DEVELOPMENTAL DISABILITIES LAW: CURRENT AND FUTURE

SUMMARY REPORT

GOVERNMENTAL AFFAIRS COMMITTEE

The National Association of Developmental Disabilities Counci 1234 Massachusetts Ave., N.W. Suite 813 Washington, D.C. 20005

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FOREWARD

To our knowledge, the methodology and findings described in this report constitute one of the first systematic examinations of opinions regarding current Developmental Disabilities legislation. To gain better insights into the perceptions regarding the legislation we have solicited opinions of the people who operate the program. In doing so, we have tapped the creative talents of many individuals whose knowledge has been invaluable to conceptualizing, operationalizing, measuring, and analyzing the scope of our effort.

Many individuals and organizations deserve acknowledgement for their contributions to the study. The authors extend appreciation to the National Association of Developmental Disabilities Councils' Governmental Affairs Committee for highlighting the need for and sponsoring this study; The Nebraska Developmental Disabilities Council for lending its Staff Director to implement and direct the study; the University of Nebraska at Omaha, College of Public Affairs and Community Service, Department of Gerontology, for assistance in research design, instrumentation, and computer assistance; the Nebraska Department of Health, Division of Health Data and Statistical Research, for assisting in the preparation of data; and to those Very patient typists who worked under great pressure to prepare the manuscript in the shortest of timelines Ms. Karen Johnson of the Nebraska Developmental Disabilities staff and Ms. Karen Forey of the UNO Gerontology staff.

Finally, our special thanks and appreciation to the 171 individuals in the developmental disabilities community who volunteered their time to respond to our questionnaire. Without their opinions, this legislative research could never have taken place on the substantive dimensions of a final report.

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THE DEVELOPMENTAL DISABILITIES LAW: CURRENT AND FUTURE

SUMMARY REPORT

INTRODUCTION AND OVERVIEW OF STUDY

The Developmental Disabilities Act, since its original passage in 1970, has undergone major revisions by amendment. These amendments have resulted in a major expansion and reorientation of the constituent disability groups served, a differentiation between the role of the Council and the state administrating agency, increased requirements on the targeting and utilization of funding, and transitions in the Council role.

The original law addressed three disabilities —mental retardation, cerebral palsy and epilepsy. The major role mandated for Councils through the Act incorporated that of planning comprehensive services for the constituent disability groups. The Act was permissive in the manner in which Councils utilized funds, provided that these funds filled identified and justifiable service gaps within a state or territory.

Public Law 94-103, passed in 1975, made significant changes in the program. Two new disability categories were added to the definition of developmental disabilities, autism and dyslexia (the latter being included if it was attributable to one of the other four disabilities). The amendments further established the role of the Council as a systemic advocate, having responsibilities for planning, influencing and advocating at the state level to insure an appropriate system of services for developmentally disabled individuals. A Bill of Rights for Developmentally Disabled Persons was added to the legislation, along with Protection and Advocacy System requirements.

Public Law 95-602 made further significant changes in the original_Act. Of major importance was the definition of developmental disabilities which emphasized functional limitations rather than disability categories. Through these latter amendments, the role of the Council has become less certain. While reference is still made to the role of the Council as an advocate at the systemic level, various portions of the law imply that the role of the Council is that of a service provider. This implication is best seen in the requirement that Councils select from one of four priority service areas and target 65% of the federal allotment to that area. Further, evaluation system requirements based upon developmental progress and individual habilitation plans infer that Councils would be in the business of providing services.

Being a program of very recent origin, the Developmental Disabilities program has been faced with the necessity of not only program development,

but program change and reorientation. Certainly, many of the amendments were justifiable in most appropriately meeting the needs of the developmentally disabled clientele. Some changes — particularly the change to the functional definition, the confusion in the Council role, and the evaluation requirements — pose many problems of implementation for Councils. The intensity of effort needed to refocus the program pursuant to the amendments has left little opportunity for the program to achieve stability in its implementation or administration.

P.L. 95-602 will expire in October of 1981. The legislative process reviewing the current law and its implementation and renewal will likely be initiated during the fall of 1980. Keeping in mind the history of the program, those associated with the Councils, as members or staff, view the legislative renewal process as a critical point for the future of the program. As front-line workers, we have seen both positive and difficult changes develop through the amendments to the original Act. With ten years of experience behind us, we view the renewal process as being one worthy of much consideration. We encourage a very thoughtful and thorough review of all components of the Developmental Disabilities Act prior to decisions being made as to whether those components should be maintained or amended. We hope that careful consideration will be given to the potential impact of those components once they have the force of law.

Having knowledge of the need for full deliberation of all components of the Act prior to their reconsideration, the Governmental Affairs Committee of the National Association of Developmental Disabilities Councils (NADDC) sponsored a legislative study which is summarized in the following pages. The study solicited the opinions of implementors of the Developmental Disabilities Act regarding both the appropriateness of current language of the law and the necessity for amendment. The purposes of the study are: first, to provide a systematic analysis of the opinions of those on the front lines of program implementation; and second, to identify areas of concern in the current Act as it relates to the formula grant program.

To carry out the purpose of the study, a questionnaire was developed which covered the following thirteern components of the Developmental Disabilities Act:

- -The definition of Developmental Disabilities
- -Priority service areas
- -The 65% funding requirement
- -Evaluation system requirements
- -Council authorization levels
- -UAF authorization levels
- -Protection and Advocacy System authorization level
- -Council staffing
- -State administrating agency role
- -Council role
- -Professional assessment requirement
- -Employee protection plan requirement
- -Council membership

For each of the thirteen components, two forced-choice questions were asked. The first question sought the respondent's degree of agreement/disagreement with the appropriateness of the current language of the Act regarding that component. The second question asked for the respondent's agreement/disagreement that the language should be amended. A third question provided an opportunity for the respondent to provide narrative information further clarifying his/her opinion.

