shall be family-centered and family-directed, and shall be provided in a manner consistent with the goal of providing families of children with disabilities with the support the families need to raise their children at home.

#### SEC. 203. DEFINITIONS AND SPECIAL RULE.

42 USC 15092.

(a) DEFINITIONS.—In this title:

(1) CHILD WITH A DISABILITY.—The term “child with a disability” means an individual who—

(A) has a significant physical or mental impairment, as defined pursuant to State policy to the extent that such policy is established without regard to type of disability; or

(B) is an infant or a young child from birth through age 8 and has a substantial developmental delay or specific

congenital or acquired condition that presents a high probability of resulting in a disability if services are not provided to the infant or child.

(2) FAMILY.—

(A) IN GENERAL.—Subject to subparagraph (B), for purposes of the application of this title in a State, the term “family” has the meaning given the term by the State.

(B) EXCLUSION OF EMPLOYEES.—The term does not include an employee who, acting in a paid employment capacity, provides services to a child with a disability in an out-of-home setting such as a hospital, nursing home, personal care home, board and care home, group home, or other facility.

(3) FAMILY SUPPORT FOR FAMILIES OF CHILDREN WITH DISABILITIES.—The term “family support for families of children with disabilities” means supports, resources, services, and other assistance provided to families of children with disabilities pursuant to State policy that are designed to—

(A) support families in the efforts of such families to raise their children with disabilities in the home;

(B) strengthen the role of the family as primary caregiver for such children;

(C) prevent involuntary out-of-the-home placement of such children and maintain family unity; and

(D) reunite families with children with disabilities who have been placed out of the home, whenever possible.

(4) SECRETARY.—The term “Secretary” means the Secretary of Health and Human Services.

(5) STATE.—The term “State” means each of the 50 States of the United States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

(6) SYSTEMS CHANGE ACTIVITIES.—The term “systems change activities” means efforts that result in laws, regulations, policies, practices, or organizational structures—

(A) that are family-centered and family-directed;

(B) that facilitate and increase access to, provision of, and funding for, family support services for families of children with disabilities; and

(C) that otherwise accomplish the purposes of this title.

(b) SPECIAL RULE.—References in this title to a child with a disability shall be considered to include references to an individual who is not younger than age 18 who—

(1) has a significant impairment described in subsection (a)(1)(A); and

(2) is residing with and receiving assistance from a family member.

**SEC. 204. GRANTS TO STATES.**

(a) IN GENERAL.—The Secretary shall make grants to States on a competitive basis, in accordance with the provisions of this title, to support systems change activities designed to assist States to develop and implement, or expand and enhance, a statewide system of family support services for families of children with disabilities that accomplishes the purposes of this title.

(b) AWARD PERIOD AND GRANT LIMITATION.—No grant shall be awarded under this section for a period of more than 3 years. No State shall be eligible for more than 1 grant under this section.

(c) AMOUNT OF GRANTS.—

(1) GRANTS TO STATES.—

(A) FEDERAL MATCHING SHARE.—From amounts appropriated under section 212(a), the Secretary shall pay to each State that has an application approved under section 205, for each year of the grant period, an amount that is—

(i) equal to not more than 75 percent of the cost of the systems change activities to be carried out by the State; and

(ii) not less than \$100,000 and not more than \$500,000.

(B) NON-FEDERAL SHARE.—The non-Federal share of the cost of the systems change activities may be in cash or in kind, fairly evaluated, including plant, equipment, or services.

(2) CALCULATION OF AMOUNTS.—The Secretary shall calculate a grant amount described in paragraph (1) on the basis of—

(A) the amounts available for making grants under this section; and

(B) the child population of the State concerned.

(d) PRIORITY FOR PREVIOUSLY PARTICIPATING STATES.—For the second and third fiscal years for which amounts are appropriated to carry out this section, the Secretary, in providing payments under this section, shall give priority to States that received payments under this section during the preceding fiscal year.

(e) PRIORITIES FOR DISTRIBUTION.—To the extent practicable, the Secretary shall award grants to States under this section in a manner that—

(1) is geographically equitable;

(2) distributes the grants among States that have differing levels of development of statewide systems of family support services for families of children with disabilities; and

(3) distributes the grants among States that attempt to meet the needs of unserved and underserved populations, such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, and individuals from underserved geographic areas (rural or urban).

#### SEC. 205. APPLICATION.

42 USC 15094.

To be eligible to receive a grant under this title, a State shall submit an application to the Secretary at such time, in such manner, and containing such information and assurances as the Secretary may require, including information about the designation of a lead entity, a description of available State resources, and assurances that systems change activities will be family-centered and family-directed.

#### SEC. 206. DESIGNATION OF THE LEAD ENTITY.

42 USC 15095.

(a) DESIGNATION.—The Chief Executive Officer of a State that desires to receive a grant under section 204, shall designate the office or entity (referred to in this title as the “lead entity”) responsible for—



(1) submitting the application described in section 205 on behalf of the State;

(2) administering and supervising the use of the amounts made available under the grant;

(3) coordinating efforts related to and supervising the preparation of the application;

(4) coordinating the planning, development, implementation (or expansion and enhancement), and evaluation of a statewide system of family support services for families of children with disabilities among public agencies and between public agencies and private agencies, including coordinating efforts related to entering into interagency agreements;

(5) coordinating efforts related to the participation by families of children with disabilities in activities carried out under a grant made under this title; and

(6) submitting the report described in section 208 on behalf of the State.

(b) **QUALIFICATIONS.**—In designating the lead entity, the Chief Executive Officer may designate—

(1) an office of the Chief Executive Officer;

(2) a commission appointed by the Chief Executive Officer;

(3) a public agency;

(4) a council established under Federal or State law; or

(5) another appropriate office, agency, or entity.

42 USC 15096.

**SEC. 207. AUTHORIZED ACTIVITIES.**

(a) **IN GENERAL.**—A State that receives a grant under section 204 shall use the funds made available through the grant to carry out systems change activities that accomplish the purposes of this title.

(b) **SPECIAL RULE.**—In carrying out activities authorized under this title, a State shall ensure that such activities address the needs of families of children with disabilities from unserved or underserved populations.

42 USC 15097.

**SEC. 208. REPORTING.**

A State that receives a grant under this title shall prepare and submit to the Secretary, at the end of the grant period, a report containing the results of State efforts to develop and implement, or expand and enhance, a statewide system of family support services for families of children with disabilities.

42 USC 15098.

**SEC. 209. TECHNICAL ASSISTANCE.**

Contracts.

(a) **IN GENERAL.**—The Secretary shall enter into contracts or cooperative agreements with appropriate public or private agencies and organizations, including institutions of higher education, with documented experience, expertise, and capacity, for the purpose of providing technical assistance and information with respect to the development and implementation, or expansion and enhancement, of a statewide system of family support services for families of children with disabilities.

(b) **PURPOSE.**—An agency or organization that provides technical assistance and information under this section in a State that receives a grant under this title shall provide the technical assistance and information to the lead entity of the State, family members of children with disabilities, organizations, service providers, and policymakers involved with children with disabilities and their families. Such an agency or organization may also provide

technical assistance and information to a State that does not receive a grant under this title.

(c) **REPORTS TO THE SECRETARY.**—An entity providing technical assistance and information under this section shall prepare and submit to the Secretary periodic reports regarding Federal policies and procedures identified within the States that facilitate or impede the delivery of family support services to families of children with disabilities. The report shall include recommendations to the Secretary regarding the delivery of services, coordination with other programs, and integration of the policies described in section 202 in Federal law, other than this title.

**SEC. 210. EVALUATION.**

42 USC 15099.

(a) **IN GENERAL.**—The Secretary shall conduct a national evaluation of the program of grants to States authorized by this title.

(b) **PURPOSE.**—

(1) **IN GENERAL.**—The Secretary shall conduct the evaluation under subsection (a) to assess the status and effects of State efforts to develop and implement, or expand and enhance, statewide systems of family support services for families of children with disabilities in a manner consistent with the provisions of this title. In particular, the Secretary shall assess the impact of such efforts on families of children with disabilities, and recommend amendments to this title that are necessary to assist States to accomplish fully the purposes of this title.

(2) **INFORMATION SYSTEMS.**—The Secretary shall work with the States to develop an information system designed to compile and report, from information provided by the States, qualitative and quantitative descriptions of the impact of the program of grants to States authorized by this title on—

(A) families of children with disabilities, including families from unserved and underserved populations;

(B) access to and funding for family support services for families of children with disabilities;

(C) interagency coordination and collaboration between agencies responsible for providing the services; and

(D) the involvement of families of children with disabilities at all levels of the statewide systems.

(c) **REPORT TO CONGRESS.**—Not later than 2½ years after the date of enactment of this Act, the Secretary shall prepare and submit to the appropriate committees of Congress a report concerning the results of the evaluation conducted under this section.

Deadline.

**SEC. 211. PROJECTS OF NATIONAL SIGNIFICANCE.**

42 USC 15100.

(a) **STUDY BY THE SECRETARY.**—The Secretary shall review Federal programs to determine the extent to which such programs facilitate or impede access to, provision of, and funding for family support services for families of children with disabilities, consistent with the policies described in section 202.

(b) **PROJECTS OF NATIONAL SIGNIFICANCE.**—The Secretary shall make grants or enter into contracts for projects of national significance to support the development of national and State policies and practices related to the development and implementation, or expansion and enhancement, of family-centered and family-directed systems of family support services for families of children with disabilities.

42 USC 15101. **SEC. 212. AUTHORIZATION OF APPROPRIATIONS.**

(a) **IN GENERAL.**—There are authorized to be appropriated to carry out this title such sums as may be necessary for each of fiscal years 2001 through 2007.

(b) **RESERVATION.**—

(1) **IN GENERAL.**—The Secretary shall reserve for each fiscal year 10 percent, or \$400,000 (whichever is greater), of the amount appropriated pursuant to subsection (a) to carry out—

(A) section 209 (relating to the provision of technical assistance and information to States); and

(B) section 210 (relating to the conduct of evaluations).

(2) **SPECIAL RULE.**—For each year that the amount appropriated pursuant to subsection (a) is \$10,000,000 or greater, the Secretary may reserve 5 percent of such amount to carry out section 211.

### **TITLE III—PROGRAM FOR DIRECT SUPPORT WORKERS WHO ASSIST INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**

42 USC 15111. **SEC. 301. FINDINGS.**

Congress finds that—

(1) direct support workers, especially young adults, have played essential roles in providing the support needed by individuals with developmental disabilities and expanding community options for those individuals;

(2) 4 factors have contributed to a decrease in the available pool of direct support workers, specifically—

(A) the small population of individuals who are age 18 through 25, an age group that has been attracted to direct support work in the past;

(B) the rapid expansion of the service sector, which attracts individuals who previously would have elected to pursue employment as direct support workers;

(C) the failure of wages in the human services sector to keep pace with wages in other service sectors; and

(D) the lack of quality training and career advancement opportunities available to direct support workers; and

(3) individuals with developmental disabilities benefit from assistance from direct support workers who are well trained, and benefit from receiving services from professionals who have spent time as direct support workers.

42 USC 15112. **SEC. 302. DEFINITIONS.**

In this title:

(1) **DEVELOPMENTAL DISABILITY.**—The term “developmental disability” has the meaning given the term in section 102.

(2) **INSTITUTION OF HIGHER EDUCATION.**—The term “institution of higher education” has the meaning given the term in section 1201 of the Higher Education Act of 1965 (20 U.S.C. 1141).

(3) **SECRETARY.**—The term “Secretary” means the Secretary of Health and Human Services.

**SEC. 303. REACHING UP SCHOLARSHIP PROGRAM.**

42 USC 15113.

(a) **PROGRAM AUTHORIZATION.**—The Secretary may award grants to eligible entities, on a competitive basis, to enable the entities to carry out scholarship programs by providing vouchers for postsecondary education to direct support workers who assist individuals with developmental disabilities residing in diverse settings. The Secretary shall award the grants to pay for the Federal share of the cost of providing the vouchers.

(b) **ELIGIBLE ENTITY.**—To be eligible to receive a grant under this section, an entity shall be—

- (1) an institution of higher education;
- (2) a State agency; or
- (3) a consortium of such institutions or agencies.

(c) **APPLICATION REQUIREMENTS.**—To be eligible to receive a grant under this section, an eligible entity shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require, including a description of—

- (1) the basis for awarding the vouchers;
- (2) the number of individuals to receive the vouchers; and
- (3) the amount of funds that will be made available by the eligible entity to pay for the non-Federal share of the cost of providing the vouchers.

(d) **SELECTION CRITERIA.**—In awarding a grant under this section for a scholarship program, the Secretary shall give priority to an entity submitting an application that—

(1) specifies that individuals who receive vouchers through the program will be individuals—

(A) who are direct support workers who assist individuals with developmental disabilities residing in diverse settings, while pursuing postsecondary education; and

(B) each of whom verifies, prior to receiving the voucher, that the worker has completed 250 hours as a direct support worker in the past 90 days;

(2) states that the vouchers that will be provided through the program will be in amounts of not more than \$2,000 per year;

(3) provides an assurance that the eligible entity (or another specified entity that is not a voucher recipient) will contribute the non-Federal share of the cost of providing the vouchers; and

(4) meets such other conditions as the Secretary may specify.

(e) **FEDERAL SHARE.**—The Federal share of the cost of providing the vouchers shall be not more than 80 percent.

**SEC. 304. STAFF DEVELOPMENT CURRICULUM AUTHORIZATION.**

42 USC 15114.

(a) **FUNDING.**—

(1) **IN GENERAL.**—The Secretary shall award funding, on a competitive basis, through a grant, cooperative agreement, or contract, to a public or private entity or a combination of such entities, for the development, evaluation, and dissemination of a staff development curriculum, and related guidelines, for computer-assisted, competency-based, multimedia, interactive instruction, relating to service as a direct support worker.

(2) **PARTICIPANTS.**—The curriculum shall be developed for individuals who—

(A) seek to become direct support workers who assist individuals with developmental disabilities or are such direct support workers; and

(B) seek to upgrade their skills and competencies related to being a direct support worker.

(b) APPLICATION REQUIREMENTS.—To be eligible to receive an award under this section, an entity shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require, including—

(1) a comprehensive analysis of the content of direct support roles;

(2) information identifying an advisory group that—

(A) is comprised of individuals with experience and expertise with regard to the support provided by direct support workers, and effective ways to provide the support, for individuals with developmental disabilities in diverse settings; and

(B) will advise the entity throughout the development, evaluation, and dissemination of the staff development curriculum and guidelines;

(3) information describing how the entity will—

(A) develop, field test, and validate a staff development curriculum that—

(i) relates to the appropriate reading level for direct service workers who assist individuals with disabilities;

(ii) allows for multiple levels of instruction;

(iii) provides instruction appropriate for direct support workers who work in diverse settings; and

(iv) is consistent with subsections (b) and (c) of section 101 and section 109;

(B) develop, field test, and validate guidelines for the organizations that use the curriculum that provide for—

(i) providing necessary technical and instructional support to trainers and mentors for the participants;

(ii) ensuring easy access to and use of such curriculum by workers that choose to participate in using, and agencies that choose to use, the curriculum;

(iii) evaluating the proficiency of the participants with respect to the content of the curriculum;

(iv) providing necessary support to the participants to assure that the participants have access to, and proficiency in using, a computer in order to participate in the development, testing, and validation process;

(v) providing necessary technical and instructional support to trainers and mentors for the participants in conjunction with the development, testing, and validation process;

(vi) addressing the satisfaction of participants, individuals with developmental disabilities and their families, providers of services for such individuals and families, and other relevant entities with the curriculum; and

(vii) developing methods to maintain a record of the instruction completed, and the content mastered, by each participant under the curriculum; and

(C) nationally disseminate the curriculum and guidelines, including dissemination through—

- (i) parent training and information centers funded under part D of the Individuals with Disabilities Education Act (20 U.S.C. 1451 et seq.);
  - (ii) community-based organizations of and for individuals with developmental disabilities and their families;
  - (iii) entities funded under title I;
  - (iv) centers for independent living;
  - (v) State educational agencies and local educational agencies;
  - (vi) entities operating appropriate medical facilities;
  - (vii) postsecondary education entities; and
  - (viii) other appropriate entities; and
- (4) such other information as the Secretary may require.

**SEC. 305. AUTHORIZATION OF APPROPRIATIONS.**

42 USC 15115.

(a) **SCHOLARSHIPS.**—There are authorized to be appropriated to carry out section 303 \$800,000 for fiscal year 2001 and such sums as may be necessary for each of fiscal years 2002 through 2007.

(b) **STAFF DEVELOPMENT CURRICULUM.**—There are authorized to be appropriated to carry out section 304 \$800,000 for fiscal year 2001 and such sums as may be necessary for each of fiscal years 2002 and 2003.

**TITLE IV—REPEAL****SEC. 401. REPEAL.**

(a) **IN GENERAL.**—The Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6000 et seq.) is repealed.

