..... a project of national significance

Expanding the Scope of Developmental Disabilities Councils

Implications for Texas

Prepared by the Texas Planning Council
for Developmental Disabilities

a project of national significance

Expanding the Scope of Developmental Disabilities Councils: Implications for Texas

Prepared by
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Mr. Bob Williams, Commissioner
Administration on Developmental Disabilities
Administration for Children & Families
Dept. of Health and Human Services
200 Independence Avenue, S.W.
Hubert H. Humphrey Bldg. 329D
Washington, D.C. 20201

Dear Commissioner Williams:

During the last reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 103-230), a national debate developed about the advisability of changing the definition of developmental disabilities to be more inclusive. A decision was reached to fund, as Projects of National Significance, up to five states to study the impact on developmental disabilities councils of adopting a more inclusive definition. The Administration on Developmental Disabilities was also authorized to study from the national perspective the advisability of changing the definition.

Texas was one of two states awarded grants to implement the study from the states' perspective. This Final Report contains the findings from the Texas study and a recommendation from the Texas Planning Council for Developmental Disabilities to eliminate the age of onset from the developmental disabilities definition. The Texas Council does not recommend any other change to the definition.

The Texas Planning Council for Developmental Disabilities wishes to acknowledge the assistance of the University Affiliated Program and its Director, Penny Seay, Ph.D., and the Texas Protection and Advocacy Agency, Advocacy, Inc., and its Executive Director, Jim Comstock-Galaghan. Both of our sister agencies have provided valuable advice and assistance during this project. The University Affiliated Program, in particular, participated in several activities of the project through a sub-grant. Without this assistance completion of the study would have been much more difficult.

Planning and advocating for independence, productivity and community inclusion.

The Texas Planning Council for Developmental Disabilities would also like to thank the people and their agencies who contributed their time and expertise through membership on the study Work Group and the consumer advocacy agencies representatives who participated in the policy analysis of the study. Their names and affiliation are included in this Report.

With the hope that this study will clarify the issues related to expanding the developmental disabilities definition, the Texas Planning Council for Developmental Disabilities respectfully submits this Final Report to the Administration on Developmental Disabilities.

Linda A Parrish

Linda Parrish, Ph.D.
Chair

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Introduction

When the Developmental Disabilities Assistance and Bill of Rights Act (the Act) was reauthorized in 1994, a national discussion among Councils and other organizations about desired changes in the Act was underway. Among the changes discussed was a changes in the definition of "developmental disabilities" so that it would be more inclusive. While no consensus on the desirability of such a change was reached during the reauthorization period, a provision was included in the reauthorized act (P.L. 103-230) authorizing up to five states to study the impact on Developmental Disabilities Councils (DD Councils) of a change to the definition.

Two states, Maryland and Texas, were awarded grants to implement studies of the impact of a definitional change. This Executive Summary provides a brief overview of the findings from the Texas study.

The Texas study proposed use of a Work Group made up of service and consumer advocacy agency representatives to guide the study implementation. Fifteen agencies were included in the Work Group. Membership is listed in Appendix B.

Components of the Study

Focus Groups. Data were collected from six Focus Groups held in widely dispersed locations in the state. The Focus Groups were asked to provide information on "what do you need to live in the way you wish to live?" and what enables you to live the way you want to live?" These questions were chosen to elicit information about Focus Group participants needs and desires to determine congruence with current DD Council priorities and activities. The questions were developed in conjunction with the Work Group.

Participants in the Focus Groups were invited to attend and were limited to 12-15 persons. Persons with disabilities or family members closely associated with the person with a disability made up the participant list. On Work Group advice, paid providers of services were not invited, although in practice many family members also self-identified as paid service providers. When this was the case, the family members were asked to answer the questions from a consumer viewpoint.

Participants were also chosen to be representative of persons currently included by the developmental disabilities definition and persons who might be expected to be included if the definition were changed by eliminating the age of onset from the definition and by reducing the number of functional limitations required from three to two. Finally, participants were chosen who represented the cultural diversity of Texas. A total of sixty-seven persons participated in the Focus Group meetings.

Focus Group information was analyzed using a grounded theory methodology. The analysis yielded the following categories of concerns:

- Personal Assistance
    - Attendant Care
    - Assistant Care
    - Respite Care
- Education of:
    - Parents and family members
    - Professionals
    - Community at large
- Transportation
- Information
- Acquiring individual assertive behavior

Further analysis revealed a central theoretical construct of "the Qualifying Game." The Qualifying Game describes the efforts and behaviors needed to obtain services, supports and options necessary for person with disabilities and their families to live as they want to live.

Comparison with the findings from the Focus Groups and the <u>1990 Reports</u>, published by the Administration on Developmental Disabilities, the National Association of Developmental Disabilities Councils and the Texas Planning Council for Developmental Disabilities showed a high level of congruence. It appears that regardless of age of onset or diagnosis, people with severe, chronic disabilities (people with three or more substantial, functional limitations) identify the same needs and concerns and identify the same barriers to service.

The picture is less clear for a comparison between people with three or more substantial functional limitations and those persons with fewer than three. The need for personal assistance services appears to fall with the number of substantial functional limitations present.

Literature Review. A literature review was undertaken as a second component of the study, primarily to develop prevalence data for disabilities that would be included if the definition was changed. The literature review also sought information on the similarity of needs among current and expanded definition groups of persons with disabilities.

The literature review was disappointing. Little data are available that are directly or even reasonably comparable to prevalence data for people with developmental disabilities. Less data were available to compare needs of the two groups. What information was available combined with professional expertise available in the Texas DD Council staff and from other professional sources lead us to conclude that people with adult onset mental illness and people who meet a definition of frail elderly would constitute the largest groups not now included who would be included under a definition expanded by eliminating the age of onset. These groups plus people with learning disabilities and less severe disabilities of all kinds make up the largest groups that would be included if the number of functional limitations were reduced.

Policy Analysis. A third component of the study was a policy analysis of the impact of expanding the definition. To obtain data on and reach conclusions about the policy impact of changing the definition, information was sought in separate meetings from the Texas DD Council staff and a group of representatives from consumer advocacy agencies and the Texas Protection and Advocacy Agency, Advocacy Inc., and the Texas University Affiliated Program. Information from the Focus Groups and the literature review were presented to both groups. Both groups concluded that the age of onset should be eliminated from the definition. Staff concluded that the number of substantial functional limitations should not be reduced. The chief reasons for this conclusion are two. First, Congress in the hearings preceding the reauthorization of the Act had indicated their desire that DD Council remain focused on people with the most severe disabilities and, second, staff (and subsequently, the Texas Council) stressed a similar desire. The Consumer agencies representatives were divided on the matter of reducing the number of substantial functional limitations. Boards of two agencies have taken a position of supporting an "ADA definition," that is, presence of any disability, or appearance or perception of a disability.

Both groups consulted were divided about the political desirability of expanding the definition of developmental disabilities in the present political climate. Opinions that it would be well to "lay low" during a period of governmental reductions were expressed. On the other hand, opinions were expressed underscoring the importance of developing a broad based constituency with like needs to advocate for desired services, supports and options during a period of political flux.

Analysis of Annual Program Performance Reports. An analysis of Annual Program Performance Reviews from 8 DD Councils was undertaken to determine the level of congruence between current DD Council activities and those that would be needed to address the concerns of a population expanded by eliminating the age of onset. The analysis revealed common themes and council activities for the participating Councils that indicate little or no need for change in Councils functioning if the age of onset is eliminated. The analysis also revealed a list of "filters" or values that overlay each Councils activities and result in unique color or focus for each.

Council Recommendation. Study findings were presented to the Texas Planning Council for Developmental Disabilities in a meeting of the Council as a Committee of the Whole in October 1995. No conclusions were reached nor recommendations made. At that meeting, Council members held an in-depth discussion of the implications of changing the definition either by eliminating the age of onset or reducing the number of substantial functional limitations. Council members requested that staff develop an analysis of "pros and cons" of changing the definition by reducing the age of onset and a list of compelling reasons for and against changing the definition by reducing the age of onset. The two lists may be found in Tables IV and V, of the report. The analyses were made available to Council members prior to their meeting in November 1995 when a recommendation decision was due.

In the November 1995 Council meeting a brief discussion was held and the Council voted to recommend a change in the developmental disabilities definition eliminating the age of onset. The Council also voted not to recommend a change in the definition reducing the number of substantial functional limitations from three to two.

EXPANDING THE SCOPE OF DEVELOPMENTAL DISABILITIES:

IMPLICATIONS FOR TEXAS

Conclusions

The Texas Planning Council for Developmental Disabilities (Council) has concluded that the definition of "developmental disability" contained in P.L. 103-230, the Developmental Disabilities Assistance and Bill of Rights Act (the Act) should be changed to eliminate the age of onset from the definition. The Council has concluded that the definition of "developmental disability" should not be changed in any other manner. The following discussion details the information studied by the Council in reaching this decision and presents the reasons supporting the conclusions.

History and Overview

Introduction

When the Act was reauthorized in 1994, a national discussion among Councils and other organizations about desired changes to the Act had been underway for some time. One aspect of the discussion centered on the desirability of changing the definition of developmental disability contained in the Act so that it would be more encompassing. The discussion was inspired, to some extent, by the desire of groups who viewed themselves as having similar needs and functional limitations as people with developmental disabilities to be directly represented by the Councils in their states. The discussion was also influenced by the recognition by some Councils that in their advocate, capacity building, and systems change activities, they were also representing other people with disabilities when advocating for various functional supports and services. Some states (Utah and Texas are examples) had developed and funded coalitions or consortia that included advocate members representing a wider constituency than people with developmental disabilities. Those states with expanded constituency coalitions recognized the advantages of formally working together to achieve goals benefiting all people with disabilities.

However, during the reauthorization period no consensus supporting changing the definition developed and a compromise position was reached. The Act, when reauthorized, contained authorization for up to five Councils to study the desirability of changing the definition and directed the Commissioner of the Administration on Developmental Disabilities (ADD) to conduct additional activities exploring the matter. As a result, ADD issued an RFP in July 1994. Texas and Maryland were funded to study the question and ADD commenced its data gathering. This report contains the findings from the Texas study.