One hundred seventy-one respondents representing the Developmental Disabilities community across the country responded to the question-naire. The respondents were widely dispersed in terms of geography, familiarity with the Developmental Disabilities Act and type of involvement with Developmental Disabilities Programs. Seventy-four percent of the respondents were either staff or Council members.

In analyzing the responses, various types of statistical analyses were employed. While these complex techniques were necessary for substantiating the validity and reliability of the instrument and results, they have not been presented in the summary document for the sake of brevity.

The responses to each of the thirteen components of the Act are presented in Table 1 in summary form. Presentation in this manner is intended to provide the reader with an overview of the opinions of the developmental disabilities community. However, the reader is encouraged to proceed through the subsequent sections which present a detailed discussion of the results.

For each of the thirteen components included in the study, three types of information are included in the summary table. First, the mean for the respondents' agreement with the current language of the Act and the need for amendment are stated. The mean is the average score for all respondents for the item in question. A neutral score would be 4.0. The smaller the mean, the higher the amount of agreement with that item.

The second type of information included for each component is that of variance, a measure of the amount of variability or stability among all responses. A high variance indicates a greater divergence of opinion on the item, whereas a small variance indicates a greater degree of consistency of opinions.

The third type of information is a summarization of narrative comments included for each of the thirteen components. It should be noted that only the major comments have been included. While the comments included were frequently mentioned, they do not necessarily represent the opinions of the entire group.

A review of the means, variance and narrative comments allows for placement of the thirteen components into three categories those in which consensus exists; for amendment, those in which consensus is generally

TABLE 1

Summary of Responses

Component of the Act	Mea	n	Variance	Narrative Comments
Definition of developmental disabilities	current amendment	3.383 3.986	3.654 5.203	 -Difficulty in operationalizing definition Eligibility difficult to determine -Need more commonality with other federal program definitions Funding level inadequate for broadened definition
Priority service areas	current amendment	3.103 4.071	3.344 4.241	<pre>-Priority service area component causes confusion on Council role as service provider or systemic advocate</pre>
65% funding requirement	current amendment	3.644 3.746	4.231 4.499	Councils need more flexibility in determining percentage -Minimum allotment and small states have difficulty funding other requirements through the remaining 35%Same diffi€u4ties-as-no£e4 w+feh priority service areas
Evaluation system requirements	current amendment	3.859 3.414	3.734 3.936	 -Strong support by Councils for evaluation of Council activities -Grossly inadequate funding available -Concern about system requirements developed by HHS
Council authorization levels	current amendment	4.382	3.942 3.853	Authorization level needs to be congruent with mandated responsibilities

Component of the Act	Mean		<u>Variance</u>	Narrative Comments
UAF authorization levels	current amendment	4.137 3.458	N/A 4.032	 -Minimum allotment states need increased UAF support which will necessitate increased funding -Definition change has expanded UAF clientele without concommitant resource increase.
P & A authorization levels	current amendment	4.812 2.774	4.198 3.721	-Resources grossly inadequate to operationalize mandates.Small states/territories most inadequately funded
Council staffing	current amendment	3.314 4.021	3.667 4.365	-National studies suggested regarding: -functional responsibilities and concommitant staffing needs -relationship of staff role to state administering agency role
State administering agency role	current amendment	3.459 4.309	2.564 3.335	-Councils' role and authority vis- a-vis state administering agency needs clarification -Resource needs- of state administerinj agency relevant to responsibilities specified under Act need examination
Council role	current amendment	3.172 4.244	2.717 3.995	-Confusion over current role as specified in Act-Conflict between roles of service provider/systemic advocate
Professional assessment requirement	current amendment	3.895 3.659	3.691 3.942	 -A more appropriate role for Councils would be as a monitor of the professional assessment process - I f maintained UAF's should carry out professional assessment jointly with Councils

Component of Act	M∈	ean	Variance	Narrative Comments
Employee protection plan	current amendment	3.783 3.791	3.838 4.434	 -Inappropriate for inclusion in DD Act -Rights of institutional employees emphasized over rights of the developmentally disabled -Requirements discourage Councils' selection of community alternative living arrangements as a priority service area
Council membership	current amendment	3.449 4.134	3.797 4.418	 Consumers meeting former definition should be allowed to be included as consumer members UAF's should be included as mandatory members

upon retaining but in which further clarification is desired, and those which constitute major problem areas.

The first category, those needing amendment, includes the three components regarding authorization levels: those for Councils, UAFs, and Protection and Advocacy Agencies. In each of these program areas respondents felt that authorization levels (not to mention appropriation levels) must be commensurate with the responsibilities mandated by Congress.

The second category encompasses those components of the Act for which general consensus exists to maintain the component but within which there is a need for further study and clarification. This category includes the definition of developmental disabilities, the priority service areas, Council staff, state administrating agency role, the Council role, and Council membership. The narrative statements provide indications of the specific points of needed study and clarification.

The final category includes problem areas. The components included here lack consensus as indicated by the mean, show a high variance, involve operationalization problems as evidenced by the narrative responses, or a combination of the three. Significant problems were noted within the 65% funding requirement, the evaluation system requirements, the professional assessment requirements, and the employee protection plan. The data indicate that significant consideration needs to be paid to these four areas prior to their being continued, amended or otherwise treated in the new legislation.

Although not reported in this document, one of the statistical analyses performed bears mention because of the pervasiveness of the findings. A factor analysis was utilized to study both the appropriateness and the amendment scales of the questionnaire. In each analysis, two components were identified which tend to be associated with respondents' opinions on the other eleven components. These two were the definition of developmental disabilities and the Council role. The heavy impact associated with the definition is likely due to its expansiveness and the transition difficulties experienced by Councils in its operationalization. Yet, consensus was apparent for maintaining the definition as it is currently stated in the Act.

The Council role is perhaps even more pervasive in impact. The law, as currently stated, provides contrary indications as to the Council's role as a systemic advocate or a service provider. The critical question arising from the divergent language of the law is this: Can the provider of services be an unbiased advocate for change and for service quality? Many of the problems identified in the narrative responses provide evidence that Councils are experiencing difficulty with the implementation of two adversarial role statements. The statistical analyses further substantiate that problems identified through the survey results are highly associated with the divergent role which the current law specifies.