(b) **CONFORMING AMENDMENTS.**—

(1) **INDIVIDUALS WITH DISABILITIES EDUCATION ACT.**—Sections 644(b)(4) and 685(b)(4) of the Individuals with Disabilities Education Act (20 U.S.C. 1444(b)(4), 1484a(b)(4)) are amended by striking “the Developmental Disabilities Assistance and Bill of Rights Act” and inserting “the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

20 USC 1485.

(2) **NATIVE AMERICAN HOUSING ASSISTANCE AND SELF-DETERMINATION ACT OF 1996.**—Section 4(17)(C) of the Native American Housing Assistance and Self-Determination Act of 1996 (25 U.S.C. 4103(17)(C)) is amended by striking “as defined in” and all that follows and inserting “as defined in section 102 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000.”

(3) **REHABILITATION ACT OF 1973.**—(A) Section 105(c)(6) of the Rehabilitation Act of 1973 (29 U.S.C. 725(c)(6)) is amended by striking “the State Developmental Disabilities Council described in section 124 of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6024)” and inserting “the State Council on Developmental Disabilities established under section 125 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(B) Sections 202(h)(2)(D)(iii) and 401(a)(5)(A) of the Rehabilitation Act of 1973 (29 U.S.C. 762(h)(2)(D)(iii),

781(a)(5)(A)) are amended by striking “Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6000 et seq.)” and inserting “Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(C) Subsections (a)(1)(B)(i), (f)(2), and (m)(1) of section 509 of the Rehabilitation Act of 1973 (29 U.S.C. 794e) are amended by striking “part C of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6041 et seq.)” and inserting “subtitle C of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(D) Section 509(f)(5)(B) of the Rehabilitation Act of 1973 (29 U.S.C. 794e(f)(5)(B)) is amended by striking “Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6000 et seq.)” and inserting “Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(4) ASSISTIVE TECHNOLOGY ACT OF 1998.—(A) Section 3(a)(11)(A) of the Assistive Technology Act of 1998 (29 U.S.C. 3002(a)(11)(A)) is amended by striking “part C of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6041 et seq.)” and inserting “subtitle C of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(B) Paragraphs (1) and (2) of section 102(a) of the Assistive Technology Act of 1998 (29 U.S.C. 3012(a)) are amended by striking “Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6000 et seq.)” and inserting “Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(5) HEALTH PROGRAMS EXTENSION ACT OF 1973.—Section 401(e) of the Health Programs Extension Act of 1973 (42 U.S.C. 300a-7(e)) is amended by striking “or the” and all that follows through “may deny” and inserting “or the Developmental Disabilities Assistance and Bill of Rights Act of 2000 may deny”.

(6) SOCIAL SECURITY ACT.—(A) Section 1919(c)(2)(B)(iii)(III) of the Social Security Act (42 U.S.C. 1396r(c)(2)(B)(iii)(III)) is amended by striking “part C of the Developmental Disabilities Assistance and Bill of Rights Act” and inserting “subtitle C of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(B) Section 1930(d)(7) of the Social Security Act (42 U.S.C. 1396u(d)(7)) is amended by striking “State Planning Council established under section 124 of the Developmental Disabilities Assistance and Bill of Rights Act, and the Protection and Advocacy System established under section 142 of such Act” and inserting “State Council on Developmental Disabilities established under section 125 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and the protection and advocacy system established under subtitle C of that Act”.

(7) UNITED STATES HOUSING ACT OF 1937.—Section 3(b)(3)(E)(iii) of the United States Housing Act of 1937 (42 U.S.C. 1437a(b)(3)(E)(iii)) is amended by striking “developmental disability” and all that follows and inserting “developmental disability as defined in section 102 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(8) HOUSING ACT OF 1949.—The third sentence of section 501(b)(3) of the Housing Act of 1949 (42 U.S.C. 1471(b)(3)) is amended by striking “developmental disability” and all that follows and inserting “developmental disability as defined in

section 102 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000.”.

(9) OLDER AMERICANS ACT OF 1965.—(A) Section 203(b)(17) of the Older Americans Act of 1965 (42 U.S.C. 3013(b)(17)) is amended by striking “Developmental Disabilities and Bill of Rights Act” and inserting “Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(B) Section 427(a) of the Older Americans Act of 1965 (42 U.S.C. 3035f(a)) is amended by striking “part A of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001 et seq.)” and inserting “subtitle C of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(C) Section 429F(a)(1) of the Older Americans Act of 1965 (42 U.S.C. 3035n(a)(1)) is amended by striking “section 102(5) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001(5))” and inserting “section 102 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(D) Section 712(h)(6)(A) of the Older Americans Act of 1965 (42 U.S.C. 3058g(h)(6)(A)) is amended by striking “part A of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001 et seq.)” and inserting “subtitle C of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(10) CRIME VICTIMS WITH DISABILITIES AWARENESS ACT.—Section 3 of the Crime Victims With Disabilities Awareness Act (42 U.S.C. 3732 note) is amended by striking “term” and all that follows and inserting the following “term in section 102 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000.”.

(11) CRANSTON-GONZALEZ NATIONAL AFFORDABLE HOUSING ACT.—The third sentence of section 811(k)(2) of the Cranston-Gonzalez National Affordable Housing Act (42 U.S.C. 8013(k)(2)) is amended by striking “as defined” and all that follows and inserting “as defined in section 102 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000.”.

(12) STATE DEPENDENT CARE DEVELOPMENT GRANTS ACT.—Section 670G(3) of the State Dependent Care Development Grants Act (42 U.S.C. 9877(3)) is amended by striking “section 102(7) of the Developmental Disabilities Assistance and Bill of Rights Act” and inserting “section 102 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(13) PROTECTION AND ADVOCACY FOR MENTALLY ILL INDIVIDUALS ACT OF 1986.—(A) Section 102(2) of the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (42 U.S.C. 10802(2)) is amended by striking “part C of the Developmental Disabilities Assistance and Bill of Rights Act” and inserting “subtitle C of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(B) Section 114 of the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (42 U.S.C. 10824) is amended by striking “section 107(c) of the Developmental Disabilities Assistance and Bill of Rights Act” and inserting “section 105 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.



(14) STEWART B. MCKINNEY HOMELESS ASSISTANCE ACT.—Section 422(2)(C) of the Stewart B. McKinney Homeless Assistance Act (42 U.S.C. 11382(2)(C)) is amended by striking “as defined” and all that follows and inserting “as defined in section 102 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000, or”.

(15) ASSISTED SUICIDE FUNDING RESTRICTION ACT OF 1997.—(A) Section 4 of the Assisted Suicide Funding Restriction Act of 1997 (42 U.S.C. 14403) is amended—

(i) by striking the section heading and inserting the following:

**“SEC. 4. RESTRICTION ON USE OF FEDERAL FUNDS UNDER CERTAIN GRANT PROGRAMS.”;**

and

(ii) by striking “part B, D, or E of the Developmental Disabilities Assistance and Bill of Rights Act” and inserting “subtitle B, D, or E of the Developmental Disabilities Assistance and Bill of Rights Act of 2000”.

(B) Section 5(b)(1) of the Assisted Suicide Funding Restriction Act of 1997 (42 U.S.C. 14404(b)(1)) is amended by striking subparagraph (A) and inserting the following:

“(A) PROTECTION AND ADVOCACY SYSTEMS UNDER THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT OF 2000.—Subtitle C of the Developmental Disabilities Assistance and Bill of Rights Act of 2000.”.

Approved October 30, 2000.

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LEGISLATIVE HISTORY—S. 1809 (H.R. 4920):

CONGRESSIONAL RECORD:

Vol. 145 (1999): Nov. 8, considered and passed Senate.

Vol. 146 (2000): Oct. 11, considered and passed House.



## Cynthia Mesa Testimony

My first initial reaction to the bill to register peoples with disabilities is it's an invasion of privacy, too intrusive and it gets under people's skin. The bill to register peoples with disabilities to law enforcement law enforcement officers and other Government of Guam agencies which in my judgment based upon personal experience as a person with a disability will only promote the stigma and get people labeled and treated differently like a former chairperson of a committee which serves the mentally ill once told me treated "like a different breed of human".

A new addition to the list of peoples with disabilities are quite a large enough number of veterans from all eras especially coming from Afghanistan and Iraq who presently many are experiencing PTSD and some may be wounded making them physically limited due to injuries sustained during combat.

It's alright if we lived in a place where people minded his business and kept his mouth shut. Face it, and you know it and you know who you are that on Guam, a small island in the Pacific and people talk all the time. I've heard mine and other consumers and other people's personal life and story even about me and other clients from the Behavioral Department being MDT patients broadcasted out in the public from a bus driver.

In Disid a woman who rides the Para transit mentioned how all our names were made public. During the permanent injunction against Mental Health, so many clients who include me received horrible letters in the mail from a former director, who I may tell you have never met in my entire life nor do I know her from Adam. I've been profiled based upon disability and my looks with people getting irritated for no good reason.

The register, excuse me for thinking what sounds evil will give way to circumvent the freedom and may potentially prove to bill counterproductive and potentially destructive if provided to the wrong people with set ideas about us especially if they are influenced by the media and environment and peoples negative talk about we being criminal, and this fear if we'll hurt their kids. The person will more than likely fell rejected because he or she is ostracized.

My experience is people leave me out all the time pretty much anywhere. I'm alone mostly even in a crowd. Ever know somebody who pounded the streets of San Francisco with very little money looking for work and a place to live alone. Well, that's me. I return back to Guam and guess what I'm still alone and have maybe 1 close friend who lives on Guam while everyone else is an acquaintance. What's funny is that I'm Chamorro and my close friend is hardly a relative of mine.

Well this place of peoples marginalizes others and treats even homeless peoples as outcasts and lepers and I've heard their snide, hateful putdowns and many of them are mentally ill and believe it or not the reason why a lot of them are like that is not because they like to be like that but it's because they're unemployable and too sick.

If you want to help someone you don't start first signaling them out, and isolating a certain percentage of the population of the Guam which I heard is a significant number roughly 40% and provide limited information about them which may be misleading and can be misconstrued which might not be helpful to the consumer and or can be used against a client which includes using the information about a clients weaknesses to psychologically affect him or her detrimentally to the point where it's bad for his or her psyche or he or she could be treated as undesirable and useless because that's how they are treated now. The language provided to the deliver might be vague for example. What makes you believe your proposed system will straighten things out. It's another form of killing. It makes the show "Criminal Minds" seem possible. There are people who have crooked ways and there is no guarantee that all people's ways are always straight and fair and charitable in their words, actions and will make a person like me for example feels comfortable.

What we need is to feel accepted. I'll be honest many of us do need help but so many of us have helped many people and if you take a look at American History for example, President Abraham Lincoln was bipolar and Albert Einstein had a learning disability.

Now finally I have a question for you what do you believe will be accomplished with such a bill? Are you sure it's what we want and need and how do you know that?

I take into consideration there's much too much hate, strife and division, prejudice and greed in the land. Charity has become harder for many people to find especially when times are hard and so are some people's hearts. You sound to me too late in 2015 for a registrar.

Let me remind you that there were a huge number of veterans on our island who received national attention not too long ago for being undeserved. There was a documentary of it shown on KGTF and the problem is still going on. As for me I got out of the hospital last month with an outrageous bill which could have killed me and I don't have medical insurance to see a doctor nor to get medicines and I don't feel I'm getting much help from people who really give a damn. Just because the system exists doesn't guarantee the consumer will always get help or what's requested and what's needed and then not ~~only~~ *always* on timely basis?

Cynthia Mesa  
472 1434

Mesa, Cynthia @ yahoo.com

(DOL - SSCEP (475-7019)  
Virginia Reyes)

Requests for Disabilities

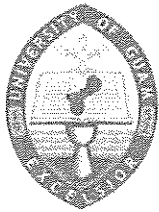
Questionnaire

(Medicaid Card)

none for about a month

Social Worker at Broward Health Center  
Klein - Social Worker





Guam Center for Excellence in  
Developmental Disabilities Education, Research, and Service  
University of Guam · *Unibetsedåt Guahan*  
Office of Academic and Student Affairs  
Hs #29 Dean Circle · UOG Station · Mangilao, Guam 96923  
(671) 735-2481 (V) · (671) 734-6531 (TTY) · (671) 734-5709 (Fax)



April 14, 2015

Vice Speaker Benjamin J.F. Cruz  
Committee on Appropriations and Adjudication  
The 33<sup>rd</sup> Guam Legislature  
155 Hesler Place, Suite 107  
Hagatna, Guam 96910

**Re: Testimony for Bill No. 70-33 (COR)**

Hafa Adai, Honorable Senator Cruz:

Thank you for inviting us to provide testimony on Bill 70-33.

We at UOG CEDDERS were pleased to have been asked by Senator Underwood for input as the bill was being crafted. It is and has been a continuing need area, and the Bill will help to address safety issues during times of disasters. CEDDERS has been involved in supporting First Responder training. Additionally, in 2010 we developed an emergency response Guidebook and Checklist and disseminated "Emergency Planning Kits" to several thousand individuals.

Bill 70-33 would help DISID to build capacity and collect very important data not only for use by first responders and village Mayors, but to collect accurate and unduplicated count of individuals with disabilities that may then be used by a variety of agencies on Guam when submitting grant applications and as services and support needs are addressed.

I am pleased to provide full support for Bill 70-33. While I am unable to attend the hearing on April 16th, I offer this written testimony.

Sincerely,

Heidi E. San Nicolas, Ph.D.  
Director



## TESTIMONY : CYNTHIA MESA

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April 21, 2015

**Vice Speaker Benjamin J.F. Cruz**

Date: 4/22/15 Time: 2:15 PM

File No.: \_\_\_\_\_

Received By: da

Guam Statewide Independent Living Council  
c/o Division of Vocational Rehabilitation, DISID  
238 AFC Flores St., 6<sup>th</sup> Floor  
Hagatna, GU 96910

**Honorable Senator/Vice speaker Benjamin J.F. Cruz**  
Chairman, Committee on Appropriations and Adjudication  
33<sup>rd</sup> Guam Legislature  
155 Hesler Place, Suite 107  
Hagatna, Guam 96910

**Subject: Testimony on Bill No. 70-33 (COR) – N.B. Underwood, Ph.D., R.J. Respicio**

**An Act to amend section 41105 of chapter 41, Article 1 of 17 Guam Code**

**Annotate, relative to the creation of a registry for individuals with disabilities.**

Dear Honorable B.J. Cruz,

Hafa Adai!

As Chairperson of the Guam Statewide Independent Living Council (SILC), I am submitting testimony on behalf of the Council that is in support of Bill No. 70-33 (COR).

The Rehabilitation Act of 1992 federally mandated the establishment of non-profit, Governor appointed Statewide Independent Living Councils. These Councils are mandated to develop and implement a State Plan every three years to address the independent living needs of persons with disabilities.

The Guam SILC is not mandated to establish a registry; however, we do believe there is a need for a single comprehensive registry with subcategories that meet the needs of the various agencies and disability groups. One of our State Plan goals is to collaborate with organizations and agencies to develop and establish such a registry.

The Council believes DISID is the most appropriate agency to be tasked to head this endeavor. Councils have neither the funding, the staff, or the constancy needed to successfully establish and maintain such a registry; however, they can assist to promote, educate and encourage persons with disabilities to participate in the registration process.

It is essential there be a central, voluntary register to meet the needs of first responders as well as provide information to persons with disabilities and their families of services available that will enable those with disabilities to live more independently. Situations that have occurred in our community speak to the need for first responders to be knowledgeable of persons with disabilities that require special attention in emergency situations. Not all persons with disabilities have the same needs, creating the need for training of personnel which should become the responsibility of those agencies providing the service, specifically the police, fire, ambulance and those providing services during disasters.

The Council commends the Senators for their concern and interest in ensuring the safety and welfare of those with disabilities.

Respectfully,

A handwritten signature in cursive script that reads "Carol Darlow".

Carol Darlow, Chairperson

WELCOME TO THE EMERGENCY ASSISTANCE VOLUNTARY REGISTRY!

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**City of Chicago  
Emergency Assistance Registry for People with Disabilities or Special Needs  
Voluntary Self-Identification Form**

The City of Chicago has created a voluntary registry for individuals who may need assistance in the event of an emergency. In accordance with Illinois Public Act 096-0788, Section 35, registry participants are advised that the provision of special needs information will not result in preferential treatment.

To submit the form, click a link below.