History of the Definition

Definitional Changes

P.L. 91-157**.** In 1970, Title I of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 was amended in order "to assist the States in developing a plan for the provision of comprehensive services to persons affected by mental retardation and other developmental disabilities originating in childhood, to assist the States in the provision of such services in accordance with such plan, to assist in the construction of facilities to provide the services needed to carry out such plan, and for other purposes." (Preamble, Public Law 91-157, 91st Congress, S. 2846). The short title for the Act created was the Developmental Disabilities Services and Facilities Construction Amendments of 1970. The definition of "developmental disability" contained in P.L. 91-157 was "a disability attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual found by the Secretary to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals[1] (sic), which disability originates before such individual attains age eighteen, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to such individual."

P.L. 94-103. By 1975, the Developmental Disabilities Services and Facilities Construction Amendments had been amended again and the definition was changed by the addition of the conditions of autism and severe dysphasia. In the 1975 version, the definition read as follows:

(7) "The term "developmental disability" means a disability of a person which-
(A)(i) is attributable to mental retardation, cerebral palsy, epilepsy, or autism;
(ii) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to

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[1] The Texas Planning Council for Developmental Disabilities uses "people first" language, that is, such terms as "person with a disability" rather than "disabled person." However, when directly quoting material that does not use "people first" language, we have chosen to retain the original language and insert (sic) following it.

that of mentally retarded persons or requires treatment and services similar to those required for such persons: or

(iii) is attributable to dyslexia resulting from a disability described in clause (i) or (ii) of this subparagraph;

(iv) originates before such person attains age eighteen;

(C) has continued or can be expected to continue indefinitely; and

(1) constitutes a substantial handicap to such person's ability to function normally in society.

P.L. 95-602. Over the next several years pressure grew to add more categorical (diagnostic) conditions. Rather than expanding the definition to include an increased list of conditions, the definition was changed in P.L. 95-602, the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978, to reflect the use of "functional limitations" rather than diagnoses as criteria, that is:

(7) 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 or physical impairments;

(B) is manifested before the person attains the 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 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.

These changes in the definition affirmed that developmental disabilities are functional, rather than categorical. The impact of this definition on the population covered under previous versions of the definition was significant. The new definition placed emphasis on serving persons with the most severe disabilities. This change dramatically reduced the number of people included with a diagnosis of mental retardation while providing services to some portions of the population, such as persons with multiple handicaps like deaf-blindness and those with severe learning disabilities not served under previous versions of the definition.

P.L. 103-230. In 1994, in P.L. 103-230 the definition was amended again to accommodate for the difficulty in diagnosis and, frequently, undesirability of diagnosis for very young children. Changes from the 1978 version are in bold.

The term 'developmental disability' means a severe, chronic disability of an individual 5 years of age or older that--

(A) is attributable to a mental or physical impairment or combination of mental or physical impairments;
(B) is manifested before the person attains the 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 sufficiency, and
(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and are individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

Service Needs

With the 1978 amendment, the Act included under the Congressional findings section, a statement about the service needs of people with developmental disabilities, "persons with developmental disabilities often require specialized lifelong services to be provided by many agencies in a coordinated manner in order to meet the person's needs." (P.L. 95-602, Section 101(A)(3)). By 1994, the service needs section of Section 101(a)(6) of P.L. 101-230 finds "individuals with developmental disabilities often require lifelong specialized services and assistance, provided in a coordinated and culturally competent manner by many agencies, professionals, advocates, community representatives, and others to eliminate barriers and to meet the needs of such individuals and their families." This section suggests, in its reference to "specialized lifelong services" and "many agencies in a coordinated manner," that Congress sought to ease the difficulties of service access for people with developmental disabilities. It could also be suggested that Congressional intent was to provide assistance to the states in meeting the needs of persons with developmental disabilities, i.e., severe, chronic disabilities.

Definition Changes Discussion

It is apparent from reading the various definitions of developmental disability contained in the Act over the last 24 years that the general movement in changes in definition has been toward:

1) Making it more encompassing of conditions; and

2) Keeping it focused on severe limitations experienced by individuals.

In fact, Congressional findings contained in the Act as early as 1978, (H.B. 12467, later P.L. 95-602, Section 101(a)(2)) state that "individuals with disabilities occurring during their developmental period are more vulnerable and less able to reach an independent level of existence than other handicapped individuals (sic) who generally have had a normal developmental period on which to draw during the rehabilitation process."

It appears in this finding that Congressional intent was to attempt to meet the needs of individuals with the most severe and limiting disabilities, those that might be described, as in later versions of the definition, as severe, chronic disabilities.

The assumption that disabilities occurring in the developmental period are more disabling than those occurring after the developmental period, i.e., after age 22, has remained an underlying, although frequently, unstated justification for limiting the definition of developmental disabilities by age of manifestation of the disability. This assumption, which has continued over time, overlooks advances in medicine and technology. The advances have resulted in an increased number of individuals who survive catastrophic traumas and illnesses that result in disabilities as profoundly limiting as those resulting from childhood onsets. This leads to the two major assumptions of this study, that is, that **the definition of developmental disability is also a definition of a severe, chronic disability** and that **severe, chronic disabilities occur at any point along the lifespan.**

The service needs section of the Act has retained its focus on attempting to improve the circumstances of people with developmental disabilities by improving access to and the quality of services and other assistance. This continuing focus led the major assumptions for this Study, that is:

- that people with severe, chronic disabilities that require long term services and assistance from many agencies would benefit from the activities of Councils;

- and that **activities of Councils would not significantly change if the definition of developmental disabilities were expanded** to include all people with severe, chronic disabilities.

Evolution of Developmental Disabilities Councils

The DD Councils have evolved over time in reaction to changes in the definition, values, and the individual states and federal service systems. In the first years of their existence, Councils focused on developing an alternative service system, that is, developing a community service system as an alternative to institutionalization. The general approach taken by Councils was to fund numerous small demonstration projects that would serve as model programs for community development and to conduct needs surveys to identify the size of the population needing services as well as the "array or continuum" of services needed in an alternative service system.

Consistent with the service definition of this period, emphasis was on people with mental retardation primarily and secondarily on the other identified populations. Texas's experience in the early years is consistent with the national trend.

In FY 1970-71, the first year money was available for grants from DD Councils, Texas awarded 68 grants to entities across the state. The list of grants awarded included projects such as:

Survey of community and State School persons for Sheltered Workshop
Pre-School program for disadvantaged
Summer Day Care Camp Program
Summer Recreation Program for (people with) mental retardation
Development of a Language Laboratory for Pre-School (children with) mental retardation
Training Program in jewelry manufacturing for (people with) mental retardation
County-wide survey of (people with) developmental disabilities
Provision of Speech Therapy services for summer

Review of the list points out that in many cases the grants were for the provision of direct services on a short term basis and in a small service area. This practice, too, is representative of the approach taken in DD Councils across the country. The assumption was that if communities saw the value of or received the benefit of these direct care services they would find means to continue the service after Council funds had ceased. Where Councils fund demonstration projects now, this assumption remains and typically Councils require an increasing percentage of the project's budget to be generated by the grantee. Also, the short term nature of the funding continues with Councils usually funding projects for three year periods.

Over the years, many Councils became dissatisfied with this approach. Consider the size of Texas, with 254 counties, over 1000 school districts and an even larger number of communities and imagine the effort of seeding service programs sufficient to effect systems change. Clearly, if a demonstration or seeding approach of funding service projects in first this and then that community were pursued, Councils would make little progress in affecting significant system development. In Texas, the utility of this approach was questioned as early as FY 1971 in relation to planning for resource utilization for FY 1972. In a letter to the Texas Council members, Dr. Gary Sluyter, Executive Director of the Council in 1971, asked members the following two questions:

> "Should [the Council] use a "shotgun" approach, funding a large number of small grants...or should we limit the focus to a smaller number of significant, demonstration types this year?" and
>
> "Should our goals be very <u>specific</u> and tight or more <u>general</u> in nature?"

Dr. Sluyter also commented to the Council members that "there are some 588,000 (persons with developmental disabilities) in Texas. That is an interesting coincidence, as 588,000 dollars was our last allocation. I'm sure you would agree that one dollar per year, per person can not make much impact unless we plan carefully."

Even with this early questioning of a "shotgun" approach, the Texas Council continued with its strategy of funding a large number of demonstration grants into the 1980s. At a watershed meeting of the Council in the mid 1980s, Mr. Max Arrell, the Commissioner of the Texas Rehabilitation Commission, the designated state agency for the Council, asked the members why they continued the practice of funding a large number of small grants. He commented that he felt the Council could be more effective by focusing on a smaller number of grants with enough money attached to make a difference. The members recognized Mr. Arrell's suggestion as a challenge to be more effective, more "strategic," in their use of resources. At that meeting, the Texas Council began its "systems change" strategy, that is, focusing on statewide systems of services, service delivery barriers, and advocacy activities.

Today, Texas expends most of its funds on large scale systems change activities. Demonstration grants are limited to model development attached to the statewide systems change grants. For example, Texas has funded an inclusive education systems change grant that has held extremely successful statewide conferences (over 2000 persons attending), developed and distributed an inclusive education videotape, provided technical assistance on inclusive education to school districts, and distributed large amounts of best practice information on inclusive education across the state. In conjunction with this systems change statewide grant, the Council has funded local inclusive education grants to three school districts which have undertaken to be totally inclusive schools by the end of the granting period. These schools provide a laboratory for inclusive education in the state.

Along with this shift in granting strategy, Texas has chosen to interpret the definition of developmental disabilities broadly and to use the broadened interpretation to develop a broad advocacy base and a network of disability consumer advocacy agencies, the Disability Policy Consortium (DPC). The DPC consists of 20 member organizations representing people with developmental disabilities and people with other disabilities. The DPC meets twice monthly using the meetings to explore policy, legislative and other systems level developments that affect people with disabilities. The meetings are also used to build coalitions among member agencies to support advocacy efforts that achieve the goals of community inclusion and integration. The Council's experiences with the Disability Policy Consortium are one reason that Texas is comfortable with expanding the definition of developmental disability.