In conclusion, the opinions expressed in the study indicate a high level of support for the Developmental Disabilities Act. Overall, respondents to the questionnaire support continuation of components of the Act with an expressed desire to amend only those portions in which significant problems are being experienced. The major problem and, according to the data, the primary focus of the legislative renewal process should be a clarification of the Council role in a singular, unambiguous manner. Attendant upon that definition of role, minor revisions are suggested by the data intendent upon insuring that the Act is internally consistent and effectively implemented.

METHODOLOGY

The purpose of NADDC's legislative study was two-fold: first, to provide a systematic analysis of the opinions of those responsible for implementation of the developmental disabilities program; and, second, to identify areas of particular concern in the current formula grant program. To carry out this purpose, a questionnaire regarding the legislation was developed and completed by individuals representative of the developmental disabilities community. Various types of analyses were performed in order to ascertain prevailing opinion and areas of concern.

The Questionnaire

An initial questionnaire, completed by NADDC Governmental Affairs Committee members, was utilized to identify components of the current Act which were felt to be of primary importance. Thirteen components were selected on the basis of responses by Committee members. These were:

- -The definition of developmental disabilities
- -Priority service areas
- -The 65% funding requirement for priority service areas
- -Evaluation system requirements
- -Council authorization levels
- -University Affiliated Facility authorization levels
- -Protection and advocacy system authorization levels
- -Council staffing
- -State administering agency responsibilities
- -Council role
- -Professional assessment requirements
- -Employee protection plan requirements
- -Council membership

A second questionnaire was then developed surrounding these thirteen components which included two major parts: forced answer pairs and openended narrative questions. The pairs of forced answer items were used to examine opinions on current and future legislation. The first item in the pair obtained opinions on appropriateness of existing legislation in regard to a component, and the second item examined opinions regarding future legislative changes in that area. The open-ended narrative provided the respondent an opportunity for further clarification.

The forced-choice answer items were set out in a format with a range of answers from stongly agree to strongly disagree. Numerical values were assigned to the answers provided by respondents as follows:

- 1 = strongly agree
- 3 = moderately agree
- 5 = moderately disagree
- 7 = strongly disagree

While a fifth category, no opinion, was included in the questionnaire,

such responses were excluded from the analysis for that particular item.

The neutral point on the scale is represented by a value of 4.0 in the construction of the questionnaire. Any score less than 4.0 indicates agreement with a given item, And a score greater than that denotes disagreement.

In addition to the items related to components of the legislation, the questionnaire requested demographic information about the respondents including the individual's state, region, type of affiliation with the developmental disabilities council, age, familiarity with types of disabilities, and familiarity with the Developmental Disabilities Act. This data was included so as to ascertain the representativeness of the sample population to the larger developmental disabilities community.

The Respondents

The questionnaire was made available to various individuals involved with the Developmental Disabilities Program throughout the country including Council members, Council staff, Protection and Advocacy Agencies, University Affiliated Facilities, state and national consumer organizations, federal and regional Developmental Disabilities administrative staff, and others selected by the individual Councils.

Responses were obtained from 171 individuals widely dispersed in terms of geography and affiliation. Geographically, fifty-two state or territorial units of government were represented within the sample population. Of the total, 126 (75%) of the respondents were affiliated with their state or territorial Developmental Disabilities Councils. Table 2 shows the distribution of the sample by affiliation, numbers and percentages.

Distribution of the Respondents by Affiliation

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Affiliation	# of Responded-s	Percentage of Sample
Council Staff Directors	34	19.9
Protection & Advocacy Directors	31	18.2
University Affiliated Fac Representatives	cility 28	16.4
Secondary Consumers	19	11.0
Other Respondents	17	9.9
Local Agency Members	13	7.6
Primary Consumers	10	5.8
Council Staff Members	9	5.3
State Agency Members	7	4.1
State Administrative Agencies	3	1.8
Totals	171	100.0

Overall, the respondents were well dispersed in terms of geography, affiliation, years of association, age and familiarity with the Act. Therefore, the group is considered to be representative of the larger developmental disabilities community.

Analysis of the Data

Initial tests were performed to determine the reliability of the questionnaire itself. Two scales were constructed, the first including the item for each component relevant to current language of the Act and the second including items relavent to amendment of the component. Both scales were found to be highly reliable.

Various statistical procedures were utilized in analyzing responses to each component among which were examination of the frequency distributions, measures of central tendency, analysis of variance, regression and multiple regression, factor analysis and path analysis. These analyses were most valuable to the understanding and interpretation, however, due to their complexity, they generally will not be reported or discussed in this document. For the purposes of summarization, the distribution of responses, the average scores for each item, and the variances will be presented.

The full statistical report is available from the NADDC Office or from the authors.

DISCUSSION OF THE FINDINGS

The findings will be reported and discussed in each of the thirteen topical areas examined through the questionnaire. An overview of the opinions regarding current language and amendment for each component will be provided in addition to a summarization of narrative comments.

For each of the thirteen components, two tables are presented: one regarding the current language of the Act and a second regarding amendment to that component. Each table includes the mean and variance for the entire group of respondents. The mean is the average score for the respondents as a whole. A neutral score would be 4.0. The smaller the mean, the higher the amount of agreement with either the appropriateness of the current language of the Act or with the need to amend the language.

Variance is a measure of the amount of variability or stability among all responses. A high variance indicates a greater divergence of opinion, whereas a small variance indicates a greater degree of consistency of opinions.

While narrative responses for each component are also reported, a word of caution is necessary. Those comments reported were frequently mentioned but do not necessarily represent the opinion of all individuals included in the study.

Throughout the discussion, reference will be made to "subgroups." This term is used to describe the type of association an individual has to the developmental disabilities program. The types of subgroups mentioned include Council chairpersons, Council members, consumer members, staff, and others not directly associated with Councils.