**LINKS**

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- [City of Chicago](#)
- [Office of Emergency Management & Communications](#)
- [AlertChicago](#)
- [NotifyChicago](#)

[Online Voluntary Registry Form](#)

[If you have already registered, click here to log in.](#)

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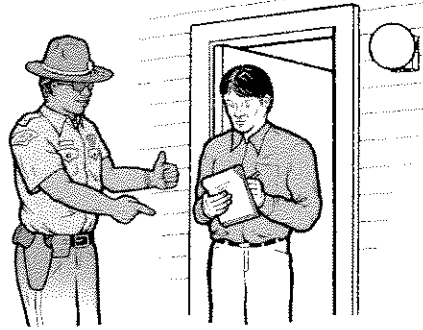




## An ADA Guide for Local Governments

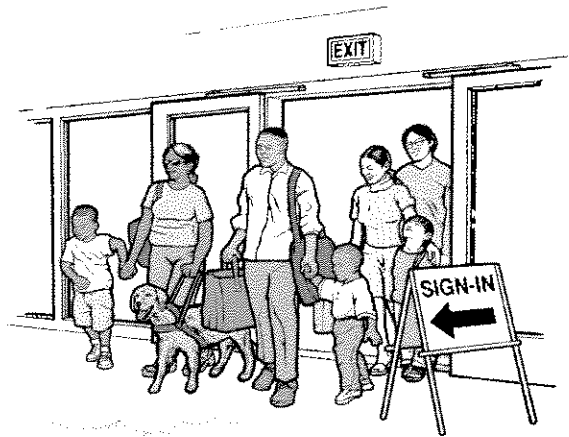
# Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities

One of the most important roles of local government is to protect their citizenry from harm, including helping people prepare for and respond to emergencies. Making local government emergency preparedness and response programs accessible to people with disabilities is a critical part of this responsibility. Making these programs accessible is also required by the Americans with Disabilities Act of 1990 (ADA).

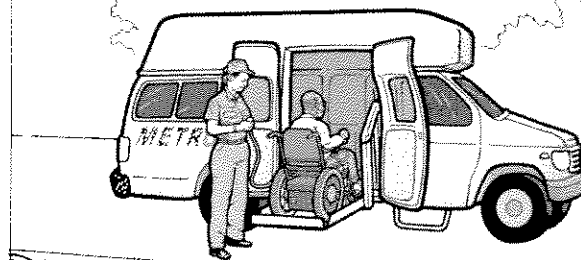


A police officer uses written notes and hand gestures to tell a man who is deaf to evacuate.

A family, including a woman with a service animal, arrives at a shelter.



A man using a wheelchair enters a paratransit van provided so he can evacuate from his home.



## PLANNING

---

If you are responsible for your community's emergency planning or response activities, you should involve people with disabilities in identifying needs and evaluating effective emergency management practices. Issues that have the greatest impact on people with disabilities include:

- notification;
- evacuation;
- emergency transportation;
- sheltering;
- access to medications, refrigeration, and back-up power;
- access to their mobility devices or service animals while in transit or at shelters; and
- access to information.

In planning for emergency services, you should consider the needs of people who use mobility aids such as wheelchairs, scooters, walkers, canes or crutches, or people who have limited stamina. Plans also need to include people who use oxygen or respirators, people who are blind or who have low vision, people who are deaf or hard of hearing, people who have a cognitive disability, people with mental illness, and those with other types of disabilities.

### Action Steps: Planning

Solicit and incorporate input from people with different types of disabilities (e.g. mobility, vision, hearing, cognitive and other disabilities) regarding all phases of your emergency management plan including:

- preparation;
- notification;
- response; and
- clean up.

## NOTIFICATION

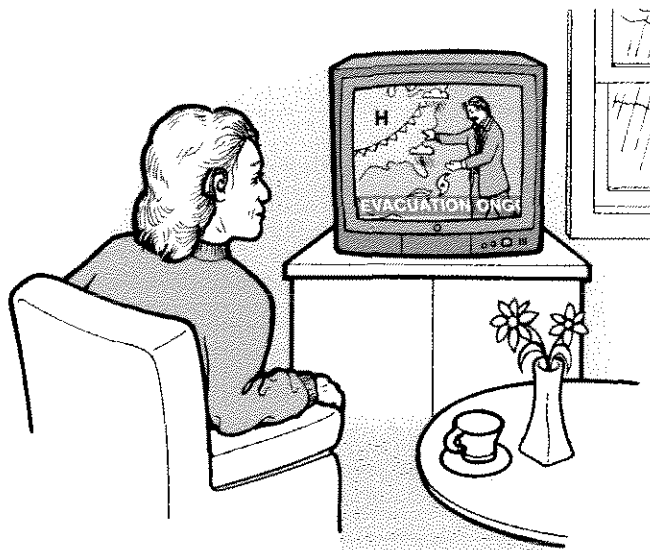
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Many traditional emergency notification methods are not accessible to or usable by people with disabilities. People who are deaf or hard of hearing cannot hear radio, television, sirens, or other audible alerts. Those who are blind or who have low vision may not be aware of visual cues, such as flashing lights. Warning methods should be developed to ensure that all citizens will have the information necessary to make sound decisions and take appropriate, responsible action. Often, using a combination of methods will be more effective than relying on one method alone. For instance, combining visual and audible alerts will reach a greater audience than either method would by itself.

**Action Steps: Notification**

Provide ways to inform people who are deaf or hard of hearing of an impending disaster if you use emergency warning systems such as sirens or other audible alerts.

When the electric power supply is affected, it may be necessary to use several forms of notification. These might include the use of telephone calls, auto-dialed TTY (teletypewriter) messages, text messaging, E-mails, and even direct door-to-door contact with pre-registered individuals.



**A woman who is deaf reads a captioned evacuation notice on her television.**

Also, you should consider using open-captioning on local TV stations in addition to incorporating other innovative uses of technology into such procedures, as well as lower-tech options such as dispatching qualified sign language interpreters to assist in broadcasting emergency information provided to the media.



**A police officer uses hand gestures and a printed note to tell a woman who is deaf that she needs to evacuate her home.**



# EVACUATION

Individuals with disabilities will face a variety of challenges in evacuating, depending on the nature of the emergency. People with a mobility disability may need assistance leaving a building without a working elevator. Individuals who are blind or who have limited vision may no longer be able to independently use traditional orientation and navigation methods. An individual who is deaf may be trapped somewhere unable to communicate with anyone because the only communication device relies on voice. Procedures should be in place to ensure that people with disabilities can evacuate the physical area in a variety of conditions and with or without assistance.

## Action Steps: Evacuation of People with Disabilities

Adopt policies to ensure that your community evacuation plans enable people with disabilities, including those who have mobility, vision, hearing, or cognitive disabilities, mental illness, or other disabilities, to safely self-evacuate or to be evacuated by others. Some communities are instituting voluntary, confidential registries of persons with disabilities who may need individualized evacuation assistance or notification. If you adopt or maintain such a registry, have procedures in place to ensure its voluntariness, guarantee confidentiality controls, and develop a process to update the registry. Also consider how best to publicize its availability. Whether or not a registry is used, your plan should address accessible transportation needs for people who use wheelchairs, scooters, or other mobility aids as well as people who are blind or who have low vision.

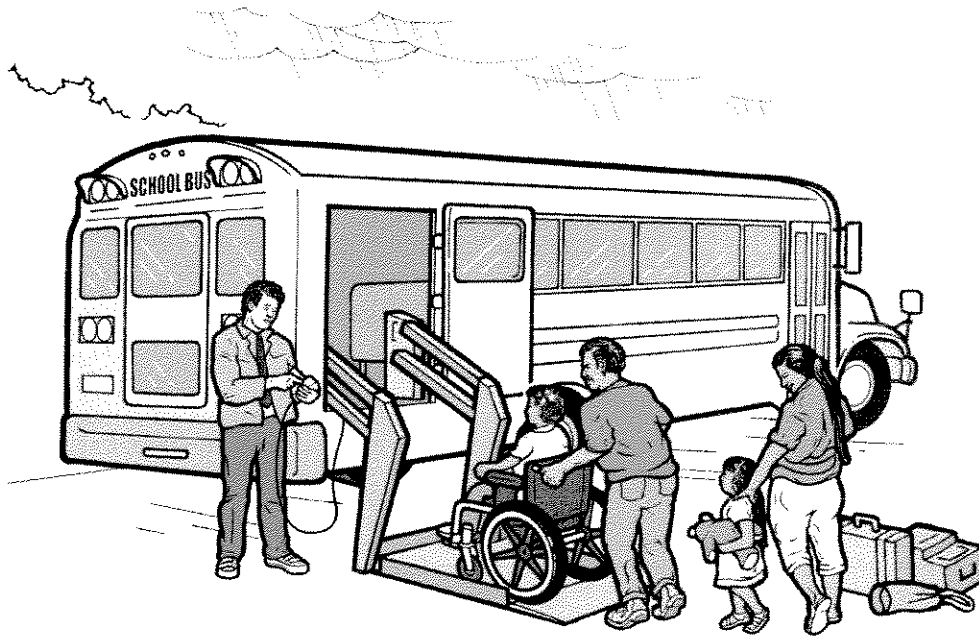


**A transit bus equipped with a wheelchair lift is used to evacuate individuals and families.**

Both public and private transportation may be disrupted due to overcrowding, because of blocked streets and sidewalks, or because the system is not functioning at all. The movement of people during an evacuation is critical, but many people with disabilities cannot use traditional, inaccessible transportation.

### Action Steps: Evacuation with Accessible Vehicles

Identify accessible modes of transportation that may be available to help evacuate people with disabilities during an emergency. For instance, some communities have used lift-equipped school or transit buses to evacuate people who use wheelchairs during floods.



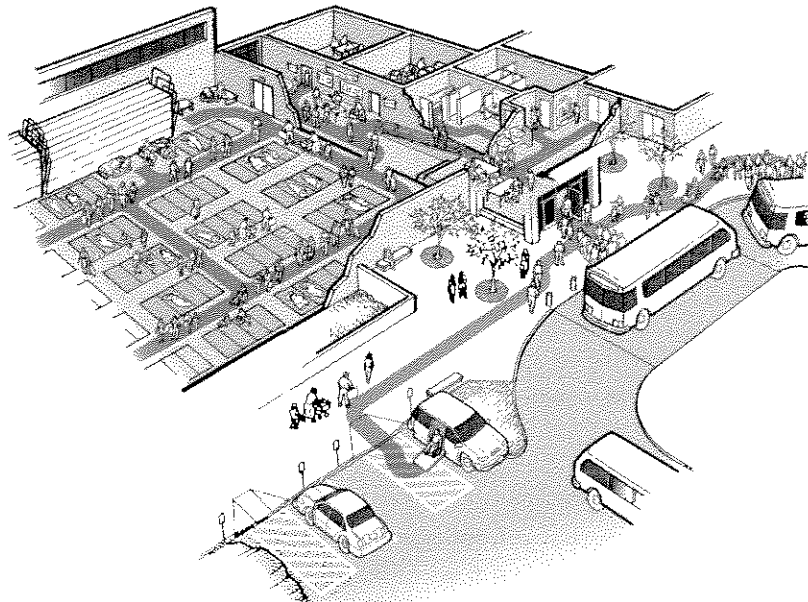
**A lift-equipped school bus is used to evacuate an individual using a wheelchair and her family.**

## SHELTERING

When disasters occur, people are often provided safe refuge in temporary shelters. Some may be located in schools, office buildings, tents, or other areas. Historically, great attention has been paid to ensuring that those shelters are well stocked with basic necessities such as food, water, and blankets. But many of these shelters have not been accessible to people with disabilities. Individuals using a wheelchair or scooter have often been able somehow to get to the shelter, only to find no accessible entrance, accessible toilet, or accessible shelter area.

### Action Steps: Accessible Shelters

Survey your community's shelters for barriers to access for persons with disabilities. For instance, if you are considering incorporating a particular high school gymnasium into your sheltering plan, early in the process you should examine its parking, the path to the gymnasium, and the toilets serving the gymnasium to make sure they are accessible to people with disabilities. If you find barriers to access, work with the facility's owner to try to get the barriers removed. If you are unable to do so, consider another nearby facility for your community sheltering needs.



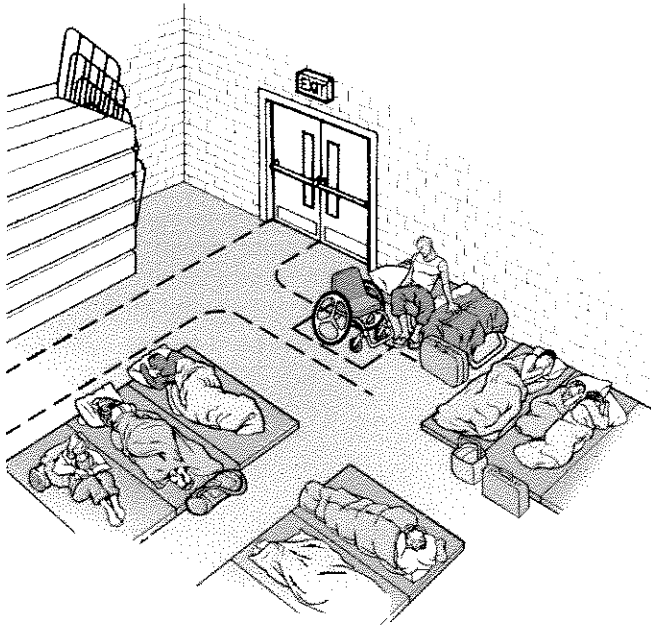
**A shelter with accessible features including parking, drop-off area, entrance, toilet rooms, and sleeping areas.**

Until all of your emergency shelters have accessible parking, exterior routes, entrances, interior routes to the shelter area, and toilet rooms serving the shelter area; you should identify and widely publicize to the public, including persons with disabilities and the organizations that serve them, the locations of the most accessible emergency shelters.

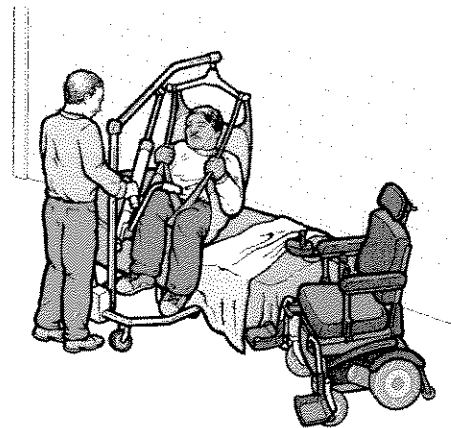
Shelter staff and volunteers are often trained in first aid or other areas critical to the delivery of emergency services, but many have little, if any, familiarity with the needs of people with disabilities. In some instances, people with disabilities have been turned away from shelters because of volunteers' lack of confidence regarding the shelter's ability to meet their needs. Generally, people with disabilities may not be segregated or told to go to "special" shelters designated for their use. They should ordinarily be allowed to attend the same shelters as their neighbors and coworkers.

### Action Steps: Input on Shelter Planning and Staff Training

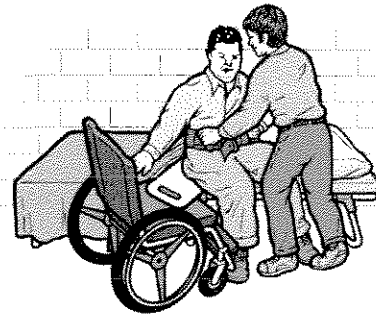
Invite representatives of group homes and other people with disabilities to meet with you as part of your routine shelter planning. Discuss with them which shelters they would be more likely to use in the event of an emergency and what, if any, disability-related concerns they may have while sheltering. Develop site-specific instructions for your volunteers and staff to address these concerns.



A individual who uses a wheelchair sits on a cot that is placed against a wall. The height of the bed and the wheelchair seat are of similar height making it possible for this person to transfer from the wheelchair to the bed.



A shelter worker helps a person onto a cot using a portable lift provided by the shelter.



A shelter worker helps a man transfer onto a cot.

## SHELTERING (continued)

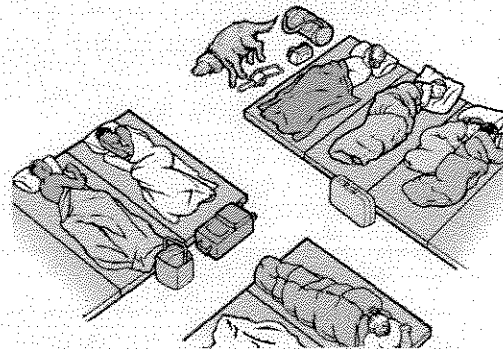
Many shelters have a “no pets” policy and some mistakenly apply this policy to exclude service animals such as guide dogs for people who are blind, hearing dogs for people who are deaf, or dogs that pull wheelchairs or retrieve dropped objects. When people with disabilities who use service animals are told that their animals cannot enter the shelter, they are forced to choose between safety and abandoning a highly trained animal that accompanies them everywhere and allows them to function independently.

### Action Steps: Service Animals

Adopt procedures to ensure that people with disabilities who use service animals are not separated from their service animals when sheltering during an emergency, even if pets are normally prohibited in shelters. While you cannot unnecessarily segregate persons who use service animals from others, you may consider the potential presence of persons who, for safety or health reasons, should not be with certain types of animals.



**A man using a wheelchair arrives at a shelter with his family and service animal.**

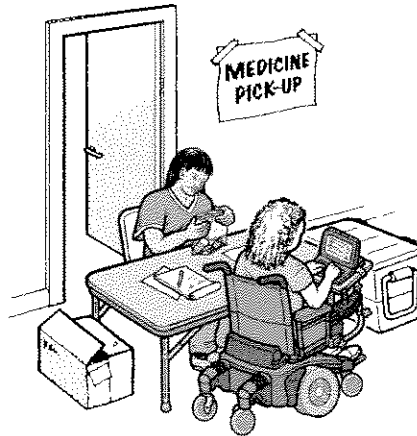


**A woman has a service animal lying on the floor next to her cot.**

Individuals whose disabilities require medications, such as certain types of insulin that require constant refrigeration, may find that many shelters do not provide refrigerators or ice-packed coolers. Individuals who use life support systems and other devices rely on electricity to function and stay alive and, in many cases, may not have access to a generator or other source of electricity within a shelter.

