

S B

5 2

FISCAL NOTE

STATE OF ALASKA
1991 LEGISLATIVE SESSION

BILL NO. SB52

Revision Date: _____ Department Affected: Education
Title: Governor's Council for the BRU: Executive Admin
Handicapped and Gifted, and the definition of Component: Executive Admin

Sponsor: Duncan
Requestor: Senate HESS COMPONENT SERIAL NO.

--	--	--	--

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY 92	FY 93	FY 94	FY 95	FY 96	FY 97
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	-0-	-0-	-0-	-0-	-0-	-0-

CAPITAL						
---------	--	--	--	--	--	--

REVENUE						
---------	--	--	--	--	--	--

FUNDING: (Thousands of Dollars)

GENERAL FUND						
FEDERAL FUNDS						
OTHER						
TOTAL	-0-	-0-	-0-	-0-	-0-	-0-

POSITIONS:

FULL-TIME						
PART-TIME						
TEMPORARY						

Estimate of current year impact: _____

ANALYSIS: (Attach a separate page if necessary.)

Prepared By: Mary Hakala Phone: 465-2800
Division: Commissioner's Office Date: 2/21/91
Approved by Commissioner: Steve Hole, Acting Commissioner
Agency: Education Date: 2/21/91

Distribution (by preparer): Legislative Finance, Legislative Sponsor, Requestor, OMB, & Impacted Agency(ies).

STATE OF ALASKA
1991 LEGISLATIVE SESSION

BILL NO. SB 52

Revision Date: _____ Department Affected: Health & Social Services
 Title: Relating to Governor's Council for the Handicapped & Gifted & definition of Developmentally Disabled thru: Community Developmental Disabilities Grants
 Component: None
 Sponsor: Duncan
 Requestor: Health Education & Social Services COMPONENT SERIAL NO.

--	--	--	--

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY 92	FY 93	FY 94	FY 95	FY 96	FY 97
PERSONAL SERVICES	0	0	0	0	0	0
TRAVEL	0	0	0	0	0	0
CONTRACTUAL	0	0	0	0	0	0
SUPPLIES	0	0	0	0	0	0
EQUIPMENT	0	0	0	0	0	0
LAND & STRUCTURES	0	0	0	0	0	0
GRANTS, CLAIMS	0	0	0	0	0	0
MISCELLANEOUS	0	0	0	0	0	0
TOTAL OPERATING	0	0	0	0	0	0

CAPITAL	0	0	0	0	0	0
---------	---	---	---	---	---	---

REVENUE	0	0	0	0	0	0
---------	---	---	---	---	---	---

FUNDING: (Thousands of Dollars)

GENERAL FUND	0	0	0	0	0	0
FEDERAL FUNDS	0	0	0	0	0	0
OTHER	0	0	0	0	0	0
TOTAL	0	0	0	0	0	0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year impact:

ANALYSIS: (Attach a separate page if necessary.)
 Identified individuals would be added to the Developmental Disabilities Wait List. Provision for services would be contingent upon funding request by the Mental Health Board and the Governor.

Prepared By: ³¹⁷ Mike Renfro *Mike Renfro* Phone: 465-3370
 Division: Mental Health & Developmental Disabilities Date: 2/22/91

Approved by Commissioner: *Theodore A. Mala* Commissioner: Theodore A. Mala, MD, M
 Agency: Department of Health and Social Services Date: 2/25/91

Distribution (by preparer): Legislative Finance, Legislative Sponsor, Requestor, OMB, & Impacted Agency(ies).

Alaska State Legislature



SENATOR JIM DUNCAN

P. O. Box V JUNEAU, ALASKA 99811-3100
(907) 465-4766

COMMITTEES:
FINANCE
VICE CHAIR —
HEALTH EDUCATION
& SOCIAL SERVICES
BUDGET & AUDIT
BANKING &
ECONOMIC
DEVELOPMENT

MEMORANDUM

DATE: January 24, 1991

TO: Senator Arliss Sturgulewski, Chair
Senate Health, Education, and Social Services Committee

FROM: Senator Jim Duncan

RE: SB 52, relating to the Governor's Council for the Handicapped and Gifted and the definition of 'developmentally disabled'.

Thank you for your interest in scheduling SB 52, relating to the Governor's Council for the Handicapped and Gifted and the definition of 'developmentally disabled'.

Section 1. Increases the number of members of the Governor's Council on the Handicapped and Gifted from 23 to 26. This change was necessitated because the Governor's Council was also designated to serve as the Interagency Coordinating Committee (I.C.C.) for P.L. 99-457, the 1986 Education and Handicapped Act Amendments affecting children from birth to 3 years of age. In other states, the Interagency Coordinating Committee has been established as a separate 15 member board charged with planning services for handicapped children between the ages of birth to 3 years. In order to blend the Council and the I.C.C. into one body, a 26 member body is necessary with the following composition:

5 Representatives of Specific Agencies or Consumer Groups

Special Education Director
Special Education Teacher
Gifted/Talented Representative
Protection and Advocacy Agency Representative
Higher Education Representative

8 State Agency Representatives, including those administering federal funds provided through the:

Rehabilitation Act of 1973 (DVR)
Education of the Handicapped Act (DOE)
Older Americans Act of 1965 (Older Alaskans Commission)
Title XIX Social Security Act (DHSS/DMA)
4 representatives of departments providing services to people with disabilities including the Division of Mental Health and Developmental Disabilities, Deputy Commissioners of DOE and DHSS who represent more than one division or program, or the Department of Community and Regional Affairs

13 Primary and Secondary Consumers representing different age groups, types of disabilities, and geographic distribution.

Thus, by increasing the membership of the Governor's Council on the Handicapped and Gifted by only 3, we can accomplish the additional planning required by the federal legislation without adding an entirely new board.