Definition of Developmental Disabilities

Table 3 summarizes the distribution of responses regarding agreement or disagreement with the appropriateness of the current definition of developmental disabilities. As indicated in the table, a large majority (71.6%) of the respondents either strongly or moderately agree with the current definition. The mean for all respondents was 3.3, somewhat lower than the midpoint score of 4.0. This distribution among the respondents suggests agreement with the current definition.

A variety of statistical analyses! were performed on the subgroups to determine where differences of opinion existed. While some variance was noted, none was statistically significant. The failure of these tests to determine differences lends support to the observation that agreement with the current definition is rather well defined within the sample population.

Table 4 includes responses regarding amendment to the definition. More variance in noted regarding amendment of than appropriateness of the current definition. Responses were almost equally distributed

Table 3

Appropriateness of DD Definition

Category Label	Code	Frequency	Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	38 78 23 23	23.5 48.1 14.2 14.2
Total		162	100.0
Mean		3.383	
Variance		3.654	

		-	
	Amendment t		
Category Label	Code	Frequency	Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	38 34 35 37	26.4 23.6 24.3 25.7
Total		144	100.0
Mean		3.986	

Variance

among the four categories, indicating a lack of consistency in the opinions. The mean score was 3.99 which, when compared to a neutral score of 4.0, denotes a lack of consensus regarding amendment.

Narrative comments brought out difficulties experienced by Councils in operationalizing the current definition. First, several respondents commented on the difficulty of determining eligibility of clients under the current definition. Suggestions were made that the definition should

5.203

be more compatible with those of other federal programs in order to consistently apply the definition across those agencies commonly utilized by developmentally disabled individuals. Compatibility would optimize the opportunity of Councils to collect data and appropriately plan for the developmentally disabled population. Finally, several respondents indicated that the funding level presents problems in light of the broadened definition.

Priority Service Areas

Table 5 summarizes the responses regarding appropriateness of priority service areas as presently stated in the law. Over three-fourths of the respondents agree wit* the current language. While various statistical analyses were performed to determine the importance of the differences in opinions, none were significant. The analyses indicate that a high level of agreement Exists in regard to the current language.

Presented in Table 6 are respondents' opinions regarding amending the priority service areas. An examination of the distribution shows that 37.0% moderately disagree and 18.9% strongly disagree with amendments. Agreement, however, on the amendment scale is not as clearly evident as that found in the appropriateness scale. A significant difference is noted in the opinions of council members and council staff as opposed to others in-the developmental disabilities community. These two groups indicate a high level of support for amendment of the priority service areas.

Table 5

Appropriateness of Prioritiy Service Areas

Category Label	<u>Code</u>	F <u>requency</u>	<u>Percentage</u>
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	45 74 21 <u>16</u>	28 8 47.4 13*5 10.3
Total		156	100.0
Mean		3.103	
Variance		3,344	

Table 6

Amendment of Priiority Service Areas

Category Label	Code	Frequency	Percentage
Strongly Agree Moderately Agree Moderately Disagree! Strongly Disagree	1 3 5 7	27 29 47 24	21.3 22.8 37.0 18.9
Total		127	100.0
Mean		4.071	
Variance		4.241	

Narrative comments indicate that a major point of concern emerges regarding priority service areas, the focal point resting upon the manner in which* those areas are interpretted. The law as currently written appears to provide Councils with considerable latitude in operationalizing its selected priority service area, allowing for either direct services or activities in support of the service area. However as will be discussed in subsequent pages, the law provides contrary inferences as to the role of the Council as a service provider or a systemic advocate. Depending upon the view taken regarding the Council's role, the priority service area component of the law takes on equally divergent meanings. It appears as though respondents are satisfied with their individual interpretations of priority service areas, but that those interpretations likely vary.

The lack of a clear and concise interpretation, combined with a lack of consensus regarding amendment, suggests this as an area of further study.

Sixty-five Percent Funding Requirement for Priority Service Areas

The responses of the sample regarding appropriateness of the 65% funding requirement are presented in Table 7. Two-thirds of the sample (66.5%) strongly agree or moderately agree with the appropriateness of this component of the law. Statistical tests pointed out that significant differences of opinion exist within one of the subgroups—the Council affiliates. Within this group, the Council staff disagree with the 65% requirement, whereas the other subgroups were in favor of the requirement.

Table 8 illustrates all responses to amendment of the 65% requirement. Respondents were equally divided among the agree or disagree categories, however, the largest single category of response was moder-. ately disagree (33.1%). Statistical analyses indicates no significant differences of opinion within the various subgroups.

Table 7 Appropriateness of 65% Requirement Category Label Code Frequency Percentage Strongly Agree 1 32 21.5 Moderately Agree 3 67 45.0 5 Moderately Disagree 13.4 20 Strongly Disagree 30 20.0 Total 149 100.0 Mean 3.644 Variance 4.231

Table 8

Amendment of 65% Requirement

Category Label	Code	Frequency	Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	33 27 39 <u>19</u>	28.0 22.9 33.1 <u>16.1</u>
Total		118	100.0
Mean		3.746	
Variance		4.499	

Narrative responses indicate Councils'need for greater flexibility in determining the percentage of funds required to support priority service areas. Responses further pointed out the problems of interpretation discussed in the previous section on priority services areas, i.e., the need to clearly define the role of the Council as an antecedent to requiring a predetermined allocation of funds.

Further comments point out difficulties experienced by small and minimum allotment states. Councils in these states argue that the

resources necessary for complying with other requirement of the law are commensurate regardless of the size of the state or territory. Notable examples are found in the planning and administrative requirements which are fairly well prescribed by law and regulation. The 65% requirement for priority service areas leaves a disproportionate availability of resources for the remaining responsibilities in smaller states and territories.