### Action Steps: Medications, Refrigeration, and Back-up Power

Ensure that a reasonable number of emergency shelters have back-up generators and a way to keep medications refrigerated (such as a refrigerator or a cooler with ice). These shelters should be made available on a priority basis to people whose disabilities require access to electricity and refrigeration, for example, for using life-sustaining medical devices, providing power to motorized wheelchairs, and preserving certain medications, such as insulin, that require refrigeration. The public should be routinely notified about the location of these shelters. In addition, if you choose to maintain a confidential registry of individuals needing transportation assistance, this registry could also record those who would be in need of particular medications. This will facilitate your planning priorities.



**A person using a wheelchair picks up medication at the shelter.**

People who are deaf or hard of hearing may not have access to audible information routinely made available to people in the temporary shelters. Individuals who are blind or who have low vision will not be able to use printed notices, advisories, or other written information.

### Action Steps: Communications

Adopt procedures to provide accessible communication for people who are deaf or hard of hearing and for people with severe speech disabilities. Train staff on the basic procedures for providing accessible communication, including exchanging notes or posting written announcements to go with spoken announcements. Train staff to read printed information, upon request, to persons who are blind or who have low vision.



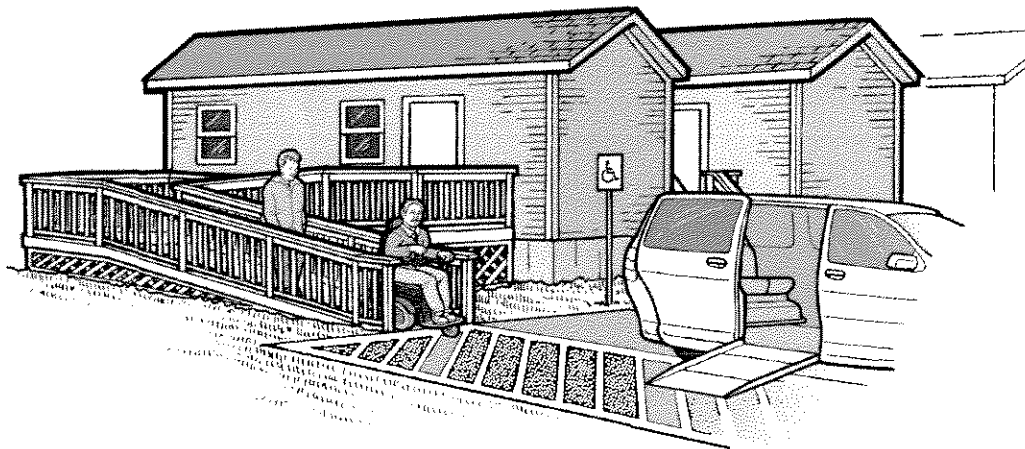
**A shelter worker reads printed information to a woman who is blind.**

## RETURNING HOME

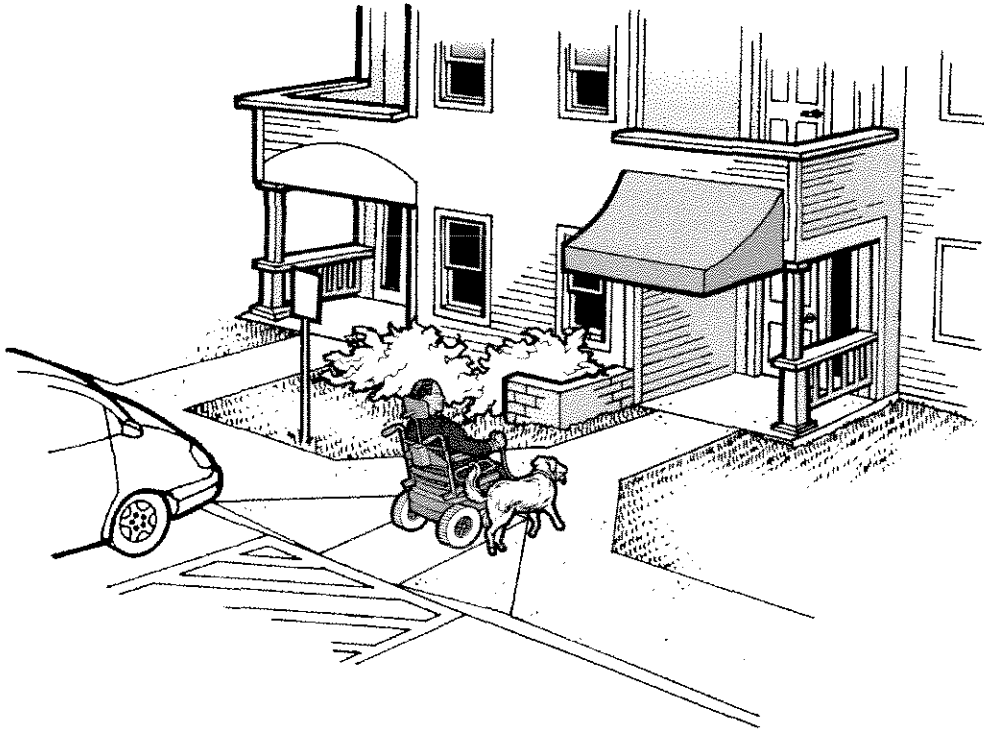
The needs of individuals with disabilities should be considered, too, when they leave a shelter or are otherwise allowed to return to their home. If a ramp has been destroyed, an individual with a mobility impairment will be unable to get into and out of the house. In case temporary housing is needed past the stay at the shelter, your emergency response plan could identify available physically accessible short-term housing, as well as housing with appropriate communication devices, such as TTY's, to ensure individuals with communication disabilities can communicate with family, friends, and medical professionals.

### Action Steps: Planning

Identify temporary accessible housing (such as accessible hotel rooms within the community or in nearby communities) that could be used if people with disabilities cannot immediately return home after a disaster if, for instance, necessary accessible features such as ramps or electrical systems have been damaged.



**A portable trailer provides temporary accessible housing for an individual who uses a wheelchair and his family. In addition to accessible features inside, the trailer also has an accessible entrance, accessible parking, and the trailer is located on an accessible route to other site features in the mobile home park.**



**A man using a wheelchair and his service animal enters temporary accessible housing provided in an apartment building.**

## CONTRACTING FOR EMERGENCY SERVICES

Many local governments provide emergency services through contracts with other local governments or private relief organizations. These entities may not fully understand the role they need to play in meeting your obligation to provide accessible emergency services.

### **Action Steps: Contracting for Emergency Services**

Make sure that contracts for emergency services require providers to follow appropriate steps outlined in this document. Review the terms of these contracts on a regular basis to ensure that they continue to meet the accessibility needs of people with disabilities. Provide training to contractors so that they understand how best to coordinate their activities with your overall accessibility plan for emergency services.





***PRACTICE GUIDELINES:***

***CORE ELEMENTS IN  
RESPONDING TO  
MENTAL HEALTH CRISES***



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Substance Abuse and Mental Health Services Administration  
Center for Mental Health Services  
[www.samhsa.gov](http://www.samhsa.gov)

*PRACTICE GUIDELINES:*

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## **DISCLAIMER**

The views, opinions, and content of this publication do not necessarily reflect the views, opinions or policies of the Center for Mental Health Services (CMHS), SAMHSA, or HHS.

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## Practice Guidelines: Core Elements for Responding to Mental Health Crises

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# I. INTRODUCTION

## CRISES HAVE A PROFOUND IMPACT ON PEOPLE WITH SERIOUS MENTAL HEALTH OR EMOTIONAL PROBLEMS.

Adults, children and older adults with a serious mental illness or emotional disorder often lead lives characterized by recurrent, significant crises. These crises are not the inevitable consequences of mental disability, but rather represent the combined impact of a host of additional factors, including lack of access to essential services and supports, poverty, unstable housing, coexisting substance use, other health problems, discrimination and victimization.

Homelessness, police contact, institutionalization and other adverse events are in themselves crises, and may also contribute to further crises. The statistics below paint a sobering picture of how crises affect the lives of people who have mental or emotional disabilities:

- From one third to one half of homeless people have a severe psychiatric disorder.<sup>1</sup>
- Approximately 7 percent of all police contacts in urban settings involve a person believed to have a mental illness.<sup>2</sup>
- The likelihood of mental illness among people confined in state prisons and local jails is three to four times higher than in the general population<sup>3</sup> and, compared with other inmates, it is *at least twice as likely* that these individuals will be injured during their incarceration.<sup>4</sup>
- About 6 percent of all hospital emergency department visits reflect mental health emergencies.<sup>5</sup>
- Due to a lack of available alternatives, 79 percent of hospital emergency departments report having to “board” psychiatric patients who are in crisis and in need of inpatient care, sometimes for *eight hours or longer*.<sup>6</sup>
- Almost one in 10 individuals discharged from a state psychiatric hospital will be readmitted within 30 days; more than one in five will be readmitted within 180 days.<sup>7</sup>
- About 90 percent of adult inpatients in state psychiatric hospitals report histories of trauma.<sup>8</sup>
- About three quarters of youth in the juvenile justice system report mental health problems and one in five has a serious mental disorder.<sup>9</sup>
- Mothers with serious mental illnesses are *more than four times as likely* as other mothers to lose custody of their children.<sup>10</sup>
- People with serious mental illnesses die, on average, *25 years earlier* than the general population.<sup>11</sup>

These statistics are incomplete; they reflect just a sampling of scenarios that, while commonplace, constitute significant life crises for individuals with serious mental illnesses.

Many such individuals experience a cascade of crisis events that place them in more than one of these statistical groups. For instance, readmission to a psychiatric institution—a high probability for adults who have been discharged from a state psychiatric hospital, based on these data—may feature a series of crisis events for the individual: the psychiatric emergency itself; forcible removal from one’s home; being taken into police custody, handcuffed and transported in the back of a police car; evaluation in the emergency department of a general hospital; transfer to a psychiatric hospital; a civil commitment hearing; and so on. And at multiple points in this series of interventions, there is a likelihood that physical restraints, seclusion, involuntary medication or other coercion may be used. Intense feelings of disempowerment are definitional of mental health crises, yet as the individual becomes the subject of a “disposition” at each juncture, that person may experience a diminishing sense of control.

In the wake of rare but highly publicized tragedies attributed to people with mental illnesses, there is often a temporary surge in political concern about mental healthcare and expanding crisis interventions. Sadly, the more commonplace crises endured every day by many thousands of adults, older adults and children with serious mental or emotional problems tend to generate neither media attention nor political concern.

While no one with a mental or emotional disorder is immune from crises, people with what are termed serious mental illnesses—defined as schizophrenia, bipolar disorder and major depression—may be most reliant on public systems. They also may be at great risk of recurrent crises and interventions that exacerbate their clinical and social problems. These guidelines focus most specifically on individuals with serious mental or emotional problems who tend to encounter an assortment of governmental or publicly funded interveners when they are in crisis. Nevertheless, the values, principles and strategies embedded in the guidelines that follow are applicable to all individuals with mental healthcare needs, across populations and service settings.

Individuals whose diagnoses do not fit “serious mental illnesses” may be vulnerable to serious mental health crises that can have devastating outcomes. Interventions on their behalf are more likely to occur within the private healthcare sector, which mirrors public mental health systems’ problems in providing early and meaningful access to help. Within these parallel systems, crisis services are provided in a broad array of settings that ultimately will require translation of the guidelines presented here into specific protocols that break cycles of crises and advance the prospects of recovery for people with mental illnesses.



## WHAT IT MEANS TO BE IN A MENTAL HEALTH CRISIS

Too often, public systems respond as if a *mental health crisis* and *danger to self or others* were one and the same. In fact, *danger to self or others* derives from common legal language defining when involuntary psychiatric hospitalization may occur—at best, this is a blunt measure of an extreme emergency. A narrow focus on dangerousness is not a valid approach to addressing a mental health crisis. To identify crises accurately requires a much more nuanced understanding and a perspective that looks beyond whether an individual is dangerous or immediate psychiatric hospitalization is indicated.

While behaviors that represent an imminent danger certainly indicate the need for some sort of an emergency response, these behaviors may well be the culmination of a crisis episode, rather than the episode in its entirety. Situations involving mental health crises may follow trajectories that include intense feelings of personal distress (e.g., anxiety, depression, anger, panic, hopelessness), obvious changes in functioning (e.g., neglect of personal hygiene, unusual behavior) or catastrophic life events (e.g., disruptions in personal relationships, support systems or living arrangements; loss of autonomy or parental rights; victimization or natural disasters).

Because only a portion of real-life crises may actually result in serious harm to self or others, a response that is activated only when physical safety becomes an issue is often too little, too late or no help at all in addressing the root of the crisis. And a response that does not meaningfully address the actual issues underlying a crisis may do more harm than good.

## THE NEED FOR CRISIS STANDARDS

Individuals experiencing mental health crises may encounter an array of professionals and non-professionals trying to intervene and help: family members, peers, healthcare personnel, police, advocates, clergy, educators and others. The specific crisis response offered is influenced by a number of variables, among them:

- where the intervention occurs,
- at what time of day it occurs,
- when it occurs within the course of the crisis episode,
- the familiarity of the intervener with the individual or with the type of problem experienced by the individual,
- interveners' training relating to crisis services,
- resources of the mental health system and the ready availability of services and supports, and
- professional, organizational or legal norms that define the nature of the encounter and the assistance offered.

## Practice Guidelines: Core Elements for Responding to Mental Health Crises

The guidelines presented here define appropriate responses to mental health crises across these variables. They were developed by a diverse expert panel (see below) that includes individuals with and without serious mental illnesses who are leaders within mental health professions and mental health advocacy.

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This report of the panel's findings is not intended to be an exhaustive resource on crisis services and best practices, but rather an explanation of factors essential to any response to mental health emergencies. In organizations that may already have protocols for responding to individuals in mental health crises (for instance, police departments, hospitals and mental health clinics), these guidelines offer an opportunity to assess the adequacy of current practices based on a set of underlying values and principles. In foster care, schools or other settings where protocols may not currently exist, the guidelines can serve as a framework for examining current activities and the need for more explicit standards. In either instance, these crisis guidelines promote two essential goals:

1. Ensuring that mental health crisis interventions are guided by standards consistent with recovery and resilience and
2. Replacing today's largely reactive and cyclical approach to mental health crises with one that works toward reducing the likelihood of future emergencies and produces better outcomes.

## II. RESPONDING TO A MENTAL HEALTH CRISIS

### TEN ESSENTIAL VALUES

Ten essential values are inherent in an appropriate crisis response, regardless of the nature of the crisis, the situations where assistance is offered or the individuals providing assistance:

- 1. Avoiding Harm.** Sometimes mental health crises place the safety of the person, the crisis responders or others in jeopardy. An appropriate response establishes physical safety, but it also establishes the individual's psychological safety. For instance, restraints are sometimes used in situations where there is an immediate risk of physical harm, yet this intervention has inherent physical and psychological risks that can cause injury and even death. Precipitous responses to individuals in mental health crises—often initiated with the intention of establishing physical safety—sometimes result in harm to the individual. *An appropriate response to mental health crises considers the risks and benefits attendant to interventions and whenever possible employs alternative approaches, such as controlling danger sufficiently to allow a period of "watchful waiting." In circumstances where there is an urgent need to establish physical safety and few viable alternatives to address an immediate risk of significant harm to the individual or others, an appropriate crisis response incorporates measures to minimize the duration and negative impact of interventions used.*

"To promote patient-centered care, all parties involved in health care for mental or substance-use conditions should support the decision-making abilities and preferences for treatment and recovery of persons with mental/substance use problems and illnesses"

Institute of Medicine. (2006) Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders. Recommendation 3-1, p. 126

- 2. Intervening in Person-Centered Ways.** Mental health crises may be routine in some settings and, perhaps, have even come to be routine for some people with serious mental health or emotional problems. Nevertheless, appropriate crisis assistance avoids rote interventions based on diagnostic labels, presenting complaint or practices customary to a particular setting. *Appropriate interventions seek to understand the individual, his or her unique circumstances and how that individual's personal preferences and goals can be maximally incorporated in the crisis response.*

- 3. Shared Responsibility.** An acute sense of losing control over events or feelings is a hallmark of mental health crises. In fact, research has shown "feeling out of control" to be the most common reason consumers cite for being brought in for psychiatric emergency care.<sup>12</sup> An intervention that is done *to* the individual—rather than *with* the individual—can reinforce these feelings of helplessness. One of the principal rationales for person-centered plans is that shared responsibility promotes engagement and better outcomes. While crisis situations may present challenges to implementing shared, person-centered plans, ultimately an intervention that considers and, to the extent possible, honors an individual's role in crisis resolution may hold long-term benefits. *An appropriate crisis response seeks to assist the individual in regaining control by considering the individual an active partner in—rather than a passive recipient of—services.*

### Personal Safety Plan

Some state mental health systems encourage consumers to complete a form intended to help staff understand an individual's preferred ways of addressing emerging crises. The following is the introduction presented from Florida's adaptation of the Massachusetts form; it affirms the perspective of a partnership between staff and the individual.