Texas is not alone in its evolution from a Council funding a large number of small demonstration grants to funding a small number of focused systems change grants. The current DD Act (P.L. 103-230) charges Councils with involving themselves in systems change activities and a review of Annual Program Performance Reports for several states confirms that other states have adopted this approach.

Texas is also not alone in developing broad based advocacy networks. In the late 1980s, only five states, Texas among them, reported having developed an advocacy network. In the recent Commissioner's Forum on expanding the definition held in Atlanta, Georgia, all states attending from Region IV (Tennessee, Kentucky, Mississippi and Georgia) and Florida report having a functioning broad based advocacy network or being in the process of developing one. No information is available on North and South Carolina, the other states in Region IV.

At this time, the Texas Council believes that issues that are a priority for people with developmental disability are frequently critical issues for people with other severe disabilities and that we are more effective when we work jointly with organizations representing that broader constituency. When we do so, we function **as though** the definition of developmental disabilities has been expanded to eliminate the age of onset.

Study Overview

Hypotheses

The assumptions related to the definition and the service needs led to the study's exploration of the similarity of needs among people with severe, chronic disabilities and, by extension, our hypothesis that the nature and scope of Council activities would not change significantly by dropping the age of onset from the developmental disabilities definition. (It should be noted here that the data collected by the Texas Council is not of a type that allows testing of an hypothesis although it is of a type that allows "confidence" in the findings. Appendix A contains the full report from the Focus Group portion of the study. The methodology section of the full report of the focus group data collection and analysis explains qualitative research methods and analyses and the confidence that may be placed in the findings. Hypotheses were stated for convenience in conceptualizing the study.)

The other hypothesis stated in the study was that the nature and scope of Council activities would not change if the functional limitations requirement of "substantial, functional limitations in three or more of the major life areas" were changed to read "two or more." The assumption underlying the study of this hypothesis was that no study had verified a substantial difference in the service needs of a population with a minimum of two functional limitations as opposed to three functional limitations.

Components of the Study

This study also assumed that it was not desirable to change the nature of the Councils' activities and that it was not desirable to change the focus on persons with severe, chronic disabiities. These assumptions were not stated but developed in discussion with the Study Work Group, the staff of the Texas Council, and the Texas Council members. Further, Congress, in authorizing the studies, had stated that Councils should continue to focus on groups with severe, chronic disabilities.

Three major components made up the study. They consisted of data collection from focus groups, a literature review and policy analysis. The focus group component was considered to be central to the study and was the major source of data for the study. The emphasis on the focus group data resulted from the investigators' belief that if the needs, issues, concerns and barriers are similar for people with severe, chronic disabilities regardless of age of onset, then the work of the Council would be the same if the age of onset were eliminated. Similarly, with the number of functional limitations, if the needs are the same, the work of the Council will be the same. All three components of the study were conducted with advice from a Work Group of stakeholders. Stakeholders were identified as members of groups covered under the current definition, groups that would be covered under an expanded definition, and agencies serving both constituency groups.

Work Group

Representatives from the following groups and agencies were invited to participate in the initial Work Group meeting:

Advocacy, Inc. (The Texas Protection and Advocacy Agency)
The Texas University Affiliated Program for Developmental Disabilities (the UAP)
Institute for Disability Access
Coalition for Texan with Disabilities (Personal Attendant Services Task Force)
United Cerebral Palsy of Texas
The Arc of Texas
Texas Head Injury Association
Texas Alliance for the Mentally Ill
Mental Health Association in Texas
Texas Mental Health Consumers
Texas AIDS Network
Texas Advocates

American Association of Retired Persons
Gray Panthers
Texas Department on Aging
Texas Department on Mental Health/Mental Retardation
Texas Rehabilitation Commission
Texas Health and Human Services Commission
Texas Commission for the Blind
Texas Commission for the Deaf and Hard of Hearing

As a result of input from the group at its first meeting, an invitation was extended to Healthsouth (an agency providing services to people who are aging) to appoint representatives. Healthsouth appointed two representatives, but did not attend on a regular basis. Texas Aids Network appointed a representative who attended no meetings. Neither AARP nor Gray Panthers responded to the invitation. (Appendix B lists the members of the Work Group by name and agency.)

Focus Groups

The Work Group advised project staff on the composition, location and the questions to be asked of the Focus Group participants. A full presentation of the focus group input, findings, and analyses may be found in Appendix A. A summary report may be found in the Focus Group Section of this report. The input of the Focus Group was the primary source of data upon which the conclusions of this study are based. Other data sources and analyses were used to confirm the conclusions reached on the data from the Focus Groups.

Literature Review

The review of literature was conducted by study staff. In the literature review, staff looked for evidence that would confirm or deny the similarity of needs among persons with severe, chronic disabilities regardless of age of onset and for persons with one, two or three or more functional limitations as defined in the Developmental Disabilities Act. A review of literature was conducted to identify incidences of severe chronic disabilities across populations included by expanding the definition, but resulted in little information since few agencies use the three functional limitations method of determining presence of a severe, chronic disability. The results of the literature review were disappointing also in that few sources gave any comparable data about comparative needs or priorities. Findings from the literature review may be found in the Literature Review Section of the study report.

Policy Analysis

Policy Analysis was conducted with consideration of the results from the focus groups, the literature review, and two meetings of staff members of the Texas Council, a meeting with representatives of consumer advocacy agencies, the Work Group and the Texas Council. The results from each of the meetings was most interesting because of the uniformity of conclusions reached by each.

Additional Analyses

Study staff also conducted additional analyses of fiscal and resource impact on the Texas Council of expanding the definition. It was determined by study staff that a review of currently funded activities of the Texas Council would shed some light on the applicability of the Council's activities to expanded populations and, therefore, illuminate the need to change the nature and scope of the Council's activities if the definition were changed. A review of Council projects and Annual Program Performance Reports from nine Councils was undertaken by the University Affiliated Program to secure these data.

Focus Groups

Introduction

The following is a summary report[2] of the results from the Focus Group discussions held as an activity of the study. The Focus Group discussions focused on the supports, needs and life issues of persons with severe, chronic disabilities. In this study, focus groups were used as a data collection technique in order to obtain in-depth interview data from individuals with severe, chronic disabilities, their families, and their advocates. These focus groups consisted of a heterogeneous group of individuals.

Research Questions

Focus Group research questions were formulated by the study work group. In particular, the work group targeted the following questions as primary in this study:

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[2] The full report may be found in Appendix A. The full report contains a complete description of the study methodology, analysis methodology, and findings.

1. What are the service and support needs of persons with severe chronic disabilities?

2. What issues, barriers and opportunities exist currently in the lives of persons with severe chronic disabilities?

These questions were selected by the Work Group to determine whether the service and support needs of individuals with disabilities varied given the age of onset of the disability or the number of functional limitations demonstrated by the individual with disabilities.

Participants

Six communities across the state of Texas were chosen as sites for focus group meetings. The communities selected differed from those proposed in the study application. The work group advised that Lubbock be substituted for Amarillo, Tyler for Denison and McAllen for Laredo. These substitutions were based on Work Group knowledge of active advocacy groups in the substituted cities. One of the intentions in selecting these communities was to provide a sample that was culturally diverse. Communities that represented geographically varied areas of Texas, as well as urban and rural populations, also were included.

Once the six communities had been selected, paid advocates and service providers in these communities were consulted to identify possible participants. However, paid advocates and service providers were asked not to participate as it was the belief of the Work Group that their presence would inhibit the candidness of responses from the other participants. In actuality, it was the case that many individuals with severe disabilities or their family members also were employed in advocacy or service capacities. In these cases, participants were asked to take part in the focus group from their vantage point as an individual with a severe disability or as a family member, rather than from the vantage point of a paid professional.

The individual participants who attended the six focus groups, as had been desired, represented a wide array of areas of disability, as well as a variety of ethnic and cultural groups. These participants also represented areas of chronic disability that occur across the life span and thus were not solely representative of those disabilities acquired prior to age 22. Each individual focus group consisted of individuals with severe disabilities, family members, or unpaid advocates. Each focus group was limited to 12 to 15 participants in order to facilitate fluid group discussion. Table I illustrates demographic data from the individuals who participated in these focus groups.

Prior to each focus group meeting, an area coordinator from a local support group was selected to identify possible participants and to facilitate setting the location for the meeting. Potential participants were contacted initially by the area coordinator who provided a brief description of the study. Interested potential participants then were sent a packet of information by the researchers, which contained a letter of introduction, an overview of the entire project, an agenda for the meeting day, and a copy of the consent form. Packet information was provided in audio tape or Braille if requested by the individual. Interpreters for people who were deaf or Spanish speaking were provided as needed. Accommodations needed by the participants were identified so that attendance at and participation in the focus group could take place.

Table I
Participant Demographic Data

Participants	
Family Members	36
Individuals	31
Cultural Groups	
Native American	3
Asian American	3
African American	2
Hispanic	15
Anglo	46

Areas of Disability Represented:
Alzheimer's, Cerebral Palsy, Cystic Fibrosis, Deaf, Diabetes, Mental Health, Polio, Mental Retardation, Mobility Impaired, Multiple Sclerosis, Seizure Disorder, Traumatic Brain Injury, Visual Impairment.

Procedure

Each focus group met once between the months of February and April of 1995. Meetings consisted of a session from 9:00 a.m. to 2:30 p.m. with an hour break for lunch. Specific meeting sites in each community were chosen based on accessibility, required accommodations for participants, and general recommendations given by area coordinators. All focus group sessions were audio-taped for later transcription and analysis.

Focus group discussions centered on three questions presented by the facilitator and followed by several probes. These questions and probes were:

1. What helps you live the way you want and manage your own life?
   Probe: If I could wave a magic wand and you had the help you needed to live the way you want and manage your own life, what would that help look like?

2. How are you getting the help you need right now?
   Probe: What or who is helping you now? When you need support, where do you turn?

3. If the TPCDD were to represent all of you here today, how might they help you?

Focus group meetings were well attended with 85% of those who had been invited to participate in attendance. The majority of the participants actively contributed in each focus group. Participant response to the initial focus group question often resulted in a two hour long discussion in which they shared their personal experiences and built on the stories and issues shared by other members of the group.

Analysis

The focus group format provided an efficient method by which to gather a large amount of interview data from a wide variety of participants. Each focus group meeting was audio taped and consent was secured from all participants to use the materials gathered in the tapings.