Evaluation System Requirements

Table 9 provides the responses regarding appropriateness of current evaluation system language. Some sixty percent of respondents agree with current language. However, the mean score of 3.859 is barely above the midpoint of 4.0, indicating that intensity of agreement is weak Statistical analyses identify that significant differences of opinion exist within the subgroups. While consumer members, agency respresentatives and other Council members agree with the requirements, Council staff disagree.

Approximately two-thirds of the respondents either strongly or moderately agree with amending the evaluation requirements as is shown in Table 10. A mean of 3.414 moves that data to the agreement end of the scale. Significant differences of opinion were noted between affiliates and non-affiliates of the Developmental Disabilities Councils A higher level of support for amending the evaluation requirements comes from the affiliates. Within the subgroups of Council affiliates, agency representatives to Councils and Council staff provide the highest level of support for amendment.

A clear-cut consensus is not apparent when the data from the two questions regarding evaluation are compared. While a large number of respondents are inclined to agree with current requirements, further analyses indicate that this agreement is not consistent among the various subgroups. Further, opinions to the two questions oppose each other.

Table 9

Appropriateness of Evaluation System Requirements

Category Label	Code	<u>Frequency</u>	<u>Percentage</u>
Strongly Agree	1	21	
Moderately Agree	3	60	15.6
Moderately Disagree	5	29	44.4
Strongly Disagree	7	25	18 5
Total		135	
		135	100.0
Mean		3.859	
Variance		* 3.734	

Table 10

Amendment of Ev	aluation System	Requirements

<u>Code</u>	Frequency	<u>Percentage</u>
1 3 5 7	32 37 29 13	28.8 33.3 26.1 11.7
	111	100.0
	3. 414	
	3. 936	
	1 3 5	1 32 37 5 29 13 111 3. 414

Nearly all individuals responding in the narrative section cited cost and resources as problematic under the present evalution system requirements. Respondents suggested that concommitant to the current requirements, additional staff and funding must be allocated if full implementation is to be seriously considered.

Other problem areas centered around the system specifications developed by the Secretary. Unrealistic time constraints imposed upon Councils since the issuance of the specifications and the comprehensiveness of the specifications in comparison to the law were also very frequently cited.

Although a lack of consensus was noted regarding the evaluation requirements as currently stated, Councils were clear in their support for the concept of evaluation. The fecal point of concern rests upon the need to relate evaluation requirements to the role of the Council. If the intent of Congress was that Councils be service providers and were the resources available for implementation of the current evaluation requirements, it appears as though respondents would provide their agreement. However, should the intent of Congress be that Councils are systemic advocates, the consensus for current requirements appears to diminish in favor of requirements more suited to that systemic role.

Presently, the evaluation system requirements are a segment of the legislation which can be characterized by a lack of consensus as to both appropriateness and amendment. The narrative comments, in combination with the quantitative data, suggest the need for an intensive review of current requirements in line with the Council role and of resource allocations commensurate with operational requirements.

Council Authorization Levels

Responses tend toward the disagreement end of the scale with regard to the current Council authorization levels. As indicated in Table 11,

the average of all resonses is 4.382. No significant differences were found within any of the subgroups.

Approximately two-thirds of the sample were in agreement with the notion of amending the Council authorization. This indicator was substantiated by a mean of 3.054 which provides a strong tendency toward agreement. Again, no statistical differences were found in the responses of the various subgroups. The disbribution of responses regarding amendment is presented in Table 12.

Table 11

Appropriateness of Councill Authorizations				
Category Label	Code	Frequency	Percentage	
Strongly Agree Moderately Agree	1 3	14 52	10.3 38.2	
Moderately Disagree Strongly Disagree	5 7	32 38	23.5 27.9	
Total		136	100.0	
Mean		4.382		
Variance		3.942		

Table 12

Amendment to Council Authorization

Category Label	Code	Frequency	- Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	43 32 28 9	38.4 28.6 25.0 8.0
Total		112	100.0
Mean		3.054	
Variance		3.853	

Narrative responses raise the issue of compatibility of Council responsibilities under the law and commensurate funding levels. The authorization levels (and appropriation levels) should be evaluated in relation to the additional responsibilities placed upon Councils by

functional definition, the evaluation system, the professional assessment requirements, and other responsibilities.

Other areas of concern which emerged form the narrative statements related to the special needs of the small and minimum allotment states; particularly the difficulties being experienced in implementing the planning and administrative responsibilities under the 35% funding category.

Protection and Advocacy System Authorization Levels

A large percentage of respondents (62%) disagree that current authorization levels are appropriate. This observation is supported by the data summary in Table 13. The mean score (4.812) shows a rather strong tendency toward the disagreement side of the scale. Analysis of the subgroups revealed significant differences, although interestingly, the differences center around how strongly the subgroups disagree. These findings illustrate the intensity of disagreement with current authorization levels.

Parallel to the disagreement with current authorization levels, respondents tend toward high agreement with amendment. Approximately 73% of the responses fall in the agreement category, with a mean of 2.744. This represents the highest level of agreement for any of the items tested in the study. Table 14 provides an overview of the data regarding amendment.

Appropriateness of P & A Authorization

Table 13

Category Label	Code	Frequency	Percentage
Strongly Agree	1	13	9.4
Moderately Agree	3	40	29.0
Moderately Disagree	5	32	23.2
Strongly Disagree	7	<u>53</u>	<u>38.4</u>
Total		138	100.0
Mean		4.812	
Variance		4.198	

Table 14

Amendment to P & A Authorization

Category Label	Code	Frequency	Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	56 35 24 9	45.2 28.2 19.4 7.3
Total		124	100.0
Mean		2.774	
Variance		3.721	

Within the narrative comments, concern was expressed with the currently low-levels of funding for the Protection and Advocacy Agencies. Other comments related the dependency of P & A Agencies on the Councils for funding in some states. Since the implementation of the 65% funding requirement for priority service areas, the availability of Council funds for other purposes, including P & A activities, has decreased. Respondents note that increased federal funding would provide greater stability of the P & A efforts.