Section 2. Provides for selection of the Executive Director of the Council by the Council pursuant to new federal requirements. P.L. 101-496 states that "Each State Planning Council shall, consistent with State law, hire a Director of the State Planning Council who shall be supervised and evaluated by the State Planning Council and who shall hire and supervise the staff of the State Planning Council." ✓

Section 3. Amends the state definition of developmental disability to comply with the federal definition. This amendment will allow severely physically handicapped individuals to receive services such as respite care, day care, homemaker and community living services. Current state law provides for such services only for mentally handicapped individuals. ✓

I urge your support for these amendments to 47.80, Persons with Handicaps.

Attachments

Senator Jim Duncan
Alaska State Senate
Room 119, Capitol Building
Juneau, AK 99811

Dear Senator Duncan:

Even though the session is almost over, I am compelled to write to you to present this issue to you.

I am a widow with two young sons and one daughter, age 13. My daughter, Leslie, is severely physically handicapped--the nature of her problem is "Arthrogryposis multiplex congenital." Leslie is unable to take care of her daily needs such as bathing, dressing, putting on her leg braces, walking without the aid of a wheelchair or walker . . . the list goes on and on. Yet, we are blessed in that Leslie is fully articulate and a bright, young lady. At least I thought we were lucky. I have gone to several sources attempting to gain help in caring for Leslie. I have contacted the Department of Health and Social Services, Division of Mental Health and Developmental Disabilities and was denied aid because Leslie was not "mentally deficient." With this denial, Leslie was deemed ineligible for REACH services, respite, health care people to come ease the strain of Leslie's daily care and basically any services we could so gratefully accept if available.

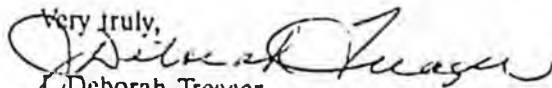
H&SS representative Alison Seymour stated to me that the Federal definition of "developmentally disabled" included those individuals termed "physically handicapped," yet the State at some point deleted that term and in effect cut off any severely handicapped individuals from State assistance to help them and their families in their struggle to live a normal life. I believe I remember when that deletion occurred, because Leslie had been enrolled in St. Jude's Center from age 2 until 5. She had been covered under their respite program until around age 4 and I remember the Director coming to me and telling me Leslie was no longer eligible for respite care. Certainly I needed the time off but sadly enough the State had decided only mentally deficient people should be assisted.

I realize this letter is lengthy, but I have tried for so long to find help to make life easier for my daughter and my family that I really know no way to shorten my plea. I have heard of those with cerebral palsy, Down's Syndrome, or even those with low I.Q.'s receiving phenomenal benefits--even up to one pastor's daughter's family given a van for her daughter. I have been worrying about how to carry Leslie in her electric wheelchair after her operations in late July, because I cannot afford a van. Because of that, Leslie is almost always homebound and cannot go many places and her quality of life is so restricted.

I deeply believe the State could help citizens like my daughter, who only by virtue of not having mental deficiencies has been cut off from care so grievously needed. Perhaps I seem over dramatic, but in my position and seeming trapped from ever providing for her as she needs, becoming drained in the strain of daily living, it feels of paramount importance.

Perhaps a bill could be introduced to make it possible for severely handicapped individuals to have the means of a better way of life? Or are there hidden sources H&SS couldn't locate? Even Alison Seymour was at a loss to offer suggestions. I am writing you and Representative Ulmer to let you know of this problem in Alaska--or is it only a fact of life in Juneau, of which I have a resident since July 1978?

Very truly,



Deborah Treager
3201 Nowell Avenue
Juneau, Alaska 99801

Employee: Department of Corrections

Southeast Region/Telephone: 465-3376

to you - done next session

FEDERAL DEFINITION:

"The term 'developmental disability' means a severe, chronic disability of a person which—

- (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (B) is manifested before the person attains age twenty-two;
- (C) is likely to continue indefinitely;
- (D) results in substantial functional limitations in three 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, and
 - (vii) economic self-sufficiency; and
- (E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated."

PL 95-602, Section 102(7)

STATE DEFINITION:

A. Developmental Disability is a Disability which:

- (A) is attributable to:
 - (i) mental retardation, cerebral palsy, epilepsy, or autism;
 - (ii) any other condition found to be closely related to mental retardation because the condition results in impairment of general intellectual functioning or adaptive behavior similar to impairment resulting from mental retardation; or
 - (iii) dyslexia resulting from a disability described in (i) or (ii) of this subparagraph, and
- (B) constitutes a substantial handicap to the person's ability to function normally in society.

P.L. 101-496

and

(2) by striking paragraphs (4) and (5) of subsection (f) and inserting the following new paragraph:

"(4) Each State Planning Council shall utilize the information developed pursuant to paragraphs (1), (2), and (3) in developing the State plan."

SEC. 12. STATE PLANNING COUNCILS.

Section 124 of the Act is amended--

(1) in subsection (a)--

(A) by striking "which will" and inserting "to"; and

(B) by striking the period at the end thereof and inserting "by carrying out priority area activities.";

(2) in paragraph (1) of subsection (c) :

(A) by striking "may" and inserting "shall"; and

(B) by striking "hire" and inserting "fund all activities under this part (except administrative costs described in section 122(d)(1)) and to hire";

(3) in subsection (c)--

(A) by redesignating paragraph (2) as paragraph (3); and

(B) by inserting after paragraph (1) the following new paragraph:

"(2) Each State Planning Council shall, consistent with State law, hire a Director of the State Planning Council who shall be supervised and evaluated by the State Planning Council and who shall hire and supervise the staff of the State Planning Council."; and

(4) in paragraph (1) of subsection (d) by striking "jointly with" and inserting "and submit after consultation with".

SEC. 13. STATE ALLOTMENTS.