Audiotapes from each focus group meeting were transcribed and read within two weeks of the meeting. A total of 25.5 hours of tape were transcribed, which produced a total of 568 pages of data. After the initial reading, transcripts of the focus group meetings were analyzed using a grounded theory methodology developed by Strauss and Corbin (1990). Such analysis allowed the researcher to generate and verify emerging theoretical constructs concerning central issues in the lives of individuals with severe chronic disabilities. During the analysis, a central phenomenon, causal conditions, context, intervening conditions and consequences were identified.

At this point in the analysis, it was felt by the researcher that a verification of the initial categories and analysis was necessary. A second researcher, familiar with grounded theory methodology, was contracted to examine and verify the initial stages of analysis. Open coding was again conducted on transcripts from all focus groups. Resultant codes and categories were listed. Categories were compared to those obtained by the first researcher. Jointly, the two researchers compared their obtained conceptual categories and agreed upon a working set of categories. From these categories, the researchers identified a phenomenon around which all categories from the focus groups were related.

Results

All six focus groups meetings provided a rich source of information from individuals with severe chronic disabilities and family members. Participants appeared comfortable when responding to focus group questions, which resulted in lengthy detailed discussions.

Central Theoretical Issue

A central theoretical construct emerging from the focus group data centered on what the participant's themselves labeled as the "Qualifying Game."

Changing Economic Status. Participants shared that constant change and turmoil is a primary feature of the "game." Entry requirements, rules for qualifying and information concerning these rules is difficult for consumers to obtain. However, consumers are not the only players confused by the game. Service providers often are confused as well resulting in misinformation being provided to the public.

This concept of the "qualifying game" is described best as a sociological contract that is, in actuality, designed by society. The "qualifying game" exists primarily because resources are scarce and difficult to obtain and because the service system is fragmented, duplicative, and, at the same time, incomplete. The service system has developed as a result of attempts to meet needs of individuals on a categorical basis; that is, based on diagnoses, ages, and other criteria, rather than a functional need basis. The "qualifying game" was described by participants in Forging A New Era: The 1990 Reports on People with Developmental Disabilities (National Association of Developmental Disabilities Council, May, 1990) (National 1990 Reports).

An outline form of the model for this theoretical concept of the "Qualifying Game" is presented in Table II. This model serves as an overview of the process by which individuals come to acquire services or at least gain more knowledge about acquiring services.

Another defining characteristic of families in which a severe or chronic disability is present is the need for support services to meet the overwhelming limitations and barriers that the disability presents. The primary issues and concerns presented in the Table III, were consistently shared as an important focus in all the focus groups. Regardless of area of disability or age of onset, these common issues remained the same and were a central focus in the family's life.

Table II
"Qualifying Game" Model

A) Causal Condition

Presence of a disability in the family

Properties

- Of disability:
  - duration; chronic
  - course; stable vs. degenerative
  - personal limitations; severe
  - type of impairment; sensory, mobility, cognitive
  - when occurred (birth vs. later onset)
- Of family;
  - family size
  - need for services

B) Central Phenomenon

Goal of acquiring services

Dimensions

- Intensity of goal
- Duration of goal

C) Context

Set by the characteristics of the social services delivery system

Under conditions where the goal of acquiring services is based on intense need and on a continuing basis, then;

D) Intervening Conditions

May facilitate or constrain strategies used:

- Gatekeepers
- Level of knowledge
- Accessibility and availability of services
- Economic services
- Presence of a family caretaker
- Communication
- Perception of disability

Action/Interaction Strategies

- Being assertive
- Gaining knowledge
- Moving to obtain services
- Changing economic status
- Attendant services

E) Consequences

Increased knowledge of the "qualifying game."

Acquire services (leading to inclusion in the community as well as economic and emotional stress relief).

Table III
Primary Categories of Concerns

Across age of onset or nature of disability,
the primary categories of concerns included:

- Personal Care
    - Attendant Care
    - Assistant Care
    - Respite Care

- Education of:
    - Parents and family members
    - Professionals
    - Community at large

- Transportation

- Information
    - Acquiring individual assertive behaviors

Causal Condition

The presence of a disability in the family was seen as personally limiting and the limitations to personal freedom were severe. Across areas of disabilities, individuals talked about the personal loneliness and desperation that resulted from being socially isolated.

Although all individuals and families with disabilities may experience the issues and concerns mentioned above, participants shared that a severe disability was marked by multiple limitations in daily functioning. Even when the area of disability may exist within a single diagnostic category, "severity" appears to exist as an extreme along a continuum of functional limitations. As the number of limitations to independent, individual functioning increases, the level of severity of the disability increases.

Just as every individual with a severe, chronic disability and family are unique, so the constellations and priorities of needs for that individual are unique. However, there exists a consistency in the patterns of needs across areas of disability. Family members and individuals with a severe, chronic disability cited often the need for information and requested repeatedly for one central location to obtain this service. National 1990 Reports describes individuals and families across the country expressing a need for information and referral services. The Texas Council responded to this stated need by funding a grant (coming to an end during FY 1996) to develop a statewide information and referral service.

Central Phenomenon

At every focus group meeting, the central issue of the entire group discussion related to the goal of acquiring services. Gaining services, which included gaining supports and accommodations in the community, was portrayed as a daily survival issue which overshadowed any other issue or concern in their life.

The goal of acquiring services is comprised of the unique constellation of needs of individuals and their families. However, the nature of this goal must be viewed within a larger framework. The goal of acquiring services is impacted greatly by the interaction between the individual and the service delivery system. In this way, the central phenomena must be viewed within the context in which it resides.

Context

While the goal of acquiring services was the central issue of focus group discussion, the backdrop for this phenomenon was the overall context of the social service delivery systems. Support services were reported as scarce and expensive.

In addition, accessing services was described as difficult and dependent on the ability of the individual or family member to physically contact the service agency. Transportation was cited as a major problem with inability to access transportation negatively impacting the ability to obtain health care, be employed, take advantage of higher education opportunities or generally be included in the community.

Intervening Variables

Eight different categories that emerged from the discussions of the focus groups affected how readily individuals with disabilities and their families were able to acquire services. These categories function as intervening variables in that they facilitated or constrained the strategies that the participants used in order to acquire services. In many cases, these variables may be seen as "barriers" to acquiring services. However, within the "qualifying game" process, these same barriers may at times become "opportunities" if the individual understands the nature of the "game." They are gatekeepers, level of knowledge (needed to obtain services), accessibility and availability of services, economic status, presence of family support (advocacy), perception of disability (by others), and communication. Each is briefly discussed below.

Gatekeepers. Participants in the focus groups made repeated references to individuals who functioned as "gatekeepers" to needed services. These gatekeepers were individuals who played a vital decision making role within the service delivery system. Roles of the described gatekeepers were to decide whether or not a person qualified for services or to supply additional information about services that might be available.

Direct service providers were also described by focus group participants as being gatekeepers that kept them from needed services, protecting access to their individual services, rather than helping individuals search for services. The National 1990 Reports referred to this phenomenon as the need for case management services, assuming that case managers have knowledge of the broader system and can coordinate service delivery.

Level of Knowledge. Participants in the focus groups described how they needed to obtain knowledge in a number of key areas in order to obtain services. First, they needed knowledge about the disability that they themselves had or that their family member had. The less knowledge they had, the more difficult it was to determine where to begin their search for services. Second, they needed knowledge about agencies and organizations that provided services to individuals with disabilities.

Accessibility and Availability of Services. One of the primary constraints that prevented individuals with disabilities and their families from obtaining services was that services were inaccessible because of long waiting lists or unavailable because they simply did not exist. These constrains were described by the participants as resulting from lack of funding, or in some cases, from the low pay that service providers received for their work.

Economic Status. The economic status of the family limited the services that they received. All of the participants in the focus group discussed how services for individuals with disabilities were expensive and that they were unable to privately finance services or an adequate amount of services. Those families who had more financial resources reported that they often did not qualify for public assistance programs, while those families who did qualify for these programs reported they had to limit how much they earned so that they did not lose benefits.

Presence of Family Support. A supportive member of the family was described by the participants as the primary person that assisted the individual with the disability with personal care, supervision, or interpretation services. In the focus groups that were part of this study the family member was usually the parent, spouse, or child of the individual with the disability, although it was occasionally a sibling.

The presence of a family caretaker affected the extent to which individuals with disabilities needed attendant or assistive care or an interpreter. Those without a family caretaker had to finance assistant services including attendant care so that they could function independently. Those family caretakers who participated in the focus groups also had to assist in seeking support services for the individual with the disability.

Perception of Disability. How others, particularly service providers, viewed the family or individual with the disability affected the ability of the family to obtain services. The perception most disturbing to those participating in the focus groups was when others emphasized what the individual with the disability could not do, rather than what they could do. Individuals whose perceptions affected the ability to obtain services were parents, educators, and the community members at large. These perceptions were usually discussed as ones that constrained the individual with disability, or their family, from obtaining services and from functioning independently.

Communication. Communication was usually a factor that directly affected the individual with the disability. When the individual with the disability might have difficulties in communicating, for example, because of speech impairments, deafness, or limited English, he or she was also severely limited in obtaining services. An assistant of some type was needed to help the individual obtain services.

Strategies

Focus group participants described common strategies that they used to obtain needed services. These strategies were actions that the individuals and family members took in their attempts to acquire services, or responses they made in reaction to barriers that they encountered during their search for services. Five categories of strategies were predominately discussed by participants; being assertive, gaining knowledge about how to play the "qualifying game," moving to an urban area that had the needed services, changing their economic status, and enlisting the help of attendants or caretakers to acquire services. These strategy categories are described in the following section.

Being Assertive. Participants discussed how it was necessary for them to be extremely assertive in order to obtain services in their communities. This assertiveness was used to obtain information about available services and to advocate for disability rights.

Gaining Knowledge. Participants indicated that knowledge about the service system was important to obtain services. Participants believed that the more knowledge they had about how to qualify for services, the more likely they were to obtain services, and the more knowledge they had about what services were available, the more successful they would be at qualifying for services.