"This form will allow you to suggest calming strategies IN ADVANCE of a crisis. It will allow you to list things that are helpful when you are under stress or are upset. It will also allow you to identify things that make you angry. Staff and individuals receiving services can enter into a 'partnership of safety' using this form as a guide to assist in your treatment plan. The information is intended only to be helpful; it will not be used for any purpose other than to help staff understand how to best work with you to maintain your safety or to collect data to establish trends. This is a tool that you can add to at any time. Information should always be available from staff members for updates or discussion. Please feel free to ask questions."

Massachusetts Department of Mental Health (1996) *Task Force on the Restraint and Seclusion of Persons who have been Physically or Sexually Abused, Report and Recommendations*

Florida Department of Children and Families, Form CF-MH 3124, <http://www.dcf.state.fl.us/DCFForms/Search/DCF-FormSearch.aspx>

4. **Addressing Trauma.** Crises, themselves, are intrinsically traumatic and certain crisis interventions may have the effect of imposing further trauma—both physical and emotional. In addition, people with serious mental illness have a high probability of having been victims of abuse or neglect. *It is essential that once physical safety has been established, harm resulting from the crisis or crisis response is evaluated and addressed without delay by individuals qualified to diagnose and initiate needed treatment. There is also a dual responsibility relating to the individual's relevant trauma history and vulnerabilities associated with particular interventions; crisis responders should appropriately seek out and incorporate this information in their approaches, and individuals should take personal responsibility for making this crucial information available (for instance, by executing advance directives).*
5. **Establishing Feelings of Personal Safety.** An individual may experience a mental health crisis as a catastrophic event and, accordingly, may have an urgent need to feel safe. What is regarded as agitated behavior may reflect an individual's attempts at self-protection, though perhaps to an unwarranted threat. *Assisting the individual in attaining the subjective goal of personal safety requires an understanding of what is needed for that person to experience a sense of security (perhaps contained in a crisis plan or personal safety plan previously formulated by the individual) and what interventions increase feelings of vulnerability (for instance, confinement in a room alone). Providing such assistance also requires that staff be afforded time to gain an understanding of the individual's needs and latitude to address these needs creatively.*
6. **Based on Strengths.** Sharing responsibility for crisis resolution means understanding that an individual, even while in crisis, can marshal personal strengths and assist in the resolution of the emergency. Individuals often understand the factors that precipitated a crisis as well as factors that can help ameliorate their impact. *An appropriate crisis response seeks to identify and reinforce the resources on which an individual can draw, not only to recover from the crisis event, but to also help protect against further occurrences.*
7. **The Whole Person.** For individuals who have a mental illness, the psychiatric label itself may shape—even dominate—decisions about which crisis interventions are offered and how they are made available. *An individual with a serious mental illness who is in crisis is a whole person, whose established psychiatric disability may be relevant but may—or may not—be immediately paramount.* That the individual may have multiple needs and an adequate understanding of the crisis means not being limited by services that are compartmentalized according to healthcare specialty. An individual's emergency may reflect the interplay of psychiatric issues with other health factors. And while the individual is experiencing a crisis that tends to be addressed as a clinical phenomenon, there may also be a host of seemingly mundane, real-world concerns that significantly affect an individual's response: the whereabouts of the person's children, the welfare of pets, whether the house is locked, absence from work, and so on.
8. **The Person as Credible Source.** Assertions or complaints made by individuals who have been diagnosed with a serious mental illness tend to be viewed skeptically by others. Particularly within the charged context of mental health

crises, there may be a presumption that statements made by these individuals are manifestations of delusional thinking. Consequently, there is a risk that legitimate complaints relating to such matters as medical illness, pain, abuse or victimization will go unheeded. Even when an individual's assertions are not well grounded in reality and represent obviously delusional thoughts, the "telling of one's story" may represent an important step toward crisis resolution.<sup>13</sup> *For these reasons, an appropriate response to an individual in mental health crisis is not dismissive of the person as a credible source of information—factual or emotional—that is important to understanding the person's strengths and needs.*

9. **Recovery, Resilience and Natural Supports.** Certain settings, such as hospital emergency departments, may see individuals only transiently, at a point when they are in acute crisis and in a decidedly high-stress environment. Even when not occurring within hospitals, mental health emergency interventions are often provided in settings that are alien to the individual and the natural supports that may be important parts of his or her daily life. It is important not to lose sight of the fact that an emergency episode may be a temporary relapse and not definitional of the person or that individual's broader life course. *An appropriate crisis response contributes to the individual's larger journey toward recovery and resilience and incorporates these values. Accordingly, interventions should preserve dignity, foster a sense of hope, and promote engagement with formal systems and informal resources.*
10. **Prevention.** Too often, individuals with serious mental illnesses have only temporary respite between crises. An appropriate crisis response works to ensure that crises will not be recurrent by evaluating and considering factors that contributed to the current episode and that will prevent future relapse. *Hence, an adequate crisis response requires measures that address the person's unmet needs, both through individualized planning and by promoting systemic improvements.*

## PRINCIPLES FOR ENACTING THE ESSENTIAL VALUES

Several principles are key to ensuring that crisis intervention practices embody these Essential Values:

1. **Access to supports and services is timely.** Ready access to assistance is important not only because it holds the promise of reducing the intensity and duration of the individual's distress, but also because as a crisis escalates, options for interventions may narrow. Timely access presupposes 24-hour/7-days-a-week availability and a capacity for outreach when an individual is unable or unwilling to come to a traditional service site.
2. **Services are provided in the least restrictive manner.** Least-restrictive emergency interventions not only avoid the use of coercion, but also preserve the individual's connectedness with his or her world. Individuals should not be unnecessarily isolated from their routine networks of formal and natural supports and should be encouraged to make contact with outside professionals, family and friends who can provide assistance through the crisis event and beyond.

The National Consensus Statement on Mental Health Recovery identifies *recovery* as an individual's journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential. It also cites 10 fundamental components for systems:

- Self-Direction
- Individualized and Person-Centered
- Empowerment
- Holistic
- Non-Linear
- Strengths-Based
- Peer Support
- Respect
- Responsibility
- Hope

US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services (2004) National Consensus Statement on Mental Health Recovery. For the complete report, see: <http://mentalhealth.samhsa.gov/publications/allpubs/ma05-4129/>

**Staff Behaviors that Consumers Feel Are Most Important to Individuals in a Mental Health Crisis**

- Having the staff listen to me, my story and my version of events
- Being asked about what treatment I want
- Trying to help me calm down before resorting to forced treatment
- Being asked about what treatments were helpful and not helpful to me in the past

Allen, M., Carpenter, D., Sheets, J., Miccio, S., & Ross, R. (2003) What do consumers say they want and need during a psychiatric emergency? *Journal of Psychiatric Practice* (9) 1, 39-58.

- 3. Peer support is available.** Services should afford opportunities for contact with others whose personal experiences with mental illness and past mental health crises allow them to convey a sense of hopefulness first-hand. In addition, peers can offer opportunities for the individual to connect with a supportive circle of people who have shared experiences—an option that may have particular relevance given feelings of isolation and fear that may accompany a mental health crisis.
- 4. Adequate time is spent with the individual in crisis.** In settings such as hospital emergency departments, there may be intense pressure to move patients through quickly.<sup>13</sup> People who provide assistance must have an adequate understanding of the crisis situation, not only objectively, but also as it is being experienced by the individual who is in crisis. Unfortunately, individuals in acute crisis—particularly following involuntary transport to an evaluation setting—may not be in a position to discuss their presenting complaints clearly and concisely. Personnel in healthcare and similar settings must regard face-to-face time with the individual not as a distraction, but as a core element of quality crisis care. Settings that cannot accommodate the individual in this way may not be appropriate venues for psychiatric crisis intervention; as is discussed elsewhere in these guidelines, such a determination should be regarded as a problem in care and drive performance improvement at both the organizational and systemic levels.
- 5. Plans are strengths-based.** It may be fairly routine for professional staff to concentrate on clinical signs and other deficits to be addressed, particularly when an individual is in a crisis state and, therefore, “symptomatic.” Yet appropriate crisis intervention gives at least equal attention to the individual’s immediately available and potentially available assets. A strengths-based plan helps to affirm the individual’s role as an active partner in the resolution of the crisis by marshalling his or her capabilities. A strengths-based approach also furthers the goals of building resilience and a capability for self-managing future crises.
- 6. Emergency interventions consider the context of the individual’s overall plan of services.** Many individuals with serious mental illnesses go into mental health crises while receiving some sort of services and supports. Appropriate crisis services consider whether the crisis is, wholly or partly attributable to gaps or other problems in the individual’s current plan of care and provide crisis measures in ways that are consistent with services the individual receives (or should receive) in the community. In addition, appropriate crisis services place value on earlier efforts by the individual and his or her service providers to be prepared for emergencies, for instance, by having executed psychiatric advance directives or other crisis plans. Incorporating such measures in a crisis response requires that interveners be knowledgeable about these approaches, their immediate and longer-term value, and how to implement them. Appropriate crisis interventions also include post-event reviews that may produce information that is helpful to the individual and his or her customary service providers in refining ongoing services and crisis plans.

- 7. Crisis services are provided by individuals with appropriate training and demonstrable competence to evaluate and effectively intervene with the problems being presented.** Crisis intervention may be considered a high-end service, that is high-risk and demanding a high level of skill. Within the course of a psychiatric emergency, various types of crisis interventions may occur—some by healthcare professionals, some by peers and some by personnel (such as police) who are outside of healthcare. Throughout, the individual experiencing a mental health crisis should be assured that all interveners have an appropriate level of training and competence. What that means may vary considerably between scenarios. For instance, a significant number of instances of police involvement with individuals in mental health crises result in injuries or even death.<sup>15</sup> Accordingly, some police departments have taken special measures to train officers in identifying and de-escalating mental health crises. Many have also established links with mental health professionals who can provide timely on-site assistance. These efforts have required police and health care professionals to connect across traditional bureaucratic boundaries.
- 8. Individuals in a self-defined crisis are not turned away.** People who seek crisis services but do not meet the service criteria of an organization should receive meaningful guidance and assistance in accessing alternative resources. This is particularly applicable in organizations or programs that carry out a screening or gatekeeping function. For instance, it is not sufficient, upon determining that an individual fails to meet the criteria for hospitalization, to tell the individual or family members to make contact again if the situation worsens. Such practices tacitly encourage the escalation of crises. Individuals and their families should be assisted in accessing services and supports that resolve issues early on, and an organization providing screening or gatekeeping services should be fluent with alternatives for when service thresholds are not met. When these alternatives are lacking, the organization should consider this a problem in care and take action accordingly. Likewise, an organization providing early intervention that routinely receives referrals from hospital gatekeepers might consider improving its outreach so that individuals seeking help are more likely to access their services directly, without placing demands on programs designed for late-stage emergencies.
- 9. Interveners have a comprehensive understanding of the crisis.** Meaningful crisis response requires a thorough understanding of the issues at play. Yet, for people with serious mental illnesses, interventions are commonly based on a superficial set of facts: behaviors are seen to present a safety issue, the individual has reportedly failed to take medications as prescribed, or an encounter with the police has occurred. An appropriate understanding of the emergency situation not only includes an appreciation for what is happening at the moment, but also *why* it is happening and how an individual fares when he or she is *not* in crisis. Crises—particularly recurrent crises—likely signal a failure to address underlying issues appropriately. When crisis intervention occurs outside of the individual's customary setting, such as in a hospital emergency department or a psychiatric inpatient unit, it may be challenging to gain a good picture of the individual's circumstances.

### An Alternative Approach

"The Hospital Diversion Program at the ROSE HOUSE is currently available to residents of Orange and Ulster counties [New York State]. This peer-operated house is designed to assist fellow peers in diverting from psychiatric distress, which may lead to a hospitalization. The program is located in a three-bedroom home set up and furnished for comfort. The house is equipped with a variety of traditional self-help and proactive tools to maintain wellness. Trained peer companions are the key ingredients in helping others learn self-help tools. Peer companions are compassionate, understanding and empowering. We exist to fill a gap in the mental health system that can brake the cycle of going from home to crisis to hospital.

The ROSE HOUSE offers a stay of up to five days to take control of your crisis or potential crisis and develop new skills to maintain your wellness. Peer companions staff the house 24 hours a day to address the needs of guests as they arise. Participation in the program is completely voluntary and free of charge. You are free to come and go as you please. We also will maintain contact and support for you, at your request, after you finish your stay. We have found that occasional calls and visits reinforce recovery and self determination."

From the website of Projects to Empower and Organize the Psychiatrically Labeled (PEOPLE, Inc.) at: <http://www.projectspeople.org>

Mobile outreach services, which have the capacity to evaluate and intervene within the individual's natural environment, have inherent advantages over facility-based crisis intervention, especially when an individual who has personal experience with mental illness and mental health crises is a part of the intervention team. Such mobile outreach capacity is even more meaningful when it is not restricted to a special crisis team, but rather when staff and peers familiar with the individual have the ability to literally meet the individual where he or she is. When intervention within an individual's normal living environment is not feasible, hospitalization is not the inevitable alternative; for many individuals facing civil commitment, consumer-managed crisis residential programs can represent a viable, more normalized alternative that produces good outcomes.<sup>46</sup>

**National Resource Center on Psychiatric Advance Directives**

Psychiatric advance directives (PADs) are relatively new legal instruments that may be used to document a competent person's specific instructions or preferences regarding future mental health treatment, in preparation for the possibility that the person may lose capacity to give or withhold informed consent to treatment during acute episodes of psychiatric illness.

Almost all states permit some form of legal advance directive (AD) for healthcare, which can be used to direct at least some forms of psychiatric treatment. In the past decade, 25 states have adopted specific PAD statutes.

<http://www.nrc-pad.org>

10. **Helping the individual to regain a sense of control is a priority.** Regaining a sense of control over thoughts, feelings and events that seem to be spinning out of control may be paramount for an individual in mental health crisis. Staff interventions that occur without opportunities for the individual to understand what is happening and to make choices among options (including the choice to defer to staff) may reinforce feelings that control is being further wrested away. The individual's resistance to this may be inaccurately regarded as additional evidence of his or her incapacity to understand the crisis situation. Incorporating personal choice in a crisis response requires not only appropriate training, but also a setting with the flexibility to allow the exercise of options. Informed decision-making in this context is not a matter of simply apprising the individual of the empirically derived risks and benefits associated with various interventions; it also includes an understanding among staff that an ostensibly sub-optimal intervention that is of the individual's choosing may reinforce personal responsibility, capability and engagement and can ultimately produce better outcomes. The specific choices to be considered are not limited to the use of medications, but also include the individual's preferences for what other approaches are to be used where crisis assistance takes place, involving whom and with what specific goals. While the urgency of a situation may limit the options available, such limitations may also highlight how earlier interventions failed to expand opportunities to exercise personal control. Post-crisis recovery plans or advance directives developed by the individual with assistance from crisis experts are important vehicles for operationalizing this principle.
11. **Services are congruent with the culture, gender, race, age, sexual orientation, health literacy and communication needs of the individual being served.** Given the importance of understanding how an individual is experiencing a crisis and engaging that individual in the resolution process, being able to effectively connect with the individual is crucial. A host of variables reflecting the person's identity and means of communicating can impede meaningful engagement at a time when there may be some urgency. Establishing congruence requires more than linguistic proficiency or staff training in cultural sensitivity; it may require that to the extent feasible, an individual be afforded a choice among staff providing crisis services.



**12. Rights are respected.** An individual who is in crisis is also in a state of heightened vulnerability. It is imperative that those responding to the crisis be versed in the individual's rights, among them: the right to confidentiality, the right to legal counsel, the right to be free from unwarranted seclusion or restraint, the right to leave, the right for a minor to receive services without parental notification, the right to have one's advance directive considered, the right to speak with an ombudsman and the right to make informed decisions about medication. It is critical that appropriately trained advocates be available to provide needed assistance. Correctly or not, many individuals with serious mental illnesses have come to regard mental health crisis interventions as episodes where they have no voice and their rights are trampled or ignored. Meaningfully enacting values of shared responsibility and recovery requires that the individual have a clear understanding of his or her rights and access to the services of an advocate. It is also critical that crisis responders not convey the impression that an individual's exercise of rights is a hostile or defiant act.

**13. Services are trauma-informed.** Adults, children and older adults with serious mental or emotional problems often have histories of victimization, abuse and neglect, or significant traumatic experiences. Their past trauma may be in some ways similar to the mental health crisis being addressed. It is essential that crisis responses evaluate an individual's trauma history and the person's status with respect to recovery from those experiences. Similarly, it is critical to understand how the individual's response within the current crisis may reflect past traumatic reactions and what interventions may pose particular risks to that individual based on that history. Because of the nature of trauma, appropriately evaluating an individual requires far more sensitivity and expertise than simply asking a series of blunt, potentially embarrassing questions about abuse and checking off some boxes on a form. It requires establishing a safe atmosphere for the individual to discuss these issues and to explore their possible relationship to the crisis event.