Paragraphs (3), (4), (5) and 6 of subsection (a) of section 125 of the Act are amended to read as follows:

"(3)(A) Except as provided in paragraph (4), for any fiscal year the allotment under paragraph (1)--

"(i) to each of American Samoa, Guam, the Virgin Islands, the Commonwealth of the Northern Mariana Islands, the Republic of the Marshall Islands, the Federated States of Micronesia, or the Republic of Palau may not be less than \$200,000; and

"(ii) to any other State may not be less than the greater of \$350,000 or the amount of the allotment (determined without regard to subsection (d)) received by the State for the fiscal year ending September 30, 1990.

"(B) Notwithstanding subparagraph (A), if the aggregate of the amounts to be allotted to each State pursuant to subparagraph (A) in any fiscal year exceeds the total amount appropriated under section 130 for such fiscal year, the amount to be allotted to a State for such fiscal year shall be an amount which bears the same ratio to the amount which is to be allotted to the State pursuant to such subparagraph as the total amount appropriated under section 130 for such fiscal years bears to the total of the amount required to be appropriated under such section for allotments to provide each State with the allotment required by such subparagraph.

"(4) In any case in which amounts appropriated under section 130 for a fiscal year exceeds \$5,000,000, the allotment under paragraph (1) for such fiscal year--

"(A) to each of American Samoa, Guam, the Virgin Islands, the Commonwealth of the Northern Mariana Islands, the Republic of the Marshall Islands, the Federated States of Micronesia, or the Republic

Position Paper

SB 52

For an Act entitled: "An Act relating to the Governor's Council for the Handicapped and Gifted and the definition of 'developmentally disabled';"

Section One of this Act changes the membership of the Governor's Council for the Handicapped and Gifted from 23 to 26.

Section Two enables the Governor's Council for the Handicapped and Gifted to hire the Council's Executive Director.

Section Three of this Act repeals AS 47.80.900 (7). In so doing, the state definition of developmental disabilities is changed to the current federal definition.

The Department of Health and Social Services supports the passage of this bill only if Section Two is removed.

Background

Public Law 99-457 requires that a council be formed to help plan for children (who suffer developmental delays) age 0 through 2. The law also spells out specific membership requirements. By adding three members to the Governor's Council for the Handicapped and Gifted they can assume this role and save the expense of forming an entirely new council. There would be zero cost for this action.

Section Two would remove the Governor's right to hire the Executive Director and give it to the Council.

At the time of passage, AS 47.80.900 (7) coincided with the federal definition. Subsequent to its passage, the federal definition changed. Adoption of the federal definition would allow individuals in need of service who currently fall through the service delivery system cracks, to receive the help they need.

Statistically, it would appear that the individuals' requesting services would be increased by about 700 (see Attachment #1). However, current research shows that states which have adopted the federal definition have not experienced the increase in applications for service that would be expected statistically (see Attachment #2). They have, however, experienced requests for services which differ from services they have traditionally offered; for example, providing programs designed specifically for persons with physical disabilities as opposed to mental disabilities.

Position Paper, SB 52, page 2

Persons made eligible by this bill would be added to the 400 person waiting list which currently exist for developmentally disabled individuals requesting services.

Position

The Department of Health and Social Services supports passage of this bill contingent on the removal of Section Two concerning the hiring of the Executive Director of the Council.

Recommended by: Mike Renfro
Mike Renfro
Program Administrator
Developmental Disabilities

Date: _____

Approved by: Theodore A. Mala
Theodore A. Mala, MD, MPH
Commissioner
Department of Health and
Social Services

Date: 2/25/91

Attachment I

The following incidence statistics were provided by the Governor's Council for the Handicapped and Gifted and were derived by use of a complex formula.

The statistical incidence of individuals experiencing a developmental disability under the state definition is 7,067. The known population seeking or receiving services at this time is 2,110. This equals 29.8% of the population.

Statistically the federal definition would increase the overall population to 9,427. Using the same 29.8% request for services rate, this would mean 2,809 persons would need services. This is an increase of 699 individuals. However, recent studies show that states adopting the federal definition do not experience as high a rate as would be predicted statistically (see attachment #2).

service in each categorical disability. However, the majority of persons would remain eligible.

Lubin, R., J.W. Jacobson, M. Kiely. (1982). Projected impact of the functional definition of developmental disabilities: The categorically disabled population and service eligibility. *American Journal of Mental Deficiency*, 87,(1), 1982, 73-79.

- o *Studies in Maryland* concluded that substantial numbers of persons receiving services in the community, or on waiting lists, would become ineligible for service depending on the strictness of the interpretation of functional limitations.

Morrison, L.H., Scull, M. & Sachs, M. (1984). Adopting the federal definition of developmental disability: A preliminary analysis of potential effects on eligibility. Baltimore, MD: University of Maryland. School of Medicine.

- o *Studies in Ohio* indicated that, using a federal definition, the majority of persons with developmental disabilities other than mental retardation are already eligible for services using the current categorical definition. That is to say, that the group of persons defined as having a developmental disability under the federal definition are comprised of persons with mental retardation, cerebral palsy, epilepsy, autism, and other neurological conditions. Ohio concluded that the overall numbers of people to be served or planned for would remain relatively stable but that the nature of the population and the constellation of needs they represent will change as other groups with low-incidence disabilities are included.

Ohio Developmental Disabilities Planning Council. (December 1986). Fiscal implications of adapting the definition of developmental disability as proposed by the Ohio Developmental Disabilities Planning Council. Columbus, OH: Author.

A detailed review of these studies leads to the following conclusions.

- 1) In general, all studies indicate that the majority of persons presently receiving and eligible for services, would remain eligible for services. There is variance in the percentage of persons presently receiving services who would be excluded from service given a functional definition.
- 2) Of those persons who would become eligible for services, several states indicated that the majority of those persons are already being served in one or more state agencies. This raises the difficult policy question of whether services for such persons

should be transferred to a developmental disability agency.