Moving To Obtain Services. Individuals with disabilities and their families who lived in rural areas spoke about the difficulty in obtaining services, particularly skilled attendant care. Many families had chosen to relocate to cities where these services were available.

Changing Economic Status. Participants repeatedly discussed the high costs of services needed by individuals with disabilities and their difficulties in obtaining services through public agencies. Families had to carefully monitor their income as a change in economic status might mean the loss of services. Some families consciously chose to impoverish themselves in order to qualify for a wider range of services.

Attendant Services. Attendant care was one of the types of services that individuals with disabilities and their families sought. Attendants, in turn, were used to obtain other services.

Consequences

Participants shared that although the ultimate goal was to obtain needed services, acquiring information about the process was seen as a positive outcome in itself. Even when necessary services were unavailable or difficult to attain, knowledge of how to begin attaining them was enough to provide the individual with an increased sense of personal control. Some level of personal independence and control over their own lives were seen as equally vital to focus group participants as the needed services.

Often, the level of services an individual or family received directly correlated with the degree of inclusion that individuals experienced within their communities. These outcomes were seen as basic life goals and provided the driving emotional force behind the search for services.

Conclusions

Based on the analysis of the focus group meetings, a storyline emerges which illustrates how the issues, barriers and opportunities in the lives of individuals with a severe, chronic disability impact these participants' lives. This storyline may be seen as follows:

What is true about all of these groups is that having a disability creates a need for services that are scarce and costly. Financial assistance is needed to obtain these services. People, at first, know very little about how to obtain services. They begin going to doctors, agencies, social workers, and teachers, none of whom are particularly satisfactory in either providing them with services, referring them for services, or in being empathetic about the needs of the individual with the disability. Often these entities are seen as being uninformed, inept, insensitive, or unhelpful.

disability need. They have the power to order services or to refer the individual to services. It also means they usually make a "yes" or "no" decision regarding the individual's eligibility and do so based on how their agency defines "disability."

This definition is a microcosm of how much of society perceives individuals with a disability, i.e., by what they cannot do rather than what they can do. Persons with a disability and their families have to become educated, assertive, and persistent to obtain services that are controlled by gatekeepers. They understand the nature of their disability, the need to network with other parents/individuals with disabilities, the need to educate themselves about services available, and the need to educate themselves about their rights.

Depending on how well this game is played the family and individual with the disability may obtain needed services. However, once a person qualifies they may not receive services because of shortages or long waiting lists. The level of services received are correlated to the degree of inclusion that the individual has in the community. The ability to receive services also influences the level of stress (economic and emotional) experienced by the family and/or the individual with the disability.

This description of living with a disability will be very reminiscent for persons with developmental disabilities, their families, professionals and advocates. It varies little, if at all, from the "personal stories" told in every venue where people with disabilities self-advocate.

Participants of the focus groups identified five primary categories of concerns with subcategories under two of the primary concerns. The five categories of concerns are: personal care services with subcategories of attendant care, assistant care and respite care; education with subcategories of parents and family members, professionals, and the community at large; transportation; information; and acquiring individual assertive behaviors. In addition, participants identified that these needs must be satisfied before other needs such as individual and family health, ability to earn a livelihood and independence could be met.

The concerns, frustrations and strategies they described are reminiscent of those identified in the National 1990 Reports. The function of these needs in the lives of the participants call for the strategies assigned to DD Councils by the Act, that is, systems change, capacity building, and advocacy.

Literature Review

Commonality of Need

Forging a New Era (National 1990 Report), and the Recommendations for Improving Services to People with Developmental Disabilities in Texas (Texas Planning Council for Developmental Disabilities)(Texas 1990 Report), proved to be valuable sources in the review of literature. The Texas 1990 Report was especially valuable in confirming the results from the study focus groups. Much confidence was developed in the study focus group results because of their marked similarity both to priority issues and comments made in the focus groups held for the Texas 1990 Report. The reports that were compiled into the National 1990 Reports were prepared as a response to a requirement in the 1987 amendments to the Act for the states to make recommendations to the Governor, State Legislature and U.S. Department of Health and Human Services about:

(A) "the most appropriate state agency or agencies of the State to be designated responsible for the provision and coordination of services for persons with developmental disabilities...;"
(B) "the steps to be taken to include the data and recommendations...in the State Planning Council's ongoing advocacy, public policy and model service demonstrating activities;" and
(C) "obtain comments on any proposed recommendations concerning the removal of barriers to services..." (P.L. 100-146, Section 122(f)(4)).

The Texas Council, in implementing this requirement, conducted a survey by mailing 12,000 questionnaires to addresses across the state. A total of 980 completed surveys were returned from service providers/professionals and parents, guardians or other relatives, volunteers/advocates and people with disabilities. Of the top ten recommendations agreed to by the survey respondents, seven apply to the results from the study focus groups. They are listed below. The associated concern from the study focus groups is shown in parentheses following the recommendation.

1. Increase funding of home and community-based services. (Accessibility and Availability of Services)
2. Establish an information and referral system. (Information, Education of parents and family members)
3. Recommend training for teachers, social workers and health professionals. (Education of professionals)
4. Develop a permanent In-Home and Family Support program. (Personal Care Services, Attendant Care, Assistant Care, Respite Care)
5. Adopt consistent definitions and eligibility criteria. (Qualifying Game)

6. Require school-to-adult transition planning. (Accessibility and Availability of Services)
7. Improve local transportation. (Transportation)[3]

The Texas Council also held a series of fourteen public forums to provide input on the Texas 1990 Report recommendations [developed by the Texas Council's 1990 Report Task Force] The forums were attended by 446 persons and 165 persons submitted written testimony. The top ten service needs identified by the forum participants ranked by the frequency of comment were:

1. respite care;
2. information and referral;
3. residential services;
4. financial assistance to pay for services;
5. vocational training and employment opportunity;
6. habilitation and rehabilitation services;
7. child care;
8. adult and child activity programs (summer programs, after school care, adult programs);
9. transportation; and
10. increased public awareness information about people with developmental disabilities to reduce discrimination and promote public acceptance and community support for home and community-based services.

Correspondence between these forum identified service needs and those identified in the focus groups are apparent. Comments made by participants of the forums and the study focus groups were virtually interchangeable. For example,

From the Texas 1990 Report:

> "You have to almost know the answer in order to ask the right question."
>
> From Study Focus Groups:
>
> "...he advocated for himself because he understood the rules...if he hadn't understood or challenged them on it...he would have went (sic) in there, they say, 'No, we can't help you.' walked out and not got anything."

Similarities are further underscored by reviewing the topics or chapter headings from the National 1990 Report and comparing them to those revealed by the study focus group analysis.

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[3] The other three recommendations were: expand housing and residential services; expand supported employment opportunities; and develop health insurance options.

1990 Topics*	Study Focus Group Concerns*
Civil Rights and Empowerment	Education of parents, family members
Supports; Personal Assistance Services	Personal Care Services**
Supports; Public Education	Education of Professionals and Community at Large
Supports; Information and Referral	Information and Referral
Transportation	Transportation
Case Management	Information

*Because of dissimilar analysis methods, the topics do not share names; however, content remains similar.

**Personal Care Services includes Personal Attendant Services, Personal Assistant Services and Respite Services.

The following issues identified by Texas 1990 Report participants were addressed by focus group participants, but as needs that could be met only after the "basics" listed above were satisfied:

Education and Learning
Work
Income
Home

Participants in the study focus groups recognized the similarities among issues regardless of conditions or age of onset and began forming alliances during breaks, sharing information and problem solving for each other without regard to age of onset or causal condition.

Prevalence

Several sources of Texas and national prevalence data were reviewed for the study. (See Appendix C, Disability Statistics, for a list of sources reviewed.) Usable prevalence data for the expanded populations under each hypothesis proved to be extremely difficult to obtain. The difficulty arose from use of different definitions of disability.

No data directly comparable to developmental disability prevalence data were found for the prevalence of severe, chronic disability occurring after age 22. The biggest difficulty with determining prevalences occurs because most estimates do not differentiate between mild and severe disabilities. Where estimates are available for severe disability prevalence, they are usually organized in such a manner that the resulting estimates are overlapping and duplicative internally to the survey or with the current definition of developmental disabilities. For example, in the Survey of Income and Program Participation (SIPP), persons were counted as having a severe disability if they were described by one of 12 statements.

Two of those twelve statements will serve as examples of the difficulty of obtaining useful prevalence data. They are: "Person 16 years old to 67 years old who were prevented from working at a business or job," (age is disconjunctive with the age for developmental disabilities and may not meet the three functional limitations criteria) and "Person 15 years old and over with mental retardation, a developmental disability such as autism or cerebral palsy, or Alzheimer's disease, senility, or dementia...." (description is duplicative of the previous description and more limited than the definition for developmental disabilities).

The SIPP which provided a figure of 9.6% for estimating the incidence of "severe disability," and Living in the Community with a Disability, a publication of the Public Policy Institute of the American Association of Retired Persons, provided the most useful sources of incidence estimates. Both sources yield national prevalence estimates. The following findings are from the SIPP:

> Of 195.7 million persons 15 years and older, 17.5% had difficulty with one or more functional activities and 7.8% were unable to perform one or more activities.
>
> Of the 34.2 million persons having difficulty with one or more functional activities, more than half had difficulty with more than one activity; 14.5 million had difficulty with one; 7.1 million had difficulty with two; and 12.6 million had difficulty with three or more.
>
> Among the 15.2 million persons who were unable to perform one or more functional activities, 7.0 million were unable to perform one activity, 4.0 million were unable to perform two activities, and 4.3 million were unable to perform three or more activities (the latter two figures are not statistically different).

Living in the Community with a Disability provides the following 1991-92 data on prevalence of children under age 18 with activity limitations:

4,047,000 have an activity limitation.
2,957,000 have a major activity limitation.
396,000 are unable to perform a major activity.
149,000 have an Activity of Daily Living limitation.
86,000 have 3 or more Activity of Daily Living limitations.

The SIPP also reports the following statistics describing the percent of the population with a severe disability by age:

1.3% of the population with a severe disability are under age 18.
5.2% of the population with a severe disability are between 18 and 44.
15.3% of the population with a severe disability are between 45 and 64.
33.9% of the population with a severe disability are 65 or older.