The minimum allotment states strongly voice the concern for the difficulty of implementing the law under current funding levels. While authorization levels, in general, were of concern, the discpepency between authorization and appropriation levels was frequently cited.

University Affiliated Facility Authorization Levels

No apparent consensus emerges from the responses regarding UAF authorization levels (see Table 15). However, the mean of 3.458 in regard to amendment supports increased authorization levels. This response is quite equally spread throughout the various subgroups and is presented in Table 16.

_____ Table 15
Appropriateness of UAF Authorization

Category Label	Code	Frequency	— Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	10 43 20 22	10.5 45.3 21.0 23.2
Total		95	100.0

Mean 4.137

Table 16

Amendment to UAF Authorization

Category Label	Code	Frequency	<u>Percentage</u>
Strongly Agree	1	26	31.3
Moderately Agree	3	• . 20	24.3
Moderately Disagree	5	29	34.9
Strongly Disagree	7	8	<u>9.6</u>
Total		83	100.0
Mean		3.458	
Variance		4.032	

Councils expressed the need for continued and increased support from UAF's to provide necessary training and assistance. Minimum allotment states in particular note the need for increased UAF resources.

As with Councils, the level of finds authorized and appropriated must be commensurate with mandated responsibilities. Concern was noted in regard to the impact of the expanded definition on the services to be provided by UAF's and the concurrent need for adequate resources.

Council Staffing

A high level of agreement exists in regard to the current language of the law regarding Council staffing. Some 70% of respondents, as indicated on Table 17, agree. This observation is supported by a mean score of 3.314, tending toward the agreement end of the scale.

A very ambiguous response was given to amendment of the Council staffing language. A mean score of 4.021 closely approximates the neutral point in the scale (see Table 18).

Table 17
Appropriateness of Council Staffing

Category Label	Code	Frequency	Percentage
Strongly Agree	1	31	25.6
. Moderately Agree	3	56	46.3
Moderately Disagree	5	18	14.9
Strongly Disagree	7	<u>16</u>	<u>13.2</u>
Total		121	100.0
Mean		3.314	
Variance		3.667	

Amendment to Council Staffing

Table 18

Category Label	Code	Frequency	Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	22 19 36 17	23.4 20.2 38.3 18.1
Total		94	100.0
Mean	;	4.021	
Variance		4.365	

The difference in responses for the questions regarding current language and amendment suggest the need for further review. In this regard, respondents suggested a national study examining the functional responsibilities given to Councils under the law and the staffing needs attendant Upon those responsibilities.

Other suggestions related to the need for futher examination of the relationship of the roles of Council staff and the state administering agencies.

Finally, several respondents commented upon the Council staffing patterns. Questions were raised relevant to the hiring authority of the Council and the need for Councils to have greater supervisory capacity.

State Administering Agency Responsibilities

Seventy-three percent of the respondents provided an affirmative score in regard to current responsibilities of state administering agency responsibilities. The mean score, reported on Table 19, supports this level of agreement. However, an ambiguous response was shown in relation to amending that component of the Act. The mean of 4.039 is nearly neutral The distribution of responses to amendment is provided in Table 20.

Table 19

Appropriateness of State Administering Agency Responsibility

Category Label	Code	Frequency	Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	18 81 23 13	13.3 60.0 17.0 9.6
Total		135	100.0

Mean 3.459

Table 20
Amendment to State Administering Agency Responsibility

Category Label	Code		Frequency	Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7		16 23 54 <u>17</u>	14.5 20.9 49.1 <u>15.5</u>
Total			110	100.0
Mean		>	4.309	
Variance			3.335	

Narrative responses suggest that Councils should be given more authority and autonomy vis-a-vis the state administering agency, thus permitting the Councils to exercise greater discretion in directing the program.

Other comments suggested that the federal government should study the resources needed by state administering agencies in carrying out responsibilities given them by the law.

Council Role

Responses to the question about Council role appear to be contradictory. According to the data, a high level of agreement exists with the role as currently stated in the law. In fact, approximately 78% of respondents strongly or moderately agree with the language of the law. The summarization of the data in Table 21 provides further support for this agreement.

A much less enthusiastic level of support is shown when respondents consider possible amendment to the Council role. The average score for the group was 4.244, indicating only slight disagreement with amendment. With the high level of agreement shown for the current language, it is surprising that a high level of disagreement for amendment was not also shown.

Table 21

Appropriateness of Council Role

Category Label	<u>Code</u>	Frequency	<u>Percentage</u>
Strongly Agree	1	33	21.9
Moderately Agree	3	84	55.6
Moderately Disagree	5	22	14.6
Strongly Disagree	7	<u>12</u>	<u>7.9</u>
Total		151	100.0

Mean 3.172

Table 22

Amendment of Council Role

Category Label	Code	Frequency	Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	22 30 49 26	17.3 23.6 38.6 20.5
Total		127	100.0
Mean		4.244	
Variance		3.995	

Narrative answers provide some explanation for the lack of consistent responses to the two previous questions. The law, as currently stated, provides contrary indications as to the Council's role as a systemic advocate or* service provider. These two roles conflict with each other. That is, how can the provider of services also be an unbiased advocate for service quality and systemic change? Many of the problems cited in the narrative section provide evidence that Councils are experiencing difficulties in implementing the two diverse and conflicting roles.

The results of other statistical analyses performed show that the Council role is highly pervasive in its effect on other components of the law. A high degree of association was found between opinions regarding the role and other components appearing to be problems among which were the evaluation system requirements, employee protection plans, priority service areas, professional assessment requirements, and the 65% funding requirement.

Professional Assessment Requirements

Opinions are unevenly dispersed regarding the professional assessment language of the current law. The mean of 3.895 shown on Table 23 is only slightly above the neutral point. A higher level of support is shown for current language by individuals not associated with Councils than by those who are Council members or staff.