- 3) Except in Maryland, researchers have been limited in their ability to predict how many persons made eligible for services who are not presently receiving services, would come forward for services. Given the reported reluctance of persons with physical disabilities to seek services from an agency providing services designed for persons with mental retardation, it may be assumed that demand for services among persons presently outside of the service system will not be substantially increased. This assumption is fortified by the knowledge that the overall numbers of persons in the low incidence disability groups who have substantial functional limitations is very small in relation to the numbers of persons who would remain eligible for developmental disability services.
- 4) Maryland data indicate that there are people, presently unserved, but who are identified as needing services, who would become ineligible for services under a functional definition. Therefore, adopting the federal definition requires an assessment of service priorities. Without careful consideration, state planners may end up excluding numerous persons, who while not presenting severe handicaps, do present significant needs for service. An example can be drawn from persons with epilepsy, who may not have severe functional limitations, but who can benefit from counseling and other minimal level interventions.
- 5) Several of the studies emphasize that while a change in the total numbers of persons served is not anticipated, planners can anticipate a change in the types of disabilities of the persons served. A developmental disability agency may or may not have the expertise, funding options, or service arrays to enhance the well-being of groups of persons with very disparate needs.
- 6) Unpublished data from Maryland indicate that the total numbers of persons eligible for services can fluctuate widely according to how strictly one interprets the federal definition. All studies used the definition as operationalized by Elinor Gollay. Still, any number of other interpretations can be made. Any given state would have to develop its own operational criteria and instrument to assess developmental disabilities. This can be a costly and time consuming operation.
- 7) Whether a state adopts an age of onset criteria at age 21 or later can have a substantial impact on the total numbers of persons who are eligible for services.
- 8) Finally, it must be remembered that the federal definition is

proposed as a planning tool to help direct funding and research activities to persons with more severe impairments. Operationalizing the definition into eligibility criteria may be inappropriate.

Numerous researchers and state planners have attempted to understand how the federal definition of developmental disabilities applies to actual state service delivery contexts. Most of the studies project an increase in potentially eligible clients; one study projects a decrease. None focus on the extent to which those persons who are unserved would demand different services other than those provided by the "DD agency" under an expanded definition, and how many of those currently outside the system would come forward.

Given the indeterminate character of potential demand for new or expanded services, other factors have to be taken into account when developing impact estimates. These factors include the proposed range of services to be provided, the quality of services, the extent of outreach and publicity associated with service offerings, and the ways in which the definition is operationalized.

What also emerges from this overview is that the federal definition was never intended to govern service eligibility at the delivery level. It was intended to focus planning and funding activities on individuals most in need and to facilitate further coordination between agencies in the development of comprehensive services. Without specific indicators and instruments to accompany the outlines of the definition, its application is ambiguous and somewhat unreliable.

The review of research also raises the question of the potential exclusion of individuals currently receiving services. Without any modifications, the federal definition does eliminate persons with less severe disabilities who may in fact require services in order to maximize functioning and well-being.

Finally, the studies underscore how the federal definition encompasses disparate disabilities, resulting in a wide range of service needs. Persons with physical disabilities, persons with brain injury, persons with severe learning disabilities, people with terminal and debilitating conditions -- all require services which do not fall neatly to one agency to provide.

2. State experiences in using a functional definition of developmental disabilities

This section reviews how other states have grappled with the adoption of a functional definition for eligibility determination.

During the course of this project, key staff were interviewed and documents were reviewed in a number of states. Four states were selected that had the most experience and that also represented a range of policy options and outcomes. Efforts in New Jersey, Maryland, Ohio, and Connecticut are reviewed below. This is followed by a brief outline of lessons learned.

New Jersey. In April, 1985, New Jersey changed its Division of Mental Retardation to the Division of Developmental Disabilities and expanded the Division's mandate to include persons with a wide range of developmental disabilities. Underlying this organizational change was a change from a categorical to a functional definition for service eligibility. For New Jersey, this was a particularly profound change since the Division of Mental Retardation had not, at that point, even expanded its service mandate to include cerebral palsy, epilepsy, and autism -- a change that had occurred in many other states. The transition to a Division of Developmental Disabilities is part of a three year planning project.

The definition that has been adopted by New Jersey is similar to the federal definition and reads as follows:

"Developmental disability" means a severe, chronic disability of a person which: (1) is attributable to a mental or physical impairment or a combination of mental or physical impairments; (2) is manifest before age 22; (3) is likely to continue indefinitely; (4) results in substantial functional limitations in three or more of the following areas of major life activity, that is, self-care, receptive and expressive language, learning, mobility, self-direction and capacity for independent living or economic self-sufficiency; and (5) reflects the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of life-long or extended duration and are individually planned and coordinated. Developmental disability includes but is not limited to severe disabilities attributable to mental retardation, autism, cerebral palsy, epilepsy, spina bifida and other neurological impairments where the above criteria are met (Bill S-1826).

This legislation specifies that, in general, the individual's disability must be manifest before the age of 22. However, a later clause gives the director of the Division discretion in expanding eligibility to any individual under the age of 55 who meets the other criteria if funds allow. Further, a caveat was added so that persons presently being served in the system would be "grandfathered" in without undergoing reassessment according to the new eligibility criteria.

To operationalize the definition into eligibility criteria, New Jersey developed a new screening instrument, the Critical Adaptive

Behaviors Inventory (CABI). CABI assesses the presence or absence of critical skills in each of the six life activity domains specified in the legislation.

To assist in planning and to monitor the transition to a Division of Developmental Disabilities, the Developmental Disabilities Council awarded a grant to the University Affiliated Facility at the University of Medicine and Dentistry of New Jersey - Robert Wood Johnson Medical School. This project is organized around nine task forces focusing on these areas: intake and eligibility; training; related services; employment; guardianship, advocacy, and self direction; housing; transportation; recodification; and mental health and developmental disabilities. The Year I report from this effort is available. The second year report is due in the winter of 1988. Volume II of the report will focus on task force papers such as: interagency agreements and decisions on staff retraining and reallocation.