From this information we may conclude that: 1) the number of persons meeting the criteria for disability decrease as the severity or number of limitations increases; and 2) as age increases, the number of persons meeting the criteria increases. This information should be interpreted remembering that "although developmental disability is most commonly associated with children, the majority of people with developmental disability are 22 to 49 years old." *(Characteristics of Persons with Developmental Disabilities,* Thornton, Craig, 1990 reported in Living in the Community with a Disability.)

Policy Analysis

Work Group

When presented with the findings from the focus groups, the Work Group agreed that there was no significant difference between the concerns stated by persons with developmental disabilities and persons with adult onset disabilities **as long as the disability was severe and chronic in nature,** i.e., met the criteria of three functional limitations and was expected to continue indefinitely. The Work Group was struck by the commonality of need for respite, personal assistance, transportation, information and referral, and assistance with access to services expressed by all-whether the parent of a young child with multiple congenital disabilities, an adult with adult onset functional limitations resulting from mental illness or closed head injury, or a relative of an individual with advanced Alzheimer's disease. The other common concern expressed by the focus group members which impressed the Work Group was the isolation and desire for inclusion stated by the participants.

The Work Group recognized that the biggest difficulty faced by all of these people was the fragmentation of services, the "qualifying game," and the long waiting lists faced by people attempting to access needed services. One service agency member of the Work Group even stated that the difficulties in accessing services was, in part, purposeful. The extent of the need would overwhelm resources if the system made it easy to access services. The Work Group was not asked to determine the advisability of changing the definition, but clearly recognized the commonalities existing among focus group participants.

Council Staff Analysis

Current Priorities

Current priority activities for the Council are driven by the Council's State Plan for Texans with Developmental Disabilities for Fiscal Years 1995-97 (State Plan). The goals of the Council State Plan are:

> *People with disabilities are included throughout all life experiences.*
>
> *People with disabilities have power and control their own lives.*
>
> *People with disabilities have available the supports and services to allow them to make choices about the way they live.*

In support of the State Plan goals, most Council activities are focused on community integration/inclusion, employment, self-advocacy, and enhancement of services and supports. (See Appendix D, Grants Profiles List, for a listing and profile of the Council's current grants.) An exception is a major Council advocacy initiative, the Disability Policy Consortium, a coalition of 20 organizations (See Appendix E, Disability Policy Consortium Membership, for a list of member organizations.) that meet regularly to identify, formulate positions on, and educate public officials regarding public policy issues of concern to persons with disabilities and their families. The Consortium offers member organizations the opportunity to jointly endorse and publicly support such positions. Membership in the Consortium is not limited to organizations for people with developmental disabilities, but is open to the larger group of organizations representing people with disabilities in Texas who support the Consortium's mission and principles. The Consortium has functioned extremely well and is considered to be one of the most important activities of the Council.

Age of Onset

In addressing the proposed change to the age of onset, staff compared and discussed the impact of eliminating age of onset from the definition. The current definition in law contains a requirement that age of onset of the disabling condition be prior to age 22. If age of onset were dropped, some people with three functional limitations (a severe disability) resulting from mental illnesses, closed head injuries, spinal cord injuries, genetic syndromes with adult onset (e.g., Huntington's Chorea), AIDS, disabilities of aging, and possibly other conditions would be eligible to benefit from Council activities. Their priorities for services and advocacy would be taken into consideration when the Council planned its activities. Staff discussion also centered around current Council priorities, current advocacy coalitions and changes that might be expected if the definition were expanded.

Discussion among Council staff also focused around the expected congruency between the Council's activities and the expressed needs and concerns of the expanded populations. The Council's staff balanced this against the perceived need to continue representing the current populations at the current level. The following discussion topics summarize the Council staffs input.

Community Integration/Inclusion Needs. These needs appear to be largely the same for people with developmental disabilities and people with adult onset severe, chronic disabilities, although individuals with disabilities who are aged may have different priorities within these needs. These differences in priorities will very likely not be significant enough to alter Council activities which will remain focused on improving the functionality of the system. For example, older persons may place greater emphasis on health care issues and less on employment and education. Staff indicated that within the population included under the current definition, priorities differ across age, covering the gamut of life activities.

All participants in the focus groups spoke of their ongoing desires to be participating members of the community who work, play, and live in the community. Assistants, whether family members or others, of persons who were aged who met the definition echoed this desire for themselves and for the person for whom they cared. Isolation was a central theme identified in the focus group results and appeared to be among the most painful outcomes of having a severe, chronic disability or being a family member of a person with a severe, chronic disability.

Staff noted that while people with developmental disabilities have been the targeted recipients of the Council's integration/inclusion activities, the changes achieved have had a broader impact by meeting the needs of other groups of people with severe, chronic disabilities. An example that was cited by staff was the Council's activities in respite care, specifically, the activities that resulted in changes in law to nurse delegation of duties for stable individuals. While the original group expected to benefit from this activity was children who are medically fragile and their parents, the changes will benefit all individuals with severe, chronic disabilities and the people who assist them regardless of age.

Options. Supports & Services. The needs, desired services, and supports reported in the study focus groups do not appear to be significantly different than those reported in the Texas 1990 Report. Respite, typically, was the first service mentioned as needed to assist persons with severe, chronic disabilities. Mention of respite was followed quickly by mention of personal assistance services and other in-home and family support services. As a means of verifying the desire of study participants for in-home and family supports, participants providing assistance at each focus group meeting were asked if they had considered placing the person with the disability in a nursing home. In each case the participants were indignant and distressed at the suggestion. They all rejected nursing home placement as anything but a very last resort or as an emergency placement.

Staff saw the desire for in-home and family supports expressed by the study focus group participants as evidence of a match with current Council activities and priorities. This was another factor supporting eliminating the age of onset from the definition.

Systems Change Activities. With the understanding that all Council activities are part of a systems change strategy, and in the presence of similar needs, issues, and concerns, dropping the age of onset will not significantly change the Council's activities. The Council has traditionally undertaken systems change activities in a manner which seeks to improve the system based on functional needs. Staff concluded that, in light of present survivorship of catastrophic accidents and illnesses, the age of onset as included in the definition is arbitrary and not related to the functional needs of individuals. Relative to this discussion, the staff gave much consideration to increasing the age of onset rather than dropping it altogether. This discussion was related to the feeling by some staff that the needs of people who are aging with disabilities might overwhelm the Council and change the focus of Council activities. Staff concluded that any new age of onset, such as 55, would also be arbitrary and not based on functional need. It would also be contrary to the findings from the focus groups that if functional limitations are present, the needs of individuals remain the same. (See Appendix F, individual Profiles, for a series of profiles of individuals of all ages and number of functional limitations that was used as a work sheet to guide this discussion. When presented to the staff the age of the individual and the accompanying diagnoses were not revealed.)

Grant Activities. Staff reviewed the current grants awarded by the Council to determine if meeting the expected needs of the expanded population would change the Council's granting activities by type or purpose. Appendix G, Council Grants Projects, shows an analysis of Council grants, the populations they affect and any negative impact that might result to any currently eligible group as a result of change in the definition. After considering the information in Appendix G, staff concluded that the only significant changes that are likely to occur are greater eligibility for the Texas consumer stipend program and the Partners in Policymaking (PIP) program. The stipend program enables people with developmental disabilities and their families to attend educational activities such as conferences, work shops and seminars. This may result in a need to allocate more funds to this activity. Although no areas have yet been identified, some demonstration projects may be required in direct support of systems change activities directed to specific populations.

The Council funds a leadership training program for consumers and their families, PIP, as its only on-going direct service program. Several other states are funding PIP programs also. PIP is an intensive training program that can be effectively delivered only to small groups (30 to 40 persons). Larger groups do not allow the individual interaction among participants and instructors that appear necessary to assuring the maximum benefit from the training. At this time, the Council funds two separate classes of PIP per year resulting in a maximum of 80 persons trained per year. It would be reasonable to conclude that eliminating the age of onset from the definition would have a negative impact on potential participants in the PIP program due to increased competition for the limited capacity for the program. This would be true for other states with PIP programs as well.

However, in Texas, this is only an apparent negative impact on currently eligible populations. The Texas program has taken a broad view of the definition of developmental disability and has, therefore, a broadly defined criteria for participation in PIP. As a result, the impact on this program in Texas is expected to be minimal if the definition is changed to eliminate age of onset. Other states with a narrower interpretation of the definition might experience a larger impact on PIP programs.

Linkages. Staff concluded the Council would need to formalize relationships with groups representing expansion populations. However, it should be noted that linkages through the Disability Policy Consortium have already been established with most of the groups that would be included in an expanded definition. (See Appendix E, Disability Policy Consortium Membership.) Staff felt the established linkages are a strong argument for the advisability of expanding the definition by dropping the age of onset. The TPCDD already works closely and well with these groups in the Disability Policy Consortium and has found the extended linkages to be functional and of significant value as advocacy alliances have been established on our common issues. Members of these alliances have found that their advocacy efforts are enhanced by working together.

Of particular importance to Council staff was the probability that Congress will establish block grants to the states for most of the programs now serving people with disabilities. Staff perceives the block grants as an opportunity and a challenge to reinvent the service delivery system for people with disabilities. As block grant implementation is designed by each state, people with disabilities should have a strong voice at the table representing their issues, concerns, and desires. Coalitions of people with disabilities will have the best chance of being heard in this environment. Splintered groups, even if requesting similar considerations will have a reduced chance of prevailing in the competitive environment block grants will create. Formalizing the linkages in the Disability Policy Consortium by expanding the definition should strengthen the position of people with disabilities as the state's block grant service system is developed.

Another point made by staff regarding eliminating the age of onset from the definition was that through Disability Policy Consortium activities and, to some extent, in systems change and other advocacy activities, the Council addresses issues as though the age of onset did not exist in the definition. It is only honest and honorable to acknowledge and formalize the reality.

Changes to Council Membership. If the definition is expanded, Council membership might need to be increased to allow immediate representation for expansion populations, particularly for the populations with the largest numbers such as people who are aging, mentally ill, or have closed head traumas. The Council now has 30 members and increasing membership does not present any problems. Expenses for Council meetings would increase, but only by a nominal sum.