Some amount of agreement for amendment is evidenced by the mean of 3.659 (see Table 24). The strongest support for amendment comes from Council chairpersons and staff, with disagreement for amendment coming from consumer members and those not associated with Councils. The differences in opinion were significant, indicating that consensus on this component of the law does not exist within the developmental disabilities community.

Table 23

Appropriateness of Professional Assessment Requirements

Category Label	<u>Code</u>	Fr <u>equency</u>	<u>Percentage</u>
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	13 54 16 <u>22</u>	12.4 51.4 15.2 <u>21.0</u>
Total		105	100.0
Mean		3.895	
Variance		3.691	

Table 24

Amendment of Professional Assessment Requirements

Category Label	Code	Frequency	<u>Percentage</u>	
Strongly Agree	1	23	27.1	
Moderately Agree	3	20	23.5	
Moderately Disagree	5	33	38.8	
Strongly Disagree	7	9_	<u>10-6</u>	
Total		85	100.0	
Mean		3.659		
Variance		3.942		

In written comments, several respondents supported the deletion of this component of the law entirely. Others thought it should be retained, but that the role of the Council in the professional assessment process should be that of a monitor only. Still others supported its inclusion, but only as the requirements would relate to Council-funded activities. Finally, suggestions were made that should the requirements be retained, implementation should be performed jointly between Councils and UAF's.

Both the numerical and narrative data points to the wide divergence of opinion on professional assessment requirements. Due to the divergence, this component is one deserving of more study and consideration.

Employee Protection Plan Requirements

The employee protection plan requirements are characterized by highly divergent opinions. While looking at the raw data (see Tables 25 and 26), slight support appears for agreement with current language and disagreement with amendment. Neither of the means are far from the neutral point (3.783 and 3.791 respectively).

Further analyses pointed out significant differences between subgroups, with Council chairpersons and staff showing strong opinions opposing current language and supporting amendment. Other subgroups supported current requirements and opposed amendment, although these responses were at best moderate. The data shows this component of the law to be a likely problem area and one on which a clear consensus is missing.

Table 25

Appropriateness of Employee Protection Plan Requirements

Category Label	Code	Frequency	Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	18 57 17 23	15.7 49.6 14.8 20.0
Total		115	100.0
Mean		3.783	
Variance		3.838	

Table 26

Amondment of Employees Divotostion Dlan Desgripements

Amenament	or rubrokee	Protection Plan Requirements	
Category Label	Code	Frequency	Percentage
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	26 16 36 13	28.6 17.6 39.6 14.3
Total		91	100.0
Mean		3.791	
Variance		4.434	

The extermity of opinion on employee protection plans was further substantiated by the number and content of the narrative responses. A clear majority of individuals providing written comments supported deleting the requirements entirely. Some pointed out that the bottom line of the requirements apppears to be an emphasis upon the rights of institutional employees over those of developmentally disabled individuals. These individuals stressed that the current requirements impede deinstitutionalization. Further, the requirements inhibit Councils from selecting community alternative living arrangements as a priority service area as a means of avoiding the employee protection plan requirements.

Clearly, a lack of consensus exists regarding this component of the act. Based upon numerical and narrative responses, rethinking of the employee protection plan requirements is indicated.

Council Membership

The majority of respondents (65%) agree with current membership requirements. The disbribution of responses shown on Table 27 and the mean of 3.449 support the tendency toward agreement. Responses tend toward disagreement with amendment, although only slightly. Table 28 shows that opinions are spread throughout the scale. Further, a divergence of opinion was noted within each of the subgroups. Overall, the group tends to support continued inclusion of the requirements, but the divergence of opinion is suggestive th)at some underlying problems are causing a moderated response.

Table 27

Appropriateness of Councill Membership

Category Label	<u>Code</u>	Frequency	<u>Percentage</u>	
Strongly Agree Moderately Agree Moderately Disagree Strongly Disagree	1 3 5 7	40 61 35 20	25 6 39 1 22 .4 12 .8	
Total		156	100 .0	
Mean		3.449		
Variance		3.797		

Table 28

Variance

Amendment of Council Membership Frequency Percentage Code Category Label 25 18.7 1 Strongly Agree 29.9 40 3 Moderately Agree 27.6 37 5 Moderately Disagree 23.9 7 32 Strongly Disagree 134 100.0 Total 4.134 Mean

Narrative answers focused upon the involvement of consumers as members of Councils. The majority of those providing narrative responses supported more flexibility within the law, providing opportunities for those less severely disabled individuals who met the prior developmental disabilities definition to serve as consumer members.

4.418

Other respondents supported the inclusion of University Affiliated Facility representatives within the required membership.

CONCLUSIONS

NADDC identified two purposes for its legislative study: first, to provide a systematic analysis of the opinions of those responsible for implementation of the developmental disabilities program; and, second, to identify areas of particular concern in the portions of the Act relevant to the formula grant program. Foregoing pages have included a detailed discussion of the opinions and areas of concern. In these final pages, a summary of the findings will be provided and conclusions stated.

A summarization of both the numerical and narrative responses is presented on Table 29. A review of the means, variance and narrative comments suggests that the components can be categorized as follows:

- -Components for which consensus is to amend
- -Components for which consensus is to retain but for which clarification is desired
- -Components for which consensus does not exist and which warrant intensive reconsideration

Each of these categories and the components falling within them will be discussed below.

Consensus to Amend

Three components fit within this category: Council authorization levels, UAF authorization levels, and Protection and Advocacy Agency authorization levels.

Referring to Table 29, it is to be noted that in each case, the mean for the current language tends toward disagreement and the mean for amendment tends toward agreement. In fact, these three components represent the highest level of agreement for amendment among the thirteen components studied.

Narrative responses supporting the agreement for amendment particularly cite the need to authorization levels to be commensurate with mandated responsibilities. Additionally, respondents state that the authorization levels must take into account the impact of the expanded definition upon the need for resources. Finally, the particular needs of small and minimum allotment states and territories in regard to adequate funding were cited.