Individuals interviewed in the state were reluctant to draw conclusions about the relative success of the transition since the process is still underway. They are anticipating an increased caseload of approximately 460 persons per year with an overall total of 1500 to 2000 at the end of five years. It is expected that this increased demand will flatten out after some of the pent up demand is accommodated. These are ball park figures based on the total prevalence of persons with disabilities drawn from census and reduced by 50%, a liberal estimate of how many of these persons are likely to come forward for service, according to the state administrators.

At present, there has not been a dramatic increase in demand for services. A registry has been created which presently lists several hundred names of new consumers requesting services. The list is expected to grow once the Division is fully operational. A survey of 30 persons on the registry indicates that housing is the service most needed. Housing in this case does not refer to typical group homes, rather it is housing adaptations or alternate living situations that promote independence and have full accessibility. State informants anticipate that the largest consumer group to come forward for service will be persons with physical handicaps who were under-served in New Jersey previously. The second highest service need identified in the survey was vocational rehabilitation and the third was for transportation.

The anticipated expansion in the numbers of persons served in New Jersey is based on the expectation that there will be an earnest undertaking to "redirect" service delivery so that persons with all developmental disabilities are indeed served. The redirection of department efforts has been well advertised and many different advocacy groups have been involved. Consonant with the change in service eligibility, New Jersey is substantially revising intake forms and service assessments and is expanding and improving their case management

system so that case workers have a greater understanding of the diverse needs of consumers. Along with a change in numbers of persons served, administrators expect that the service mix will change (e.g., more emphasis on after-school services, etc.).

The opportunity to include a diverse number of disability types into the service system has encouraged New Jersey administrators to rethink how they currently provide services to persons having mental retardation. Rather than adopt a "womb to tomb" approach to the new disability consumers, case workers are being trained to adapt to a truly "client driven system" with an emphasis on least restrictive environments, very individualized treatment planning, and provision of the minimum level of service intervention. Service providers are discovering that small adjustments such as an adaptive device can ameliorate urgent needs. In like fashion, creative solutions to traditional mental retardation service needs are being sought. Although there has reportedly been some resistance by non mentally retarded disability groups to come to the Division for services, the modest increase in legislative funding allocated and the efforts of the department described above have helped to alleviate the associated stigma.

With respect to the elimination of individuals currently eligible for services, persons in New Jersey have several observations. First, the new definition will not be used to reassess those currently receiving services. Second, the instrument that has been developed should not screen out anyone in need of services. However, in order to ensure that no one is adversely or unjustly affected by the new definition, the state intends to conduct an evaluation at the end of a year.

Ohio. Ohio's Department of Mental Retardation and Developmental Disabilities had been using a categorical definition for service eligibility that included mental retardation, cerebral palsy, epilepsy, and autism. The current definition, while still limited to these four categories of disabilities, requires that the disability be manifest prior to age 18, and requires a substantial handicap. A substantial handicap is defined as equivalent to the abilities of persons with moderate, severe, or profound retardation.

Because of concerns that many individuals with developmental disabilities, other than the four categories specified in the definition, were being unfairly excluded from services, a new definition has been proposed and is currently before the legislature. This definition is similar to the federal definition with the following exceptions: it excludes individuals with a sole diagnosis of mental illness, it includes individuals whose disability is likely to result in substantial functional limitations without some intervention (not just those who already have substantial functional limitations), it includes all children under the age of three who have only one developmental

delay, it includes children between the ages of three and six who have two developmental delays, and it gives the director of the Office of Mental Retardation and Developmental Disabilities discretion in accepting additional persons for service. Individuals interviewed in Ohio are hopeful that this legislation will pass. They do not expect a dramatic increase in demand for services as a result of the definitional change. In the first place, the legislation does not operationalize eligibility criteria. The Office of Mental Retardation and Developmental Disabilities will define these criteria at a later date and it is unlikely that they will set the criteria so that they will admit persons for whom they have no resources. Second, current Ohio law authorizes service delivery to certain categories of persons with disabilities. It does not mandate that all eligible persons be served. As a result, OMR/DD has the ability to control the amount of service provided.

Maryland. In considering strategies for expanding service delivery for persons with disabilities in Maryland, the federal definition of developmental disabilities (PL 98-527) was the first to be evaluated. The full federal definition was not adopted. The major reservation was that the definition did little to operationalize eligibility criteria and left too much ambiguity in the concept of substantial functional impairment. A study conducted by Michael Smull suggested how much variability could be expected given different ways of defining "substantial impairment." Smull and his colleagues conducted a study of 1,602 fifteen-year-olds who were in special education. They found that different definitions of functional limitation yielded eligibility rates ranging from .57% to 2.05% of the general population.

In July, 1986 the Maryland legislature passed a bill authorizing the Mental Retardation and Developmental Disabilities Administration to adopt a "modified" developmental disabilities definition. This act moved the state from a categorical definition that included mental retardation, cerebral palsy, autism, and epilepsy, to a more functional definition.

Maryland's definition differs from the federal definition in some interesting ways. In the first place, the definition clearly excludes those individuals whose disability results solely from mental illness. These persons will continue to receive services through the state's Mental Hygiene Administration. Secondly, where the federal definition specifies that an individual must be substantially functionally limited in at least three of seven major life activity areas, Maryland's modified definition focuses only on the individual's ability to live independently. This variable is measured in terms of personal and household management and use of community resources. The third, and perhaps most interesting departure from the federal definition involves the establishment of a two-tiered eligibility screen. As noted in the earlier discussion, individuals who meet all criteria specified in the definition (i.e. a diagnosis other than mental illness alone, age of onset before 22, and substantial functional limitation in the ability to

live independently) are eligible for the full range of services offered by the state agency.

Those individuals who fail to meet all of the criteria for developmental disabilities may still be eligible for individual support services. To be eligible for the upper tier of services two conditions of disability must still be met. The individual support services for persons with milder limitations do not include full day services and residential services, but include support services focusing on prevention, and enhancing the individual's ability to live independently in the community, which may include limited day services and residential supervision.