Resource Impacts. The overall resource impacts to the Council of expanding the definition appear to be minimal. As noted above, the consumer stipend program might need to be increased so that a larger number of persons representing the new populations could attend educational events. However, the program does not now expend the full amount allocated to it. Council membership expansion would result in increased traveling costs for Council meetings. Review of the current Councils grants produced the Table in Appendix G, Council Grants Projects, which shows that the Councils grant activities have been directed to persons of all ages and have covered activities addressing the study focus groups concerns. Therefore, it is assumed that grant activities would continue as they have with new topics and foci as the Council implements its Strategic Plan. Staff activities, particularly in advocacy, already address an expanded population's issues.

Another point on resource impact should be made. Except for unique situations such as leadership training programs, DD Councils are not service agencies. DD Councils are authorized to engage in advocacy, systems change and capacity enhancement activities and their grants are time limited, one to five years typically. Therefore, a DD Council will not experience the service resource impact of an expansion that a direct service agency would. A DD Council can be responsive to a greatly increased constituency without a significant resource increase. This has become more evident as Councils have evolved from a demonstration or seed money model to a systems change, advocacy model.

Advocacy Needs. Everything the TPCDD does can be considered an advocacy effort. Whether the activity is a demonstration project or direct training of consumer advocates or staff activity with the State Legislature, the Council is attempting to achieve its three State Plan goals. The needs identified in the focus groups, and verified by staff experiences with the expanded populations, were generally the same as those identified for our current populations, differing in the priority for each according to individual circumstances and goals. As postulated in the hypothesis, it appears that with the definition expanded by dropping the age of onset, our advocacy efforts would not change in nature, but rather in scope. That is, the number of people for whom we formally advocate would increase. As is true now, with a definition expanded by dropping the age of onset, TPCDD priorities for action may change from year to year within the framework of common needs; they would not be a different set of needs from which to choose our priorities.

Advantages to Eliminating the Age of Onset The major advantage identified was that the Council would have a broader constituency and broader voice addressing such common expressed needs as respite. This advantage also applies to shaping the block grants within the state if Congress does, in fact, move in this direction. Staff did, however, note that this advantage could be at least partially achieved by collaboration within the Disability Policy Consortium even if the definition is not changed.

Disadvantages of Eliminating Age of Onset. No significant disadvantages were proposed other than being drawn into aging issues vs. children's issues. Strong advocate input on adult issues could cause a reduced focus on children's issues.

Number of Substantial Limitations

Language from the Senate Committee on Labor and Resources Report 103-230 makes reference to "...expansion of part B programs [the portion of the DD Act which establishes Councils] to individuals with severe disabilities other than developmental disabilities..." The discussion that follows assumes that this language reflects Congressional intent and that any change that would result in targeting the activities of DD Councils away from individuals with the most severe disabilities would not meet that intent. The current definition in law contains provisions limiting identification of developmental disabilities to individuals with at least three substantial functional limitations from a list of seven areas of major life activities. If the definition is changed to require two rather than three functional limitations to be considered a severe, chronic disability, some people with disabilities resulting from learning disabilities, mental illnesses, closed head injuries, mild and borderline mental retardation, sensory impairments and spinal cord injuries would be eligible to benefit from TPCDD activities. The impact of such a change was one focus of this study.

Staff took the same approach in addressing the proposed change to the number of substantial limitations as it did in addressing age of onset, considering the needs of people with disabilities, the role of the Council, our current style of functioning, and political considerations related to the current and expansion populations. The discussion was based on staff experience, perceptions, and focus group findings.

Community Integration/Inclusion. The major difference identified by the staff that might affect the role of the Council revolved around the issue of segregation. While focus group participants representing people with two areas of substantial functional limitations expressed the same desire for supports in the community and for integration/inclusion, there were differences expressed. Parents of students with learning disabilities favor pull out resource room or segregated classroom delivery of instruction. Also, people with sensory impairments, particularly people who are deaf, favor specialized segregated, even institutionalized, instructional settings at least until Braille and/or sign language is learned. The matter of the "deaf culture" came up in the focus group discussions and the segregated nature of the culture was supported by most participants who were deaf.

These positions are contrary to the inclusive, deinstitutionalized policies of the Councils, which were created, in part, to assure alternative community services. Staff felt that it would be contradictory to advocate for segregated or institutional services for those populations if the definition were changed to two functional limitations.

Options, Supports & Services. With the exception of changes in the community integration needs noted in the section above, the needs do not appear to be significantly different for the current population and the expanded population. However, staff were concerned that reducing the number of functional limitations would result in shifting the focus of the Council from that of advocacy for those with the most severe disabilities and, therefore, the most severely disadvantaged population to a population with lesser disabilities and more resources. This would not be consistent with Congressional intent.

Systems Change Activities. With the understanding that all Council activities are part of a systems change strategy, decreasing the number of functional limitations will not significantly change the Council's activities, but will expand them. The Council could realize difficulty in delivering its strong message for inclusion, while also advocating for specialized, segregated instructional settings. In the same context, linkages and alliances that were **all** inclusive could be expected to be difficult to achieve. For example, the Council's inclusive education project was unable to develop a consensus position statement because the representative for children with learning disabilities supported retaining specialized segregated settings. Similar difficulties might develop with the well elderly and with people experiencing only single sensory impairments.

The issues of this expanded population may include the same issues of concern as those of the current population and of a population created by eliminating age of onset. However, it might expand to cover issues such as recreational activities, marriage, family and child development. Priorities within issues may differ. These differences may be significant and may deflect the Council's activities from focusing on improving the functionality of the system.

Grant Activities. With reduction of the number of functional limitations, systems change activities may be expanded to include new options, supports and services as well as new access and eligibility issues. For example, with people with lesser disabilities, priority might shift from increasing supported employment activities to increasing access to main line jobs. Greater eligibility for the Council's stipend program may become problematic because of applications from a much larger number of eligible organizations and additional funds may need to be allocated. Although no areas of activity have yet been identified, some demonstration projects may be required in direct support of changes in services to specific populations.

Linkages. The Council would need to formalize relationships with groups representing expansion populations. These linkages do not currently exist; the Disability Policy Consortium is one vehicle which could be used to establish the needed linkages.

Changes to Council membership. If the definition is expanded, Council membership would need to be increased to allow representation for expansion populations, particularly for the populations with the largest numbers such as people with learning disabilities and sensory impairments. The Council now has 30 members and increasing membership does not present any problems. Expenses for Council meetings would increase, but only by a nominal sum.

Resource impacts. The overall resource impacts to the Council of expanding the definition appear to be minimal. As noted above, the consumer stipend program might need to be increased so that a larger number of persons representing the new populations could attend educational events. Council membership expansion would result in increased traveling costs for Council meetings. Review of the current Council grants for produced the charts in Appendix G, Council Grants Projects, which shows that the Councils grant activities have been directed to persons of all ages and have covered activities addressing the study focus groups concerns. However, they do not reflect any additional areas of priority interest that might be brought to the Council by a population with lesser disabilities. Therefore, it can not be assumed that grant activities would continue as they have with new topics and foci as the Council implements its Strategic Plan. They would expand and make it impossible to address the identified needs with the kinds of staff resource allocation the Council now has. Staff activities, particularly in advocacy, would need to expand to include the educational issues brought by children with learning disabilities and sensory impairments and possible employment issues.

The overall resource impacts to the Council of expanding the definition by reducing the number of functional limitations does not appear to be large, although it may be larger than the increase that might be expected from eliminating the age of onset. The larger increase would be due to an expanded number of topic or issue areas from a population with less severe disabilities.

Another point on expanding the definition by reducing the number of functional limitations should be made. There is no evidence that reducing the number would not include groups with significantly less severe disabilities. In fact, the evidence appears to support the opposite conclusion. As one focus group participant observed and as is intuitively apparent, the number of functional limitations present defines the severity of the disability. To reduce the number of functional limitations, even by one, would reduce the focus of DD Councils on individuals with the most severe disabilities.

Advocacy Needs. The problems discussed under the Systems Change section above apply here also. The advocacy voice of the Council might be split and thus weakened as attempts were made to speak to contrasting and opposing positions of populations within an expanded population. Further, staff pointed out the focus of the Council on people with severe, chronic disabilities might be adversely affected. Staff felt that changing the definition from three to two functional limitations would cause Councils to lose the focus-possibly completely-and leave the very group we represent without an advocate. This last point-losing the focus on people with the most severe, chronic disabilities- became the point against recommending this change to the definition. In other words, the decision was value based rather than data based.

Advantages to Reducing the Number of Functional Limitations. A broader constituency and a broader voice would be acquired. This could also be accomplished without expansion through collaboration with other agencies.

Disadvantages of Reducing the Number of Functional Limitations. Expansion to include more people who have less severe disabilities might significantly change the scope and nature of Council activities. This study was undertaken to determine the impact of a change in definition on the Texas Council. The unstated study question was the impact on other state DD Councils of changing the definition. Inherent in a study of this sort is the question of the proposed changes on the organization's purpose and mission. Staff were in agreement that a change in the age of onset would result in little or no change in the nature or focus of activities undertaken by the Council. Staff were also in agreement that changing the definition from three to two functional limitations would change the scope and nature of activities of the Council and possibly would change the focus and intensity of current activities. The changes were perceived to be due to a shift in focus from a constituency of people with severe disabilities to one which included people with mild or moderate disabilities. Staff was not comfortable with this change of emphasis and identity for the Council and recommended that the definition not be changed in the area of functional limitations. Such a change would appear also to be contrary to Congressional intent.

Consumer Agency Representatives Input

Representatives of the United Cerebral Palsy of Texas, Texas Alliance for the Mentally Ill, The Arc of Texas, Coalition of Texans with Disabilities, Institute for Disability Access, Governor's Committee for People with Disabilities, Texas Rehabilitation Commission, Advocacy, Inc., and Texas Advocates met with staff of the Texas Planning Council for Developmental Disabilities to discuss the expansion of the developmental disabilities definition. Staff gave the group a brief review of the evolution of the definition and an overview of the study and its findings. Following this orientation, the group was invited to discuss the impact on people with disabilities, their constituencies and their organizations of expanding the definition on either of the two changes studied by TPCDD. Finally, the group was asked to consider the advisability of changing the definition in this political environment.