Consensus to Retain but Clarify

Within this category are included the definition of developmental disabilities, the priority service areas, Council staff, state administering agency responsibilities, Council role, and Council membership.

For each of these components, several characteristics can be observed from data presented on Table 29. The mean for each tends toward agreement,

Table 29
Summary of Responses

Component of the Act	Mean	<u>1</u>	<u>Variance</u>	Narrative Comments
Definition of developmental disabilities	current amendment	3.383 3.986	3.654 5.203	 -Difficulty in operationalizing definition -Eligibility difficult to determine -Need more commonality with other federal program definitions -Funding level inadequate for broadened definition
Priority service areas	current amendment	3.103 4.071	3.344 4.241	Priority service area component causes confusion on Council role as service provider or systemic advocate
65% funding requirement	current amendment	3.644 3.746	4.231 4.499	 Councils need more flexibility in determining percentage Minimum allotment and small states have difficulty funding other requirements through the remaining 35% Same difficulties as noted with priority service areas
Evaluation system requirements	current amendment	3.859 3.414	3.734 3.936	 Strong support by Councils for evaluation of Council activities -Grossly inadequate funding available -Concern about system requirements developed by HHS
Council authorization levels	current amendment	4.382 3.254	3.942 3.853	Authorization level needs to be congruent with mandated responsi- bilities

Component of the Act	<u>Mean</u>		Variance	Narrative Comments
UAF authorization levels	current amendment	4,137 3.458	N/A 4.032	Minimum allotment states need increased UAF support which will necessitate increased fundingDefinition change has expanded UAF clientele without concommitant resource increase.
P & A authorization levels	current amendment	4.812 2.774	4.198 3.721	-Resources grossly inadequate to operationalize mandates.-Small states/territories most inadequately funded
Council staffing	current amendment	3.314 4.021	3.667 4.365	 -National studies suggested regarding: -functional responsibilities and concommitant staffing needs relationship of staff role to state administering agency role
State administering agency role	current amendment 	3.459 4.309	2.564 3.335	Councils' role and authority vis- a-vis state administering agency needs clarification -Resource needs of state administering agency relevant to responsibilities- specified under Act need examination
Council role	current amendment	3.172 4.244	2.717 3.995	<pre>-Confusion over current role as specified in Act -Conflict between roles of service provider/systemic advocate</pre>
Professional assessment requirement	current amendment	3.895 3.659	3.691 3.942	A more appropriate role for Councils would be as a monitor of the professional assessment processIf maintained UAF's should carry out professional assessment jointly with Councils

Component of Act	Me	<u>ean</u>	<u>Variance</u>	Narrative Comments
Employee protection plan	current amendment	3.783 3.791	3.838 4.434	 Inappropriate for inclusion in DO Act Rights of institutional employees emphasized over rights of the developmentally disabled Requirements discourage Councils' selection of community alternative living arrangements as a priority service area
Council membership	current amendment	3.449 4.134	3,797 4.418	 Consumers meeting former definition should be allowed to be included as consumer members UAF's should be included as mandatory members in states where UAF's exist.

with the current language of the law, and as a group they represent the components with highest level of agreement. The mean scores for amendment are all higher than the means for agreement with the current language, but all center close to the neutral point of 4.0. These same means all show a high variance. The) tendency toward agreement with current language is the basis for categorizing the components as those which respondents feel should be retained. The high variance level regarding amendment suggests the need for clarification.

Narrative comments point out problems experienced by Councils in operationalizating the components in this category as they are currently stated in the law. The comments suggest the need for clearer articulation of the intent of Congress within each component. Further, the components are seen to be highly related and need to be evaluated and further clarified on the basis of their interrelationships. Of most importance is the impact which Council role has on the other components.

No Consensus: Reconsideration Indicated

Four components fall in this category and, according to the data, constitute major problem areas. Included are the 65% funding requirement, the evaluation system requirements, the professional assessment requirements, and the employee protection plan requirements.

The data indicates a commonality of these four components in that consensus could not be established for any. The failure to develop consensus is shown through the means for the two separate scales regarding current language and amendment. All means (for each scale) are very close to the neutral score of 4.0, stowing that no direction of opinion for the group emerges. When reviewing the pair of means for each component, each mean in the pair tends (though slightly) in the same direction, again an indication that consensus is not apparent. Finally, the magnitude of difference between each pair of means is very slight.

The major problems illustrated through the narrative responses center around the relationship that each component bears to the role of the Council that is, depending upon the interpretation of the Council role, these four components may or may not be consistent with that role Also noted was the relationship of the four components to the fiscal resources of the program and the need for authorization levels to reflect implementation costs.

A Supplementary Analysis

Although not reported in this document, one of the statistical analyses performed bears mention because of the pervasiveness of its findings. A factor analysis was utilized to study both the scales relating to current language and to amendment. In each of the analyses two components were identified which tend to be highly associated with respondents opinions on the other eleven components. These two were the definition of developmental disabilities and the Council role The heavy degree of impact associated with the definition is likely due to its

and the transition difficulties experienced

by Councils in its operationalization. Yet, consensus was apparent for maintaining the definition currently stated in the Act.

The Council role is perhaps even more pervasive in impact. The law now provides contrary indications as to the Council role of service provider and of systemic advocate. The critical question arising from the divergent language is this: Can the provider of services be an unbiased advocate for service quality and system change? Many of the problems brought out by the narrative comments provide evidence that Councils are experiencing difficulty in implementing these adversarial role statements. The statistical analyses further substantiate that problem areas in other components are highly associated with the divergence of roles specified in the law.

Concluding Statement

The opinions, when taken in sum, indicate a high level of support for the Developmental Disabilities Act. In an overall sense, respondents support the continuation of components of the Act with an expressed desire to amend only those portions in which significant problems are being experienced.

The major problem and, according to the data, the primary focus of the legislative renewal process should be a clarification of the Council role in a singular, unambiguous manner. Attendant upon that definition of role, minor revisions are suggested by the data to insure that the Act is internally consistent, and effectively implemented.