It is anticipated that this modified definition will, in fact, reduce the number of persons eligible (though not necessarily the actual numbers of persons served) for the full range of services in Maryland. Under the categorical definition, slightly more than 1% of the population were eligible for the full range of services. Under the new modified definition, only 1.7% are expected to qualify for the full range of services. Individuals who would have qualified under the old definition will remain eligible for individual support services, but will not be eligible for full day and residential services. A grandfather clause in the legislation protects the eligibility status of people already in the service system.

Despite an overall reduction in the number of persons eligible for service, the adoption of the functional definition opened the service doors to a broader spectrum of disability groups, and consequently a waiting list of 2,000 persons with disabilities other than mental retardation has formed in Maryland. Needs assessments have been conducted by Morrison, Sachs & Skull (1986) on the persons on the waiting list. The waiting list represents the best information known in any of the states that have changed definitions to project the numbers of persons with disabilities other than mental retardation that will actually come forward for service, given changed service eligibility, and what their service needs are. However, Maryland researchers view this data as an underestimate of the total numbers of persons with disabilities other than mental retardation that may come forward for service. They explain that limited funds and a limited service array discourage many potential consumers from identifying themselves for service.

Hawaii. In 1983, Hawaii changed from a categorical definition of disabilities that included mental retardation, epilepsy, autism and cerebral palsy to the federal definition of developmental disabilities. Persons eligible for services under the old categorical definition were automatically eligible for services under the new definition. However, it is anticipated that persons with mild impairments will be screened out in future years.

Persons in Hawaii note that they had anticipated an increase in demand for services as a result of this change. However, to date, there has not been an increase in the amount of service provided. Two reasons are cited to explain this. In the first place, the change in eligibility was not advertised widely. Second, the Hawaii statute does not mandate that all service applicants be served. The department operates within a budget and provides services only within its means. New resources were not allocated, and thus new services were not developed.

The most noticeable change has occurred in the area of case management. Since the state agency is now dealing with more individuals having more complex physical disabilities, case managers have had to adapt their strategies and reach out to different types of service providers.

Currently, the state is attempting to operationalize the eligibility criteria and to develop an instrument for assessing substantial impairment in three of the seven major life activities specified in the federal definition. They are also working on due process and grievance procedures for persons who are determined to be ineligible for services under the federal definition.

California. California considered adopting a functional definition for developmental disabilities in the early 1980's. The Health and Welfare Agency contracted with Berkeley Planning Associates (BPA) to explore the implications of making this change. As noted above, the BPA study described alternative organizational arrangements that were possible for the state to consider and summarized data on prevalence rates for various disabilities using both the federal definition of developmental disabilities and the categorical definition employed in California. On the basis of data from the 1976 Survey of Income and Education, BPA concluded that the transition to the federal definition might mean that four times as many individuals as are currently eligible for the services of the D. D. Division would become eligible. On the basis of these projections and their assessment of the current service delivery system in the state, California officials decided against the federal definition and kept the categorical definition that included mental retardation, cerebral palsy, epilepsy and autism.

Persons in the state do not feel that there are substantial numbers of individuals who are unserved. They believe that those persons who do not meet the eligibility criteria of their categorical definition are receiving services through other state agencies.

Summary of Lessons from Other States. The review of experiences in other states with changing definitions of developmental disabilities includes some considerations of import to Arkansas, including the following:

1. As found in the Hawaii experience, changes in agency mandates tend to have an immediate impact on case managers who must reach out to different groups and learn different service systems and providers.
2. The Ohio experience illustrates a way to focus attention on persons with severe disabilities while also recognizing the support needs of persons with more moderate disabilities. By including a section in the definition that allows eligibility for persons who would develop severe limitations in the absence of intervention. Maryland's "two tier" approach is also a response to assuring persons with less severe disabilities receive needed support.
3. The New Jersey approach recognizes the importance of an evaluation in order to ensure that the application of a new definition does not unduly penalize any particular disability group. New Jersey's three year phase-in is also a useful way of ensuring orderly implementation.
4. The review of changes in Hawaii's system reinforces the importance of developing a grievance mechanism to ensure the any definitional changes do not result in unjust service exclusion.
5. The New Jersey and Maryland reviews draw attention to the necessity to develop instruments that are capable of discriminating among those who are eligible and those who are not eligible for services.

SB 52

Senator Jim Duncan
State Capitol Building
Juneau, AK 99811

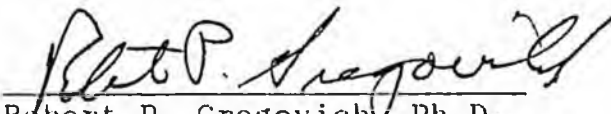
Feb 15, 1991

Dear Senator Duncan,

I support Senate Bill 52, a Bill to change the definition of Developmental Disabilities to conform with the Federal Definition. We have been too long in changing the definition to be more reasonable and fair for all children and families who experience a developmental disability.

Therefore, your Bill is welcomed. As a former Director of the State's Developmental Disabilities Program in The Department of Health and Social Services, I wish to tell you that my job would have been made more efficient had we had a more appropriate definition to work with such as you are proposing. If I can be of help in your efforts, please contact me at 586-2243 or 586-1627.

Sincerely,



Robert P. Gregovich Ph.D.
202 Troy Ave
Juneau, Alaska 99801

5B52

source but for the enactment of this part, except that whenever considered necessary to prevent the delay in the receipt of appropriate early intervention services by the infant or toddler or family in a timely fashion, funds provided under section 673 may be used to pay the provider of services pending reimbursement from the agency which has ultimate responsibility for the payment.

"(b) REDUCTION OF OTHER BENEFITS.—Nothing in this part shall be construed to permit the State to reduce medical or other assistance available or to alter eligibility under title V of the Social Security Act (relating to maternal and child health) or title XIX of the Social Security Act (relating to medicaid for handicapped infants and toddlers) within the State.