**14. Recurring crises signal problems in assessment or care.** Many organizations providing crisis services—including emergency departments, psychiatric hospitals and police—are familiar with certain individuals who experience recurrent crises. They have come to be regarded as "high-end users." In some settings, processing these individuals through repeated admissions within relatively short periods of time becomes so routine that full reassessments are not conducted; rather, clinical evaluations simply refer back to assessments and interventions that were conducted in previous (unsuccessful) episodes of care. While staff sometimes assume that these scenarios reflect a patient's lack of understanding or willful failure to comply with treatment, recurrent crises are more appropriately regarded as a failure in the partnership to achieve the desired outcomes of care. And rather than reverting to expedient clinical evaluations and treatment planning that will likely repeat the failed outcomes of the past, recurrent crises should signal a need for a fresh and careful reappraisal of approaches, including engagement with the individual and his or her support network.

"Confounding and complicating the prevalence of trauma in public mental health service recipients is the fact that mental health services themselves are often experienced as traumatic. The use of coercive interventions such as seclusion and restraint, forced involuntary medication practices, and philosophies of care based on control and containment vs. empowerment and choice often cause unintentional re-traumatization in already vulnerable populations."

National Association of State Mental Health Program Directors (2002) NASMHPD Position Statement on Services and Supports to Trauma Survivors

“Most performance measurement efforts tend to operate in isolation from one another to meet the specific needs of their sponsors. Frequently, data collection efforts are particular to specific care settings—such as hospitals or ambulatory care organizations—or to particular payers, whether private or public... Since data are collected and used in fragmented ways, they rarely provide a picture of the overall quality of performance for a specific clinician or organization, or how well patients fare, or the state of the public’s health at large.”

Health Care at the Crossroads: Development of a National Performance Measurement Data Strategy. The Joint Commission, 2008, p. 8.

- 15. Meaningful measures are taken to reduce the likelihood of future emergencies.** Considering the deleterious impact of recurrent crises on the individual, interventions must focus on lowering the risk of future episodes. Crisis intervention must be more than another installment in an ongoing traumatic cycle. Meaningfully improving an individual’s prospects for success requires not only good crisis services and good discharge planning, but also an understanding that the crisis intervener—be it police, hospital emergency department, community mental health program, or protective service agency—is part of a much larger system. Performance-improvement activities that are confined to activities within the walls of a single facility or a specific program are sharply limited if they do not also identify external gaps in services and supports that caused an individual to come into crisis. Although addressing certain unmet needs may be beyond the purview of one facility or program, capturing and transmitting information about unmet needs to entities that have responsibility and authority (e.g., state mental health programs, housing authorities, foster care and school systems) is an essential component of crisis services.

### III. INFRASTRUCTURE

An organization's infrastructure should support interventions consistent with the values and principles listed above. Given the nature of crises affecting individuals with serious mental or emotional problems, these values and principles are applicable to a very broad array of organizations—hospital emergency departments, psychiatric programs, foster care, education, police, schools, and courts. While needed infrastructure will necessarily vary by setting, population served and the acuteness of crises being addressed, there are some important common denominators:

- **Staff that is appropriately trained and that has demonstrated competence** in understanding the population of individuals served, including not only a clinical perspective, but also their lived experiences.
- **Staff and staff leadership that understands, accepts and promotes the concepts of recovery and resilience**, the value of consumer partnerships and consumer choice, and the balance between protection from harm and personal dignity.
- **Staff that has timely access to critical information**, such as an individual's health history, psychiatric advance directive or crisis plan. Such access is, in part, reliant on effective systems for the retrieval of records, whether paper or electronic.
- **Staff that is afforded the flexibility and the resources**, including the resource of time, to establish truly individualized person-centered plans to address the immediate crisis and beyond.
- **Staff that is empowered to work in partnership with individuals being served** and that is encouraged, with appropriate organizational oversight, to craft and implement novel solutions.
- **An organizational culture that does not isolate its programs or its staff** from its surrounding community and from the community of individuals being served. This means that the organization does not limit its focus to "specific" patient-level interventions, but also positions itself to play a meaningful role in promoting "indicated" strategies for the high-risk population it serves and "universal" strategies that target prevention within the general population. The intent here is not to dissipate the resources or dilute the focus of an organization, but to assure recognition that its services are a part of a larger spectrum and that it actively contributes to and benefits from overall system refinements.
- **Coordination and collaboration with outside entities** that serve as sources of referrals and to which the organization may make referrals. Such engagement should not be limited to service providers within formal networks, but should also include natural networks of support relevant to the individuals being served.
- **Rigorous performance-improvement programs** that use data meaningfully to refine individuals' crisis care and improve program outcomes. Performance improvement programs should also be used to identify and address risk factors or unmet needs that have an impact on referrals to the organization and the vulnerability to continuing crises of individuals served.



## IV. MAKING IT HAPPEN

The need for major improvements in crisis services for adults, children and older adults with serious mental or emotional problems is obvious. The statistics presented in the introduction to these guidelines make a clear case that people with mental illnesses are vulnerable to repeated clinical and life crises that can have deleterious effects on the individual, families and social networks, and communities. Many interventions could have a significant, positive impact on the frequency and severity of mental health crises, but they are not readily available to most of the individuals who need them.<sup>17</sup>

Properly applied, these guidelines should work to improve the quality of services for people who are in or are vulnerable to mental health crises. Embedded in the guidelines is the notion that crisis services should not exist in isolation; crises are a part of an individual's life experiences and the assistance provided during crisis periods is part of a larger set of services and supports provided to the individual. While the values, principles and infrastructure recommendations presented here focus on crises affecting people with serious mental illnesses, they also have wider application; they reflect generally accepted approaches to working with individuals who have mental or emotional problems, whether or not they are in crisis. Stated differently, these guidelines challenge any disjuncture between responses to mental health crises and routine mental healthcare. They demonstrate how appropriate emergency mental health responses should affirm the principles of recovery and resilience that are the benchmarks for appropriate mental healthcare even though crisis scenarios may test the application of these values.

From a practice standpoint, these guidelines may be most effectively enacted when they are embedded in the various quality-control and performance-improvement mechanisms that operate within an organization. When appropriately conducted, quality control and performance-improvement processes should be data-driven and attuned to demonstrating not only what segments of the service population are prone to mental health crises, but also what factors underlie their vulnerability. An adequate understanding of these factors requires much more than the "encounter" data now routinely collected by both healthcare organizations and police. Data collection should clearly reflect the premise that mental health crises represent problems in care (whether individual or systemic) and should facilitate the root-cause analyses that are required when significant problems in care occur. Similarly, data should be used as tools for identifying gaps, developing remedies and monitoring the impact of these remedies. Providers and provider organizations should have access to these data for purposes of ensuring the quality of care and the appropriate use of resources. To the extent that the causes of mental health crises extend beyond the domains of an emergency department, a hospital, a mental health system, a police department, and/or a housing authority, data without personal identifiers should be routinely shared across systems. Entities having oversight responsibility should ensure that these performance-improvement activities are being carried out and that opportunities exist for cross-agency/cross-system analysis of information and the implementation of strategies to reduce mental health crises. And the partnerships between providers and consumers that are appropriate in the context of individual crises should be mirrored at the performance-improvement level.

In addition to the human case for improving crisis services, a strong business case can be made and data should be collected accordingly. Current approaches to crisis services needlessly perpetuate reliance on expensive, late-stage interventions (such as hospital emergency departments) and on settings that have inherent risks for harm for people with mental health needs (for instance, jails and juvenile justice facilities). Resources and personnel that might otherwise be available for more effective, less risky and less expensive interventions are now channeled into these costly and suboptimal settings. The factors that sustain late-stage crisis interventions may be linked to reimbursement practices and political considerations, yet in some ways the service system is itself complicit. Performance-improvement data derived from on-the-ground case experience can paint a compelling story of how “the right services at the right time” would look for individuals who are currently at high risk for future crises. These data can also set the stage for concrete discussions of the costs and the benefits of changes in policies governing the provision and funding of services and supports.

In short, the approach to crisis services must be forward-looking rather than merely reactive, with success seen as the ability of the individual served to return to a stable life in the community. Rather than leading merely to an increase in the number of beds available for mental health care, it must have as its goal a reduction in the number of crises among people with mental illnesses and therefore a reduced need for emergency services.

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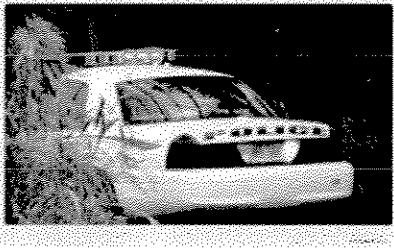






## Maui Police to Launch New Crisis Intervention Team

Updated 11:01 AM HST, January 14, 2013  
Posted 09:31 AM HST, January 14, 2013



Maui police, file photo by Wendy Osher.

By Wendy Osher

The Maui Police Department will launch a new Crisis Intervention Team Program this week, the first of its kind in the state, according to department officials.

Lieutenant Wayne K. Ibarra with the Maui Police Department's Community Relations Section said the team will consist of three sergeants, 15 police officers, one supervising emergency services dispatcher, and one police chaplain.

The inaugural class will graduate during a ceremony on Friday afternoon, Jan. 18, 2013.

Members of the Crisis Intervention Team received part of their training from Dr. Dara Rampersad, forensic coordinator, of the Maui Community Health Center.

According to Lt. Ibarra, the CIT will handle incidents involving the mentally ill and those in crisis with care and expertise, ensuring that such individuals receive a response which is appropriate to the needs of the person involved.

"They are trained to interact with persons who are mentally ill, or are in an emotional crisis, and to de-escalate crisis events and move them away from violent outcomes whenever possible," said Lt. Ibarra.

"Our dedication and compassion for our people of this community will always be a priority which gives us the strength and courage to carry out our mission statement and leaving a legacy for the future generation," said Lt. Ibarra.



## Third Class Trained as Part of Maui Crisis Intervention Team

Posted 01:55 PM HST, April 3, 2014



2nd Class – MPD Crisis Intervention Team, 8/9/13. Photo courtesy Dr. Dara Rampersad, forensic coordinator of the Maui Community Health Center, who served as a trainer for the program.

By Wendy Osher

The Maui Police Department's Crisis Intervention Team will add new members to its list of trained personnel with a third class to undergo training April 11-17, 2014.

The program was the first-of-its-kind in the state when it launched with an inaugural class in January of last year.

Since then, an additional 19 members joined the team in August of 2013, bringing to 34 the number of patrol officers on the road with specialized training in mental health.

The team, trained under the guidance of Maui County Forensic Coordinator Dr. Dara Rampersad, utilizes community partnerships to better respond to critical incidents involving individuals with mental illness.

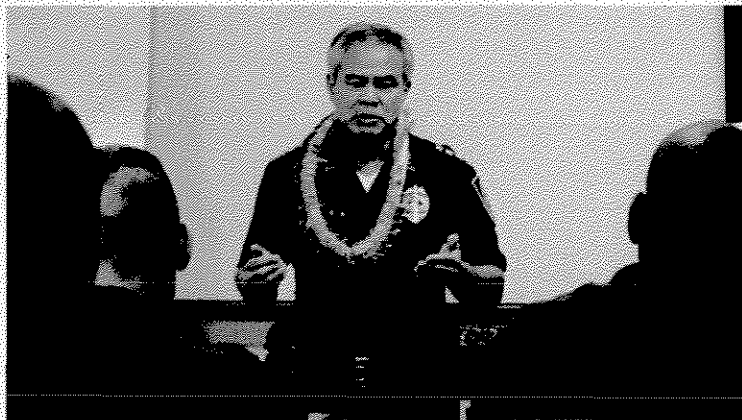


Officials with the Maui Police Department say the CIT handles incidents involving the mentally ill and those in crisis with care and expertise, ensuring that such individuals receive a response which is appropriate to the needs of the person involved.

Police say the hands-on training addresses response to mental health issues, identification, assistance, referral and follow up.

In addition to police and dispatchers from the Maui Police Department, participants also include personnel from the Honolulu Police Department, Hawai'i Police Department, Sheriff's Office, Maui Fire Department, Maui Memorial Medical Center security staff, and the Maui Prosecutor's Office.

\*\*\*Maui Now file video from inaugural CIT graduation in Jan. 2013.



Maui Police Chief Gary Yabuta addresses graduates during a ceremony recognizing members of the department's new Crisis Intervention Team. File photo by Wendy Osher, Aug. 2013.

## Top Story

# Saving Lives, Changing Communities

*By Laura Usher, NAMI CIT Program Manager*

In 1986, when Ann Dino's injured son Bubba was transported to the hospital in a police car because he had a mental illness and the ambulance wouldn't take him, she knew things had to change. Dino, then the president of NAMI Memphis, turned to her good friend and fellow NAMI Memphis member at the time, Helen Adamo. Adamo recalls meeting with the mayor and asking him, "How would you like to read the headline tomorrow, 'Mentally Ill Man Bleeds Out in the Back of a Squad Car'?"



Dino and Adamo were no strangers to calling the police for help when their sons, both living with serious mental illness, were in crisis. Adamo says, "The first time I called the police for my son, they came in with their hands on their guns and their billy clubs and they didn't know what to do."

Adamo wrote a proposal for the mayor and city council, asking them to support training for police officers in responding to people with mental illness. Her proposal was based on a team created by the Los Angeles police and focused on the need to reduce injuries of police officers in responding to mental health crisis calls. While some officials were sympathetic, it was a slow going; they pushed the issue for about a year and a half.

Then, in September 1987, Joseph Robinson was shot and killed by Memphis police.



Robinson's mother had called the police because he was hurting himself in the midst of a mental health crisis. Robinson was African American and outrage over the shooting rocked the community.

While community members were calling for the police chief's resignation, Dino and Adamo looked for a different solution. They approached the mayor with the plan for police mental health training. While speaking at a city council meeting, Dino recalls the crowd pressing against her back. "The police had to escort us out."

After Robinson's shooting, things moved quickly. The police chief appointed then-Lt. Walter Crews to head a community taskforce to come up with a response. The taskforce included Dino and Adamo from NAMI Memphis, the heads of the local mental health institutes and the Med, the Regional Medical Center at Memphis. In addition, private mental health providers clamored to be involved in the program. Dino credits Crews' diplomacy with getting all the players working together.

The taskforce called the new program a crisis intervention team (CIT) and it was built around the partnerships developed through the taskforce. Police training was vital to program's success, but what made it unique were the personal interactions between individuals with mental illness, their families, mental health professionals and police. Dino says those interactions helped change the way the whole crisis response system worked. "When the officers went to the consumer drop in center and saw consumers who were not in a crisis, saw that they were a real person, that was a tremendous help. Then the professionals rode in the car with officers on involuntary commitment calls... It was an education for everybody. This is what made it work, for everyone to see everything, experience the whole thing."

After the first CIT training in 1988, Crews handed the reins of the program to Lt. Sam Cochran. Dino recalls being nervous that the program would be handed off to a new person but, she says, "Sam took it into his heart and soul."

Twenty-five years later, the Memphis CIT program has had remarkable success – cutting injuries to police officers, developing a crisis assessment system for people with mental illness, reducing arrests and improving community relations. Its success has inspired 2,800 communities in 45 states across the country to start CIT programs (/cit).

Adamo says that it makes all the difference in the world. Years ago, her family moved to a small town outside of Memphis, and when she had to call police recently, "I asked the officer at the police department, have you had crisis intervention training and he had... It was all the difference in the world. When they come, they know what to do."

# CIT

## Crisis Intervention Teams (CIT)

Home (<http://www.nami.org/template.cfm?section=CIT2>)

Getting Started (<http://www.nami.org/Template.cfm?>

Section=CIT&Template=/ContentManagement/ContentDisplay.cfm&ContentID=15024

FAQs (<http://www.nami.org/Template.cfm?>

Section=CIT&Template=/ContentManagement/ContentDisplay.cfm&ContentID=15050

CIT for Youth ([http://www.nami.org/template.cfm?section=CIT\\_for\\_Youth](http://www.nami.org/template.cfm?section=CIT_for_Youth))

Find a CIT Program (<http://cit.memphis.edu/CitMap/>)

## About Us

The mission of the NAMI CIT Center is to promote the expansion of crisis intervention teams (CIT) nationwide. We provide NAMI Affiliates and State Organizations, local law enforcement, mental health providers and other community leaders with assistance and up-to-date information about implementing CIT programs. We also engage in national networking and partnerships to establish standards and promote innovation in the CIT movement.

For more information, or to sign up for our mailing list, email Laura Usher at [laurau@nami.org](mailto:laurau@nami.org) (<mailto:laurau@nami.org>)

. To subscribe on our e-newsletter, *CIT in Action*, go to [www.nami.org/subscribe](http://www.nami.org/subscribe) ([.././subscribe](http://www.nami.org/subscribe))

and follow the instructions to subscribe to a newsletter.