42 USC 701.
42 USC 1396.

"STATE INTERAGENCY COORDINATING COUNCIL .

"SEC. 682. (a) ESTABLISHMENT.—(1) Any State which desires to receive financial assistance under section 673 shall establish a State Interagency Coordinating Council composed of 15 members.

20 USC 1482.

"(2) The Council and the chairperson of the Council shall be appointed by the Governor. In making appointments to the Council, the Governor shall ensure that the membership of the Council reasonably represents the population of the State.

"(b) COMPOSITION.—The Council shall be composed of—

"(1) at least 3 parents of handicapped infants or toddlers or handicapped children aged 3 through 6, inclusive,

"(2) at least 3 public or private providers of early intervention services,

"(3) at least one representative from the State legislature,

"(4) at least one person involved in personnel preparation, and

"(5) other members representing each of the appropriate agencies involved in the provision of or payment for early intervention services to handicapped infants and toddlers and their families and others selected by the Governor.

"(c) MEETINGS.—The Council shall meet at least quarterly and in such places as it deems necessary. The meetings shall be publicly announced, and, to the extent appropriate, open and accessible to the general public.

"(d) MANAGEMENT AUTHORITY.—Subject to the approval of the Governor, the Council may prepare and approve a budget using funds under this part to hire staff, and obtain the services of such professional, technical, and clerical personnel as may be necessary to carry out its functions under this part.

"(e) FUNCTIONS OF COUNCIL.—The Council shall—

"(1) advise and assist the lead agency designated or established under section 676(b)(9) in the performance of the responsibilities set out in such section, particularly the identification of the sources of fiscal and other support for services for early intervention programs, assignment of financial responsibility to the appropriate agency, and the promotion of the interagency agreements,

"(2) advise and assist the lead agency in the preparation of applications and amendments thereto, and

"(3) prepare and submit an annual report to the Governor and to the Secretary on the status of early intervention programs for handicapped infants and toddlers and their families operated within the State.

Report.

"(f) CONFLICT OF INTEREST.—No member of the Council shall cast a vote on any matter which would provide direct financial benefit to that member or otherwise give the appearance of a conflict of interest under State law:

"(g) USE OF EXISTING COUNCILS.—To the extent that a State has established a Council before September 1, 1986, that is comparable to the Council described in this section, such Council shall be considered to be in compliance with this section. Within 4 years after the date the State accepts funds under section 673, such State shall establish a council that complies in full with this section.

"FEDERAL ADMINISTRATION

"Sec. 683. Sections 616, 617, and 620 shall, to the extent not inconsistent with this part, apply to the program authorized by this part, except that—

"(1) any reference to a State educational agency shall be deemed to be a reference to the State agency established or designated under section 676(b)(9),

"(2) any reference to the education of handicapped children and the education of all handicapped children and the provision of free public education to all handicapped children shall be deemed to be a reference to the provision of services to handicapped infants and toddlers in accordance with this part, and

"(3) any reference to local educational agencies and intermediate educational agencies shall be deemed to be a reference to local service providers under this part.

"ALLOCATION OF FUNDS

"Sec. 684. (a) From the sums appropriated to carry out this part for any fiscal year, the Secretary may reserve 1 percent for payments to Guam, American Samoa, the Virgin Islands, the Republic of the Marshall Islands, the Federated States of Micronesia, the Republic of Palau, and the Commonwealth of the Northern Mariana Islands in accordance with their respective needs.

"(b)(1) The Secretary shall make payments to the Secretary of the Interior according to the need for such assistance for the provision of early intervention services to handicapped infants and toddlers and their families on reservations serviced by the elementary and secondary schools operated for Indians by the Department of the Interior. The amount of such payment for any fiscal year shall be 1.25 percent of the aggregate of the amount available to all States under this part for that fiscal year.

"(2) The Secretary of the Interior may receive an allotment under paragraph (1) only after submitting to the Secretary an application which meets the requirements of section 678 and which is approved by the Secretary. Section 616 shall apply to any such application.

"(c)(1) For each of the fiscal years 1987 through 1991 from the funds remaining after the reservation and payments under subsections (a) and (b), the Secretary shall allot to each State an amount which bears the same ratio to the amount of such remainder as the number of infants and toddlers in the State bears to the number of infants and toddlers in all States, except that no State shall receive less than 0.5 percent of such remainder.

"(2) For the purpose of paragraph (1)—

State and local governments. Education. 20 USC 1483, 20 USC 1416, 1417, 1420.

Guam. American Samoa. Virgin Islands. Republic of the Marshall Islands. Federated States of Micronesia. Republic of Palau. Commonwealth of the Northern Mariana Islands. 20 USC 1434.

20 USC 1416.

P.O. Box Y - State Capital Juneau, Alaska 99811

"(A) t
birth to
"(B) t
scribed i
"(d) If any
tion (c)(1), th
amounts fro

"Sec. 685.
this part \$5
1988, and su
ing fiscal ye
(b) STUDY
retary of Ex
ices shall c
services for
shall jointl
resources fo
handicape
programs, c
capped Act.
(2) Not li
this Act, th
Human Se:
ing the fin
describing

TITL
SEC. 201. PR
(a) AMEN
ed to read

"Sec. 61
1990 if the
fiscal year
"(A
"(B
"(C
cappe
"(2)(A) 1
paragraph
"(i)
who
State
"(ii
the p
dren
catio:
611(a

BOARD: HANDICAPPED AND GIFTED, GOVERNOR'S COUNCIL FOR THE

BOARD IDENTIFICATION NUMBER: 43

TITLE: Governor's Council for the Handicapped and Gifted

DEPT: Department of Health and Social Services

AUTHORITY: AS 14.30.231 & 47.80.030; PL 100-146 & 99-457

STATUS: ACTIVE TERM: 3 years

DESCRIPTION: 18-23 members appointed by Governor: 50% must represent the developmentally disabled (D.D.) or parents or guardians of same (as noted in the Special Facts below); with geographic balance and variety of handicaps represented. 1/3 must represent the principal state agencies concerned with services for handicapped/gifted; 1 member must be a State legislator; 1 must represent the Older Alaskans Commission (which may also double as a State Agency representative). Members serve at pleasure of Governor. Council selects chair.

SPECIAL FACTS: Serve at the pleasure of the Governor. Federal funding. Federal law (which supersedes state law) requires that the state council must be comprised of at least 50% consumers: (A) 1/3 of 50% must be primary consumers - persons with D.D. which is a severe/chronic mental or physical impairment manifested before age twenty-two; (B) balance may be secondary consumers - who are parents or guardians of such D.D. persons; and (C) 1/3 of 50% consumers must be persons who are immediate relatives or guardians of persons with mentally impairing D.D. (at least one of these individuals shall be an immediate relative or guardian of an institutionalized or previously institutionalized person with a D.D.). For Alaska, this means a minimum of 9 parents or guardians, or people with developmental disabilities. They may not be employees of a state agency or any other agency which receives funds or provides services under this Public Law.

FUNCTION: Interdepartmental planning/coordinating agency of the Dept. of Health and Social Services, the Dept. of Education, and other departments which deliver services to handicapped or gifted. State planning council for purposes of federal laws relating to the handicapped or gifted.

COMPENSATION: Standard travel/per diem. MEETINGS: 3 times per year, committee meetings included; 15 days maximum.

*FOR FURTHER INFORMATION CONTACT: Director, Governor's Council for the Handicapped and Gifted, University Plaza Office West, Suite B, 600 University Avenue, Fairbanks, AK 99709
PHONE: 474-2440 (Revised 1/14/91)

REVISION DATE: 1/15/91

HANDICAPPED AND GIFTED

MEMBER	APPT	REAPT	REAPPT	TERM
Kathy Allely P.O. Box 773333 Eagle River 99577 Consumer/Secondary	88/09/14	0/00/00	0/00/00	91/06/30
Keith Anderson DOE, Div. Voc. Rehab., Box F Juneau 99811 State Agency/DOE, Voc. Rehab.	87/10/01	90/11/05	0/00/00	93/06/30
Josephine G Barresi P.O. Box 711 Bethel 99559 Special Ed/Teacher	88/09/14	0/00/00	0/00/00	91/06/30
Susan M Beck Box 82556 Fairbanks 99708 Consumer/Secondary	88/09/14	0/00/00	0/00/00	91/06/30
Mary Cattanach P.O. Box 6614 Anchorage 99519 Gifted/Talented	88/09/14	89/08/28	0/00/00	92/06/30
Roger Claussen 2210 Roosevelt Drive Anchorage 99517 Consumer/Primary	89/11/09	0/00/00	0/00/00	92/06/30
DHSS Staffmember DHSS, P.O. Box Juneau 99811 Comm./DHSS/Des.	90/00/00	0/00/00	0/00/00	0/00/00
Duane M French 3710 Woodlawn Avenue Anchorage 99503 Consumer/Primary Chair	86/03/03	86/09/19	89/08/28	92/06/30
Bob Gore 119 Austin Street, #911 Ketchikan 99901 State Agency/OAC	88/09/14	0/00/00	0/00/00	91/06/30

REVISION DATE: 1/15/91

HANDICAPPED AND GIFTED

MEMBER	APPT	REAPT	REAPT'	TERM
Steve Hole Commissioner, DOE, Box 7 Juneau 99811 Comm./DOE/Designee	86/10/02	89/08/28	0/00/00	92/06/30
Eileen Lally 6508 Fairweather Place Anchorage 99518 Higher Education	90/11/30	0/00/00	0/00/00	91/06/30
Robert "Bob" Locke 4133 Aspen Avenue Juneau 99801 Consumer/Secondary Chair	88/09/14	0/00/00	0/00/00	91/06/30
Susan K Nelson 4601 Reka Drive, C-8 Anchorage 99508 Consumer/Primary	90/11/05	0/00/00	0/00/00	93/06/30
Mike Renfro P.O. Box H-04 Juneau 99811 State Agency/DHSS/Div.Ment.Health & D.D.	88/09/14	0/00/00	0/00/00	91/06/30
James Rich DOE/Ed. Program Support/P.O. Box F Juneau 99811 State Agency/DOE/Education Support	90/11/05	0/00/00	0/00/00	93/06/30
Brenda Trumble P.O. Box 136 Klawock 99925 Consumer/Secondary	86/09/19	89/08/28	0/00/00	92/06/30
Valerie A Van Brocklin 9631 Hillside Drive Anchorage 99516 Advocacy Representative	89/11/09	0/00/00	0/00/00	92/06/30
VACANT	0/00/00	0/00/00	0/00/00	93/06/30
Legislator (Governor Appointment)				

REVISION DATE: 1/15/91

HANDICAPPED AND GIFTED

MEMBER	APPT	REAPT	REAPPT	TERM
Blanche Walters P.O. Box 728 Nome 99762 Consumer/Secondary	81/06/30	90/11/05	87/10/01	93/06/30
Sandra Watson P.O. Box 1063 Wrangell 99929 Special Ed./ Admin.	90/11/05	0/00/00	0/00/00	93/06/30
Jenny Weaver Box 703 Pelican 99832 Consumer/Secondary	88/09/14	0/00/00	0/00/00	91/06/30
Jonni Wingfield 3236 LaTouche, Apt. #4 Anchorage 99508 Consumer/Primary	88/09/14	0/00/00	0/00/00	91/06/30
Leslie H Yamamoto P.O. Box 83496 Fairbanks 99708 Consumer/Secondary/Institution	90/11/05	0/00/00	0/00/00	93/06/30