April 21, 2015

Guam Statewide Independent Living Council  
c/o Division of Vocational Rehabilitation, DISID  
238 AFC Flores ST., 6<sup>th</sup> Floor  
Hagatna, Gu 96910

Mrs. Rosanne S. Ada  
Executive Director  
Guam Developmental Disabilities Council  
130 University Drive Suite 17, Mangilao, Guam 96913

Dear Mrs. Ada,

At the last meeting of the Guam Statewide Independent Council, your written testimony in response to Bill No. 70-33 (COR) was presented during Council consultation about this bill. The Council brings to your attention, as well as to the attention of the sponsors of the bill, facts regarding the Guam Statewide Independent Council that were incorrectly stated in your written testimony.

The Rehabilitation Act of 1992 federally mandated the establishment of a Statewide Independent Living Council, which is a non-profit, Governor appointed council, whose mandate is the development and implementation of a state plan that addresses independent living for individuals with disabilities. We are **not specifically** mandated to establish a registry of individuals with disabilities; however, our plan **does provide for the collaboration** with other organizations and agencies to establish a single comprehensive registry with

subcategories that meet the needs of the various agencies and disability groups. The goal activity description for this plan is *"The SILC and DVR will support and conduct outreach activities through website postings, participation in Fairs and other promotional activities."*

As to the establishment of a website, the Council is consulting as to the most effective and efficient way to use our funding to make use of the internet for our needs.

I'm attaching a copy of our plan so you can become better informed of the activities we are striving to implement. You are always welcome to attend the meetings and contribute during the portion to be designated for public input, or if GDDC wishes, to formally request to meet with us on a particular issue. The Council would be happy to do so. We look forward to collaborating on common goals such as this with the Guam Developmental Disabilities Council.

Respectfully,

Carol Darlow

Chairperson



GOVERNMENT OF GUAHAN



GUAM DEVELOPMENTAL DISABILITIES COUNCIL
Konsehelon Guahan para i Taotao ni' Maninutet desde ki Manhoben
130 University Drive Suite 17, Mangilao, Guam 96913

Guam Developmental Disabilities Council

EDDIE B. CALVO
Governor

ROSANNE S. ADA
Executive Director

RAYMOND TENORIO
Lieutenant Governor

ERLINDA TYDINGCO
Chairperson

April 23, 2015

Mrs. Carol Darlow, Chairperson
Guam Statewide Independent Living Council
c/o DISID Division of Vocational Rehabilitation
238 Archbishop Felixberto Flores., Suite 6
Hagatna, GU 96910

Dear Mrs. Darlow,
Thank you for your letter of April 21 which you had personally delivered to my Office on April 22, 2015 at 4:30pm.

Although your Council is "not specifically mandated" to establish a registry of individuals with disabilities, the State Plan for Independent Living (SPIL) for Guam for 2014-2016, page 7 did state as its "Goal Name: Establish a Comprehensive Registry for Persons with Disabilities."

On page 8 The Objective to be achieved is stated:
"The Guam Statewide Independent Living Council (SILC) will collaborate with organizations and agencies to include the Division of Vocational Rehabilitation for the utilization of a single comprehensive registry with subcategories that meet the needs of the various agencies and disability groups."


The Guam State Plan for Independent Living is an approved, and official document for which DISID/DVR has assured the federal government that the goals, objectives, and activities shall be implemented. I interpret that as the obligation of the designated state agency, DISID/DVR, to monitor compliance to the State Plan.

I conclude that actions to implement the State Plan can be safely identified as a moral and civic responsibility of the Division of Vocational Rehabilitation, the designated state agency for SILC. The word, "mandate" may be strong, but it is still the responsibility of DVR to ensure compliance with the State Plan goals and objectives. Failure to comply is forgivable provided reasonable justification. The consequence may be to return federal funds and re-allot to the other states and territories.

Continued:
Letter to Carol Darlow

If you have any questions please call our Office.

Sincerely yours,

  
Rosanne S. Ada

Attachments (2)

Pg. 7 SPIL Section 1.1

Pg. 8, 1.2 Objectives

Cc

Senator B.J. Cruz

Senator N.B. Underwood

Senator R.J. Respicio

Benito Servino, Director DISID

2015-48

## Part II: Narrative: Section 1 - Goals, Objectives and Activities

### Section 1: Goals, Objectives and Activities

#### 1.1 Goals and Mission

Describe the overall goals and mission of the State's IL programs and services. The SPIL must address the goals and mission of both the SILS and the CIL programs, including those of the State agency for individuals who are blind as they relate to the parts of the SPIL administered by that agency.

Goal Name: Re-established the Guam Center for Independent Living (CIL)

Goal Description:

MISSION: The 2014-2016 Guam State Plan for Independent Living (SPIL) is to systematically promote and support self-determination, independence, and community integration of persons with disabilities living on Guam reflecting the diverse cultural and traditions on Guam:

GOAL 1 Description: The Guam SILC and DVR will promote the availability of the CIL application for Non-Profit Organization on Guam by disseminating information through web postings, public service announcements, etc. The Guam SILC will support the application of a qualified and established local Non-Profit Organization(s) to apply for the Centers for Independent Living grant upon announcement of grant availability by RSA.

Goal Name: Establish a Comprehensive Guam Registry for Persons with Disabilities:

Goal Description:

The SILC and DVR will support and conduct outreach activities through website postings, participation in Fairs and other promotional activities.

Goal Name: Promote and Support an independent living philosophy.

Goal Description:

The philosophy of independent living is underdeveloped within the Guam community in regards to the availability of supports.

Goal Name: Improve Data Collection and SPIL monitoring

Goal Description:

The SILC will collaborate with at least four disability related organizations to conduct a mid-year and annual year review and evaluation of SPIL goals and objectives during the grant period. DVR will also provide quarterly data reports to the SILC on services and activities relevant to the SPIL.

Goal Name: Ensure the SILC membership is fully constituted

Goal Description:

Semi-Annually the Guam CIL and DVR will submit names of individuals with disabilities to the SILC for nomination. Prior to the close of each grant year, the Guam SILC will ensure that the Council recruits members to meet the requirement of full participating membership and submit nominations, as required, to the Governor for appointment.

Goal Name: The SILC will be knowledgeable of Independent Living philosophy and services

Goal Description:

DVR and the Guam CIL will support the participation of annual training through on-line training (Smooth as SILC training), local conference relevant to the SILC, the annual SILC Congress, and the annual PacRim conference and on-island assistance/training.

Goal Name: The Guam SILC will be supported in the goals and objectives

Goal Description:

DVR will provide supports such as venue, part-time personnel, communications and other materials and activities as appropriate.

1.2 Objectives

1.2A. Specify the objectives to be achieved and the time frame for achieving them.

Goal(s) from Section 1:1	Objective to be achieved	Time frame start date	Time frame end date
Re-established the Guam Center for Independent Living (CIL)	A Guam Non-Profit organization will have submitted an application for the establishment of a local Center for Independent Living (CIL)	10/01/2014	09/30/2016
Establish a Comprehensive Guam Registry for Persons with Disabilities.	The SILC will collaborate with organizations and agencies to include DVR for the utilization of a single comprehensive registry with subcategories that meet the needs of the various agencies and disability groups	10/01/2014	09/30/2016
Promote and Support an independent living philosophy.	SILC will collaborate with the Division of Vocational Rehabilitation, a new Guam CIL, once established, the Department of Education, the Department of Public Health and Social Services, veteran organizations, and other disability groups to promote the IL philosophy and IL services	10/01/2014	09/30/2016





GOVERNMENT OF GUAHAN

GUAM DEVELOPMENTAL DISABILITIES COUNCIL  
*Konsehelon Guahan para i Taotao ni' Maninutet desde ki Manhoben*  
 130 University Drive Suite 17, Mangilao, Guam 96913



Guam Developmental  
 Disabilities Council

EDDIE B. CALVO  
 Governor

ROSANNE S. ADA  
 Executive Director

RAYMOND TENORIO  
 Lieutenant Governor

ERLINDA S. TYDINGCO  
 Chairperson

May 6, 2015

Senator Nerissa Bretania Underwood, Ph.D.  
 Chairperson, Committee on Early Learning, Juvenile Justice, Public Education,  
 And First Generation Initiative  
 33<sup>rd</sup> Guam Legislature  
 155 Hesler Place, Suite 104  
 Hagatña, Guam

Reference: Bill No. 70-33 (COR), An Act to Amend Section 41105 Chapter 41 of 17 GCA,  
 Relative to the Creation of a Registry for Individuals with Disabilities.

Dear Honorable Senator Underwood,

Relative to the aforementioned Bill No. 70-33, I am **opposed** to establishing a Registry for  
 Individuals with Disabilities and designating the Department of Integrated Services for  
 Individuals with Disabilities to facilitate and implement the Registry.

**My objections are as follows:**

1. Personal data or information that identifies a person is confidential in nature. Examples of personal data are telephone numbers, addresses, financial information, photographs, satellite images, car registrations, ID numbers, e-mail addresses, health records, etc.
2. Personal data collected should not be used to justify funding for a government agency. Data can be intrusive; it is a violation of the right to privacy, a violation of our civil liberties.
3. It is a human monitoring service.
4. Individuals on the registry can fall prey to evil elements.
5. Identify of individuals can be stolen.
6. Assets, bank accounts, credit cards can fall prey to thieves.
7. Data can be abused by attorneys to file suit against businesses and government agencies on behalf of individuals with disabilities.

Telephone No.: 1.671.735.9127 • 1.671.735.9128 \* Fax No.: 1.671.734.9121

Email: [guamddc@gddc.guam.gov](mailto:guamddc@gddc.guam.gov)

**Questions to ask yourself:**

1. Who will have access to the data?
2. Is the data secured?
3. How long will the data be stored?
4. How can we remove our data?
5. Will the listing be sold to another entity?

It would be wiser to establish a registry of services for individuals with disabilities similar to the Guam GetCare System which was federally funded by the Aging and Disability Resources Center for five years. In search of programs across the nation, there were benefits cited favoring the Registry of Services versus the Registry of Individuals with Disabilities.

**Benefits of Registry of Services for Individuals with Disabilities:**

1. Individuals with disabilities can get special benefits.
2. A certificate of impairment/disability can be obtained.
3. Accessible parking permit can be made available.
4. Individuals can get help and advice they may need.
5. You may be entitled to travel concessions/benefits.
6. You can access services quicker.

I thank you for the opportunity to submit my comments. If you have any questions, please do not hesitate to contact our office at 735-9129 or email me at [Rosanne.ada@gddc.guam.gov](mailto:Rosanne.ada@gddc.guam.gov).

Sincerely,

  
Rosanne S. Ada



# COMMITTEE ON RULES

*I Mina'trentai Tres na Liheslaturan Guåhan* • The 33rd Guam Legislature  
155 Hesler Place, Hagåtña, Guam 96910 • [www.guamlegislature.com](http://www.guamlegislature.com)  
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Senator  
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MAJORITY LEADER

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Thomas C. Ada  
VICE CHAIRPERSON  
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Senator  
Michael F.Q. San Nicolas  
Member

Senator  
Nerissa Bretania Underwood  
Member


V. Anthony Ada  
MINORITY LEADER

Mary C. Torres  
MINORITY MEMBER

April 16, 2015

## Memorandum

**To:** **Rennae Meno**  
*Clerk of the Legislature*

**From:** **Senator Rory J. Respicio**   
*Majority Leader & Rules Chair*

**Subject:** **Fiscal Notes**

*Hafa Adai!*

Attached please find the fiscal notes for the bill numbers listed below. Please note that the fiscal notes are issued on the bills as introduced.

### FISCAL NOTES:

- Bill No. 56-33(COR)
- Bill No. 66-33(COR)
- Bill No. 70-33(COR)
- Bill No. 74-33(COR)

Please forward the same to MIS for posting on our website. Please contact our office should you have any questions regarding this matter.

*Si Yu'os ma'åse'!*

2015 APR 16 PM 11:04  


**Bureau of Budget & Management Research  
Fiscal Note of Bill No. 70-33 (COR)**

**AN ACT TO AMEND SECTION 41105 OF CHAPTER 41, ARTICLE 1 OF 17 GUAM CODE ANNOTATED, RELATIVE TO THE CREATION OF A REGISTRY FOR INDIVIDUALS WITH DISABILITIES.**

Department/Agency Appropriation Information	
Dept./Agency Affected: Integrated Services for Individuals with Disabilities	Dept./Agency Head: Benito Servino, Director
Department's General Fund (GF) appropriation(s) to date:	1,245,705
Department's Other Fund (Specify) appropriation(s) to date:	
<b>Total Department/Agency Appropriation(s) to date:</b>	<b>\$1,245,705</b>

Fund Source Information of Proposed Appropriation			
	General Fund:	(Specify Special Fund):	Total:
FY 2014 Unreserved Fund Balance		\$0	\$0
FY 2015 Adopted Revenues	\$648,044,542	\$0	\$648,044,542
FY 2015 Appro. (P.L. 32-181 thru 32-233)	(\$648,094,811)	\$0	(\$648,094,811)
Sub-total:	(\$50,269)	\$0	(\$50,269)
Less appropriation in Bill	(\$150,000)	\$0	(\$150,000)
<b>Total:</b>	<b>(\$200,269)</b>	<b>\$0</b>	<b>(\$200,269)</b>

Estimated Fiscal Impact of Bill						
	One Full Fiscal Year	For Remainder of FY 2015 (if applicable)	FY 2016	FY 2017	FY 2018	FY 2019
General Fund	\$0	\$150,000	\$83,000	\$83,000	\$83,000	\$83,000
(Specify Special Fund)	\$0	\$0	\$0	\$0	\$0	\$0
<b>Total</b>	<b>\$0</b>	<b>\$150,000</b>	<b>\$83,000</b>	<b>\$83,000</b>	<b>\$83,000</b>	<b>\$83,000</b>

- Does the bill contain "revenue generating" provisions? / / Yes /X/ No  
If Yes, see attachment
- Is amount appropriated adequate to fund the intent of the appropriation? / / N/A /X/ Yes / / No  
If no, what is the additional amount required? \$ / / N/A
- Does the Bill establish a new program/agency? /X/ Yes / / No  
If yes, will the program duplicate existing programs/agencies? / / N/A / / Yes /X/ No  
Is there a federal mandate to establish the program/agency? / / Yes /X/ No
- Will the enactment of this Bill require new physical facilities? / / Yes /X/ No
- Was Fiscal Note coordinated with the affected dept/agency? If no, indicate reason: /X/ Yes / / No  
/ / Requested agency comments not received by due date / / Other:

Analyst: William P. Takingsong Date: 4/15/15 Director: Jose S. Calvo Date: 4-15-15  
 William P. Takingsong, BMA Supvr. Jose S. Calvo, Acting Director

Comments:  
 Per DISID, funding requirements for subsequent years to maintain the registry is estimated at a cost of \$83,000 annually to continue the program staff, multi-media marketing outreach, printing costs, training and maintenance.



## COMMITTEE ON RULES

*I Mina'trentai Tres na Liheslaturan Guåhan* • The 33rd Guam Legislature

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Senator

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Member

V. Anthony Ada

MINORITY LEADER

Mary C. Torres

MINORITY MEMBER

April 8, 2015

VIA E-MAIL

[joey.calvo@bbmr.guam.gov](mailto:joey.calvo@bbmr.guam.gov)

Jose S. Calvo

Acting Director

Bureau of Budget & Management Research

P.O. Box 2950

Hagåtña, Guam 96910

RE: Request for Fiscal Notes– Bill Nos. 69-33(COR) through 74-33(COR)

*Hafa Adai* Mr. Calvo:

Transmitted herewith is a listing of *I Mina'trentai Tres Na Liheslaturan Guåhan's* most recently introduced bills. Pursuant to 2 GCA §9103, I respectfully request the preparation of fiscal notes for the referenced bills.

*Si Yu'os ma'åse'* for your attention to this matter.

Very Truly Yours,

**Senator Rory J. Respicio**

*Chairperson of the Committee on Rules*

Attachment (1)

Cc: Clerk of the Legislature

Bill Nos.	Sponsor	Title
<b>69-33 (COR)</b>	Rory J. Respicio N.B. Underwood, Ph.D.	AN ACT TO AMEND §715 ITEM 12 SUBSECTION (m) OF CHAPTER 7 TITLE 1, GUAM CODE ANNOTATED RELATIVE TO THE GUAM PUBLIC SCHOOL SYSTEM'S USE OF EASTER AND CHRISTMAS BREAKS AS MAKE-UP DAYS IN THE SCHOOL CALENDAR.
<b>70-33 (COR)</b>	N.B. Underwood, Ph.D. Rory J. Respicio	AN ACT TO AMEND SECTION 41105 OF CHAPTER 41, ARTICLE 1 OF 17 GUAM CODE ANNOTATED, RELATIVE TO THE CREATION OF A REGISTRY FOR INDIVIDUALS WITH DISABILITIES.
<b>71-33 (COR)</b>	FRANK B. AGUON, JR.	AN ACT TO REQUIRE THE GOVERNMENT OF GUAM TO CONDUCT A HEALTH ASSESSMENT OF ALL PEACE OFFICERS PRIOR TO THE IMPLEMENTATION OF PUBLIC LAW 32-232, RELATIVE TO THE PEACE OFFICER STANDARDS AND TRAINING (POST) PHYSICAL FITNESS QUALIFICATION TEST (PFQT).
<b>72-33 (COR)</b>	D. G. Rodriguez, Jr.	AN ACT TO AMEND SECTION 9(c) OF PUBLIC LAW 32-054, RELATIVE TO REQUIRING THAT THE NATIONAL CLINICAL MENTAL HEALTH COUNSELOR EXAM IS THE SOLE REQUISITE EXAM FOR LICENSURE FOR LICENSED MENTAL HEALTH COUNSELOR.
<b>73-33 (COR)</b>	Tommy A. Morrison F. B. Aguon, Jr. F. F. Blas, Jr.	AN ACT TO STRENGTHEN PUBLIC SAFETY EFFORTS THROUGH THE INTEGRATION OF SURVEILLANCE CAMERAS WITHIN GUAM'S EMERGENCY REPORTING SYSTEM, BY AMENDING SECTION 12304 OF ARTICLE 3, CHAPTER 12, TITLE 12, GUAM CODE ANNOTATED.
<b>74-33 (COR)</b>	B. I.F. Cruz	AN ACT TO AMEND SECTION 13, CHAPTER XII OF PUBLIC LAW 32-181; RELATIVE TO ENHANCING FISCAL DISCIPLINE AND EFFICIENCY BY AUTHORIZING THE EXPENDITURE OF FISCAL YEAR 2015 CONTINUING APPROPRIATIONS SUBJECT TO SPECIFIC REQUIREMENTS.



# COMMITTEE ON RULES

*I Mina'trentai Tres Na Liheslaturan Guåhan* • The 33rd Guam Legislature

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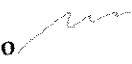
Mary C. Torres  
MINORITY MEMBER

April 6, 2015

## MEMORANDUM

**To:** **Rennae Meno**  
*Clerk of the Legislature*

**Attorney Therese M. Terlaje**  
*Legislative Legal Counsel*

**From:** **Senator Rory J. Respicio**   
*Chairperson, Committee on Rules*

**Subject:** **Referral of Bill No. 70-33(COR)**

As the Chairperson of the Committee on Rules, I am forwarding my referral of **Bill No. 70-33(COR)**.

Please ensure that the subject bill is referred, in my name, to the respective committee, as shown on the attachment. I also request that the same be forwarded to all members of *I Mina'trentai Tres Na Liheslaturan Guåhan*.

Should you have any questions, please feel free to contact our office at 472-7679.

*Si Yu'os Ma'åse!*

Attachment

*I Mina'Trentai Tres Na Liheslaturan Received*  
**Bill Log Sheet**

BILL NO.	SPONSOR	TITLE	DATE INTRODUCED	DATE REFERRED	CMTE REFERRED	PUBLIC HEARING DATE	DATE COMMITTEE REPORT FILED	FISCAL NOTES
70-33 (COR)	N.B. Underwood, Ph.D. Rory J. Respicio	AN ACT TO AMEND SECTION 41105 OF CHAPTER 41, ARTICLE 1 OF 17 GUAM CODE ANNOTATED, RELATIVE TO THE CREATION OF A REGISTRY FOR INDIVIDUALS WITH DISABILITIES.	04/03/15 3:01 p.m.	04/06/15	Committee on Appropriations and Adjudication			





Benjamin J.F. Cruz &lt;senator@senatorbjcruz.com&gt;

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## FIRST NOTICE of Public Hearing – April 16, 2015

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Dani Reyes &lt;danireyes@senatorbjcruz.com&gt;

Thu, Apr 9, 2015 at 11:10 AM

To: PH Notice &lt;phnotice@guamlegislature.org&gt;

Cc: "Senator Rory J. Respicio" &lt;cor@guamlegislature.org&gt;, "Sergeant-at-Arms (Legislature)"

&lt;sgtarms@guamlegislature.org&gt;, Management Information System &lt;mis@guamlegislature.org&gt;, Clerks

&lt;clerks@guamlegislature.org&gt;

**Please see attached the CORRECTED first notices. Please note that the fourth item on the agenda should read as Bill 74-33.**

April 9, 2015

**MEMORANDUM**

To: All Members / All Senators

From: Vice Speaker Benjamin J.F. Cruz, Chairman

Re: **FIRST NOTICE of Public Hearing – April 16, 2015**

*Håfa Adai!* The **Committee on Appropriations and Adjudication** will conduct a Public Hearing of Bills beginning at **10:00AM** on **Thursday, April 16, 2015**, in the ***Liheslatura* Public Hearing Room** with the following schedule:

**10:00AM - Public Hearing of Bills**

- **Bill No. 56-33 (COR)** – F.B. Aguon, Jr. – “An act to amend §2101.1(f) and §2101.3 of Chapter 2, Title 5 of the Guam Code Annotated relative to recognizing the independence of the Judiciary of Guam relative to the receipt of Federal funds.”
- **Bill No. 66-33 (COR)** – B.J.F. Cruz – “An act to amend Section 2(II)(AF) of Chapter I and Section 1 of Part I, Chapter II of Public Law 32-181; to add a new Section 17 to Part I, Chapter II of Public Law 32-181; and to amend Section 22425(q) of Chapter 22, Title 5 of the Guam Code Annotated; relative to appropriating start-up funds from the Territorial Educational Facilities Fund for the Guam Department of Education (GDOE) early childhood education program/pre-kindergarten program and to provide additional funds to the GDOE for its operations as a result of the enactment of Public Law 32-219.”
- **Bill No. 70-33 (COR)** – N.B. Underwood, Ph.D. / R.J. Respicio – “An act to Amend Section 41105 of Chapter 41, Article 1 of 17 Guam Code Annotated, Relative to the registry for Individuals with Disabilities.”
- **Bill No. 74-33 (COR)** – B.J.F. Cruz – “An act to amend Section 13, Chapter XII of Public Law 32-181; relative to enhancing fiscal discipline and efficiency by authorizing the expenditure of fiscal year 2015 continuing appropriations subject to specific requirements.”

*(The links provided above, as shown in the boldfaced and underlined text, direct to the respective PDF documents posted on the Guam Legislature website. For direct access, go to <http://www.guamlegislature.org>; bills are found under Bills > Introduced > 33rd).*

Testimonies may be submitted via hand delivery to the Office of Vice Speaker Benjamin J.F. Cruz at the Guam Legislature; via postal mail to 155 Hesler Street, Hagåtña Guam 96910; via facsimile to 477-2522; or via e-mail to senator@senatorbjcruz.com. Please submit testimonies at least one day prior to the date of the hearing.

All government activities, programs, and services are accessible for people with disabilities in compliance with Title II of the Americans with Disabilities Act (ADA). Should you or interested parties require assistance or special accommodations to fully participate in this public hearing, please contact Mr. Carlo J. Branch at the Office of the Vice Speaker at 477-2521 or via e-mail at [carlo.branch@senatorbjcruz.com](mailto:carlo.branch@senatorbjcruz.com).

We look forward to your attendance and participation.

cc: COR  
Sgt-at-Arms  
MIS  
Clerks  
Media

—  
**Dani Reyes**  
*Policy Analyst*

**Vice Speaker Benjamin J.F. Cruz**  
*I Mina'trentai Tres na Liheslaturan Guåhan*  
T 671-477-2520 | F 671-477-2522  
<http://www.senatorbjcruz.com>

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**2 attachments**

 **FIRST NOTICE MEMO PH 04162015.pdf**  
901K

 **FIRST NOTICE PR PH 04162015.pdf**  
894K

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**VICE SPEAKER BENJAMIN J.F. CRUZ**

Committee on Appropriations and Adjudication  
senator@senatorbjcruz.com | www.senatorbjcruz.com



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**THE 33RD GUAM LEGISLATURE**

155 Hesler Place, Suite 107, Hagåtña, Guam 96910  
T: (671) 477-2520/1 | F: (671) 477-2522

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April 9, 2015

**MEMORANDUM**

To: All Members/ All Senators  
From: Vice Speaker Benjamin J.F. Cruz, Chairman

Re: **FIRST NOTICE of Public Hearing - April 16, 2015**

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*Håfa Adai!* The **Committee on Appropriations and Adjudication** will conduct a Public Hearing of Bills beginning at 10:00AM on **Thursday, April 16, 2015**, in the *I Liheslatura Public Hearing Room* with the following schedule:

**10:00AM**

- **Bill No. 56-33 (COR)** - F.B. Aguon, Jr. - "An act to *amend* §2101.1(f) and §2101.3 of Chapter 2, Title 5 of the Guam Code Annotated; relative to recognizing the independence of the Judiciary of Guam relative to the receipt of federal funds."
- **Bill No. 66-33 (COR)** - B.J. Cruz - "An act to *amend* Section 2(II)(AF) of Chapter 1 and Section 1 of Part I, Chapter II of Public Law 32-181; to *add a new* Section 17 to Part I, Chapter II of Public Law 32-181; and to *amend* Section 22425(q) of Chapter 22, Title 5 of the Guam Code Annotated; relative to appropriating start-up funds from the Territorial Educational Facilities Fund for the Guam Department of Education (GDOE) early childhood education program/pre-kindergarten program and to provide additional funds to the GDOE for its operations as a result of the enactment of Public Law 32-219."
- **Bill No. 70-33 (COR)** - N.B. Underwood, Ph.D. / R.J. Respicio - "An act to *amend* Section 41105 of Chapter 41, Article 1 of 17 Guam Code Annotated; relative to the registry for Individuals with Disabilities."
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Testimonies may be submitted via hand delivery to the Office of Vice Speaker Benjamin J.F. Cruz at the Guam Legislature; via postal mail to 155 Hesler Street, Hagåtña Guam 96910; via facsimile to 477-2522; or via e-mail to senator@senatorbjcruz.com. Please submit testimonies at least one day prior to the date of the hearing.

All government activities, programs, and services are accessible for people with disabilities in compliance with Title II of the Americans with Disabilities Act (ADA). Should you or interested parties require assistance or special accommodations to fully participate in this public hearing, please contact Mr. Carlo J. Branch at the Office of the Vice Speaker at 477-2521 or via e-mail at carlo.branch@senatorbjcruz.com.

We look forward to your attendance and participation.

---

VICE SPEAKER BENJAMIN J.F. CRUZ

Committee on Appropriations and Adjudication  
senator@senatorbjcruz.com | www.senatorbjcruz.com



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THE 33RD GUAM LEGISLATURE

155 Hesler Place, Suite 107, Hagåtña, Guam 96910

T: (671) 477-2520/1 | F: (671) 477-2522

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FOR IMMEDIATE RELEASE  
April 9, 2015

## FIRST NOTICE OF PUBLIC HEARING

In accordance with the Open Government Law, P.L. 24-109, relative to notice for public meetings, let this release serve as five (5) days' notice for a Public Hearing by the **Committee on Appropriations and Adjudication** scheduled on **Thursday, April 16, 2015**, in the Guam Legislature Hearing Room in Hagåtña, on the following:

### 10:00AM

- **Bill No. 56-33 (COR)** – F.B. Aguon, Jr. – “An act to *amend* §2101.1(f) and §2101.3 of Chapter 2, Title 5 of the Guam Code Annotated; relative to recognizing the independence of the Judiciary of Guam relative to the receipt of federal funds.”
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Individuals requiring assistance or special accommodations should contact Mr. Carlo J. Branch at the Office of the Vice Speaker at 477-2521, or by e-mail at carlo.branch@senatorbjcruz.com.

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Benjamin J.F. Cruz &lt;senator@senatorbjcruz.com&gt;

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## SECOND NOTICE of Public Hearing – April 16, 2015

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**Dani Reyes** <danireyes@senatorbjcruz.com>

Tue, Apr 14, 2015 at 9:30 AM

To: PH Notice <phnotice@guamlegislature.org>

Cc: Management Information System <mis@guamlegislature.org>, "Senator Rory J. Respicio"

<cor@guamlegislature.org>, "Sergeant-at-Arms (Legislature)" <sgtarms@guamlegislature.org>, Clerks

<clerks@guamlegislature.org>

April 14, 2015

### MEMORANDUM

To: All Members / All Senators

From: Vice Speaker Benjamin J.F. Cruz, Chairman

Re: **SECOND NOTICE of Public Hearing – April 16, 2015**

*Håfa Adai!* The **Committee on Appropriations and Adjudication** will conduct a Public Hearing of Bills at **10:00AM on Thursday, April 16, 2015**, in the **Liheslatura Public Hearing Room** with the following agenda:

#### **10:00AM - Public Hearing of Bills**

- **Bill No. 56-33 (COR)** – F.B. Aguon, Jr. – “An act to amend §2101.1(f) and §2101.3 of Chapter 2, Title 5 of the Guam Code Annotated; relative to recognizing the independence of the Judiciary of Guam relative to the receipt of federal funds.”
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We look forward to your attendance and participation.

cc: COR  
Sgt-at-Arms  
MIS  
Clerks  
Media

—

**Dani Reyes**  
*Policy Analyst*

**Vice Speaker Benjamin J.F. Cruz**  
*I Mina'trentai Tres na Liheslaturan Guåhan*  
T 671-477-2520 | F 671-477-2522  
<http://www.senatorbjcruz.com>

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**2 attachments**



**SECOND NOTICE PR PH 04162015.pdf**

895K



**SECOND NOTICE Memo PH 04162015.pdf**

901K

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**VICE SPEAKER BENJAMIN J.F. CRUZ**

Committee on Appropriations and Adjudication  
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April 14, 2015

**MEMORANDUM**

To: All Members/ All Senators  
From: Vice Speaker Benjamin J.F. Cruz, Chairman  
Re: **SECOND NOTICE of Public Hearing - April 16, 2015**

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*Håfa Adai!* The Committee on Appropriations and Adjudication will conduct a Public Hearing of Bills at 10:00AM on Thursday, April 16, 2015, in the *I Liheslatura Public Hearing Room* with the following agenda:

**10:00AM**

- **Bill No. 56-33 (COR)** – F.B. Aguon, Jr. – “An act to amend §2101.1(f) and §2101.3 of Chapter 2, Title 5 of the Guam Code Annotated; relative to recognizing the independence of the Judiciary of Guam relative to the receipt of federal funds.”
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We look forward to your attendance and participation.

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FOR IMMEDIATE RELEASE

April 14, 2015

## SECOND NOTICE OF PUBLIC HEARING

In accordance with the Open Government Law, P.L. 24-109, relative to notice for public meetings, let this release serve as forty-eight (48) hours' notice for a Public Hearing by the **Committee on Appropriations and Adjudication** scheduled on **Thursday, April 16, 2015**, in the Guam Legislature Hearing Room in Hagåtña, on the following:

### 10:00AM

- **Bill No. 56-33 (COR)** – F.B. Aguon, Jr. – “An act to *amend* §2101.1(f) and §2101.3 of Chapter 2, Title 5 of the Guam Code Annotated; relative to recognizing the independence of the Judiciary of Guam relative to the receipt of federal funds.”
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###



**Listserv: [phnotice@guamlegislature.org](mailto:phnotice@guamlegislature.org)**  
**Updated as of March 25, 2015**

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**Listserv: [phnotice@guamlegislature.org](mailto:phnotice@guamlegislature.org)**

Updated as of March 25, 2015

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**Listserv: [phnotice@guamlegislature.org](mailto:phnotice@guamlegislature.org)**  
Updated as of March 25, 2015

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**VICE SPEAKER BENJAMIN J.F. CRUZ**

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*I Mina'trentai Tres na Liheslaturan Guåhan*

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## **PUBLIC HEARING AGENDA**

Thursday, April 16, 2015

Guam Legislature Public Hearing Room • Hagåtña, Guam

**10:00AM**

### **PUBLIC HEARING OF BILLS**

**Bill No. 56-33 (COR)** - F.B. Aguon, Jr. - "An act to *amend* §2101.1(f) and §2101.3 of Chapter 2, Title 5 of the Guam Code Annotated; relative to recognizing the independence of the Judiciary of Guam relative to the receipt of federal funds."

**Bill No. 66-33 (COR)** - B.J. Cruz - "An act to *amend* Section 2(II)(AF) of Chapter I and Section 1 of Part I, Chapter II of Public Law 32-181; to *add a new* Section 17 to Part I, Chapter II of Public Law 32-181; and to *amend* Section 22425(q) of Chapter 22, Title 5 of the Guam Code Annotated; relative to appropriating start-up funds from the Territorial Educational Facilities Fund for the Guam Department of Education (GDOE) early childhood education program/pre-kindergarten program and to provide additional funds to the GDOE for its operations as a result of the enactment of Public Law 32-219."

**Bill No. 70-33 (COR)** - N.B. Underwood, Ph.D. / R.J. Respicio - "An act to *amend* Section 41105 of Chapter 41, Article 1 of 17 Guam Code Annotated; relative to the registry for Individuals with Disabilities."

**Bill No. 74-33 (COR)** - B.J. Cruz - "An act *amend* Section 13, Chapter XII of Public Law 32-181; relative to enhancing fiscal discipline and efficiency by authorizing the expenditure of Fiscal Year 2015 continuing appropriations subject to specific requirements."