The group was most united in supporting the elimination of the age of onset from the definition. Most comments were supportive of this change because of the way Texas has implemented the definition to this time-broadly interpreting age of onset and the statement in the Act that says "nothing in this Act should be interpreted to keep Councils from advocating for people with disabilities." The perceived commonality of needs of people who meet the three functional limitations portion of the definition and the systems change nature of the Council's activities were reasons given for supporting this change. The impending federal funding changes toward block grants and the "medigrant" changes to the Medicaid Act were also given as reasons to support the change.

The group was less united in its support for maintaining the number of functional limitations at three rather than reducing to two or even one. Representatives from two agencies said that their constituencies had stated positions supporting cross age, cross disability, and cross limitations supports. Other agencies felt strongly that the emphasis of the DD Councils should remain on "severe, chronic disabilities," that is, those that meet the current definition without age of onset. Among the reasons given for this position was that the DD Councils are the only entities focusing on this group, our successes in the past, the long term nature of the needs of people with severe, chronic disabilities, and the similarity of the stated needs when the needs are chronic and severe. It was felt that if the definition was changed in such a manner that people with lesser disabilities or acute disabilities were included, Council priorities would shift to focus more on short term supports and acute health care needs.

The discussion on "functional limitations" led into an interesting discussion about the problems with the functional limitations portion of the definition as it stands. Most of the representatives felt that the application of the functional limitations was highly subjective and therefore, open to abuse or misinterpretation. The current backlash against the use of functional limitations for determining SSI eligibility for children was mentioned as an example. A suggestion was made that the definition might benefit from a change to eligibility based on "functional need" rather than functional limitation. For example, a child who needed assistive technology devices to enable him or her to learn at school would be one with a functional need. It was noted that another study would be needed to explore the impact of such a change.

Discussion of how the question of definitional change is perceived by the rest of the country noted that most other Councils have assumed that change meant moving to an "ADA definition," that is, a very broad definition and that the general feeling is not to recommend such a change. As noted above the majority of the group and Congressional intent supported the continued focus on people with severe, chronic disabilities.

The group discussed the political advisability of changing the definition at this time. Two positions developed. Some representatives advised against any change at this time even though change itself made sense. These representatives felt it would be unwise to call attention to the program during a period when small programs are being folded into larger ones. Other representatives felt that change in the definition by eliminating age of onset made sense—in fact, is the only way the DD Councils will maintain their leadership role in the disability community as drastic changes in the funding and service delivery systems are made by Congress.

Analysis of Annual Program Performance Reports

As a further analysis of the congruence of current DD Council practice and practice as it might occur if the definition were expanded, an analysis of Annual Program Performance Reports (APPRs) from eight Councils was undertaken. The APPRs analyzed were for FY 1994 or FY 1995 depending on which year's report was submitted by the participating Councils.

The APPRs were reviewed by a consultant and the activities reported grouped into common categories or "themes" of activities. Each theme was found to have subcategories or "subthemes" of activities. The themes and subthemes can be viewed as broadly describing areas of activities that are representative of DD Councils actions. In part, they can be used to determine if DD Council current activities would address the concerns of expanded populations as identified by the Focus Groups. The identified themes and subthemes are shown in Table IV.

In many cases, the APPRs reviewed revealed specific Council concerns that "colored" or acted as a "filter" for the actual activities of the individual Councils and gave a "unique" character or expressions of values to each Council's activities. Identified filters included multicultural sensitivity, individualization or "person first" approach, education/information dissemination, and quality of life issues.

The kinds of activities that DD Councils undertake were also analyzed and yielded a fairly short list that describes the systems change, capacity building and advocacy efforts of DD Councils. The activities identified were: 1) sponsor/cosponsor conferences/symposiums, 2) develop informative materials, 3) research study activities, 4) disseminate materials, 5) develop training initiative/model programs, 6) sponsor training workshops, 7) collaborate/network with service or advocacy agencies, and 8) perform policy reform activities. Incidentally, these activities can be viewed as the measurable activities of DD Councils and should be considered as categories when a national data base for Councils is developed.

This analysis yields mixed results. DD Council activities indicate little or no need to change activities if the Council is now funding activities that affect people with disabilities across diagnoses. However, if the Council is funding activities that address issues or populations that demonstrate particular services for particular populations, e.g., cognitive assistance for people with mental retardation, a definitional change would change the nature of the Council's activities substantially. It may be concluded that the Texas Council would experience little or no change in the nature or scope of its activities.

Table IV
DD Council Themes and Subthemes

- Leadership/Empowerment
  - Self-advocacy Efforts
  - Personal Futures Planning
  - Assistive Technology
  - Transition Planning

- Community Integration
  - Housing Initiatives
  - Deinstitutionalization Efforts
  - Employment
  - Education

- Family Supports
  - Networking (grassroots efforts)
  - Information/Referral Services

- Interagency Partnerships/Communication
  - Systems Coordination
  - Strategic Planning

- Policy Reform
  - Statewide and National Advocacy Efforts
  - Policy Papers
  - Health Care Reform

DD Council Discussion

The Council met as a Committee of the Whole in October 1995 to hear the results from the study and to identify and discuss the issues associated with expanding the definition. The Council was concerned whether the focus groups were representative of both the current population and those of an expanded definition and that participants represented the cultural diversity of Texas. They were also concerned whether the analyses conducted yielded data in which they could have confidence. Staff shared information about the focus group participants that assured the Council that most of their concerns were satisfied. Although Council members readily recognized the similarity of needs, issues and concerns of people with severe, chronic disabilities of all ages of onset, they were concerned that the needs of people with developmental disabilities not be lost in an expanded definition. They also reiterated the desire to keep the focus on people with severe, chronic disabilities.

The political advisability of changing the definition at this point in time was discussed at length with both advantages and disadvantages being identified. After lengthy discussion the Council asked staff to prepare a comparison table of pros and cons for changing the definition by eliminating the age of onset as well as a table contrasting compelling reasons for and against changing the definition-again by eliminating the age of onset. (See Tables V and VI below.) A decision on a recommendation changing the definition was postponed until the Council meeting in November 1995. Staff were asked to mail the requested charts to Council members in time for their consideration before the Council meeting. The charts below were mailed to Council members.

Table V
Age of Onset

Pros	Cons
Council constituency would expand resulting in an expanded base of support for the Council.	An expanded definition would include populations that do not self-identify as "disabled," for example, some frail elderly people. Therefore, the constituency might continue to be fragmented.
Council constituency would expand resulting in an expanded base of support for advocacy efforts.	An expanded constituency would dilute the focus of the Council on its traditional constituency and traditional issues, for example, children and education.
Confusion about who is a member of our constituency would lessen if our definition covers all persons with a severe, chronic disability.	An expanded definition would create confusion about who is our constituency by changing the public perception of DD Councils.

Table V Age of Onset (Continued)	
Pros	**Cons**
The Texas Council is functioning, in many ways, as if the definition were expanded beyond what some Councils accept; that is, including conditions that have a genetic or chromosomal cause but do not produce symptoms until after age 22, for example, some mental illnesses. Expanding the definition would reflect our actual function.	Councils are known as Developmental Disability Councils, or DD Councils, in most states including Texas. Expanding the definition makes this name nondescriptive. Other organizations such as TASH and The Arc have had similar problems as their mission and focus have changed.
The Disability Policy Consortium (DPC) has representation from groups that would be included in the expanded definition. The successful functioning of the DPC has shown the value of working within a broader constituency. Expanding the definition might strengthen this coalition and serve to expand its influence.	We are doing well with our current definition. The Disability Policy Consortium serves our purposes well now. "If it ain't broke, don't fix it." We're doing it through collaboration, so why change the definition.
Our research shows that the needs, concerns, barriers, and issues expressed by people with a severe, chronic disability are the same regardless of age of onset.	While our research shows congruence among needs, etc., among people with severe, chronic disabilities regardless of age of onset, it is possible that in actuality, inclusion of additional groups might introduce new issues into the Council and change the direction and focus of Council activities, for example, health care issues.

Table V
Age of Onset (Continued)

Pros	Cons
The expected changes in federal programs supporting people with disabilities, create an opportunity for changing the service delivery system away from an institutional bias and toward a community integrated system. A broader constituency speaking with a single voice would have a better chance of prevailing in an environment of systemic change. "It's the right time to change."	The expected changes in federal programs funding, create an environment where changes to our definition and resulting confusion about our identity and constituency could reduce our efficiency and effectiveness. "It's not the right time."
A "DD carve out" will not have much support in the current environment.	We are already advocating for a broader constituency now. Why change?
Councils missions are not understood by the Administration on Developmental Disabilities or Congress, the exclusionary nature of our definition with a small group of people being designated as our population while others with similar characteristics and needs are excluded makes understanding difficult ad results in our undertaking systems change that affects many more people than our targeted population.	The Washington environment of reducing funding, particularly to small programs with abstract missions, creates a situation where a request to change our definition may result in additional confusion among lawmakers about Councils and their reason for existing resulting in a decision to defund Councils.
Determining eligibility for participation in our grants where a service component exists is administratively burdensome both to our grantees and our monitoring staff.	
"Its the right thing to do."	"It's not what we're supposed to do."

Table V
Age of Onset (Continued)

Pros	Cons
Council members are responsible to represent "the people," not just their own situation.	Expanding the definition might require more Council members to represent new constituencies. More of the Council's funds would be spent on supporting the new members.

Table VI
Compelling Reasons to Change the Definition

Compelling Reasons to Change	Compelling Reasons Not To Change
In a Block Grant environment, a small program such as the DD Councils need a broad constituency to speak for continued funding.	In a period of major change and funding cuts, small programs need to "lay low and not make waves." Little will be achieved except exposure to additional cuts by drawing attention to ourselves during this period of "slash and cut."
In a Block Grant or other major change environment, the Council's mission can be best achieved and people with severe, chronic disabilities can be best served, by representing all groups with severe disabilities who are institutionalized, at risk of institutionalization, isolated and in need of advocacy, systems change, and capacity building.	We are doing well with our current definition. The Disability Policy Consortium serves our purposes well now. "If it ain't broke, don't fix it." We're doing it through collaboration, so why change the definition.

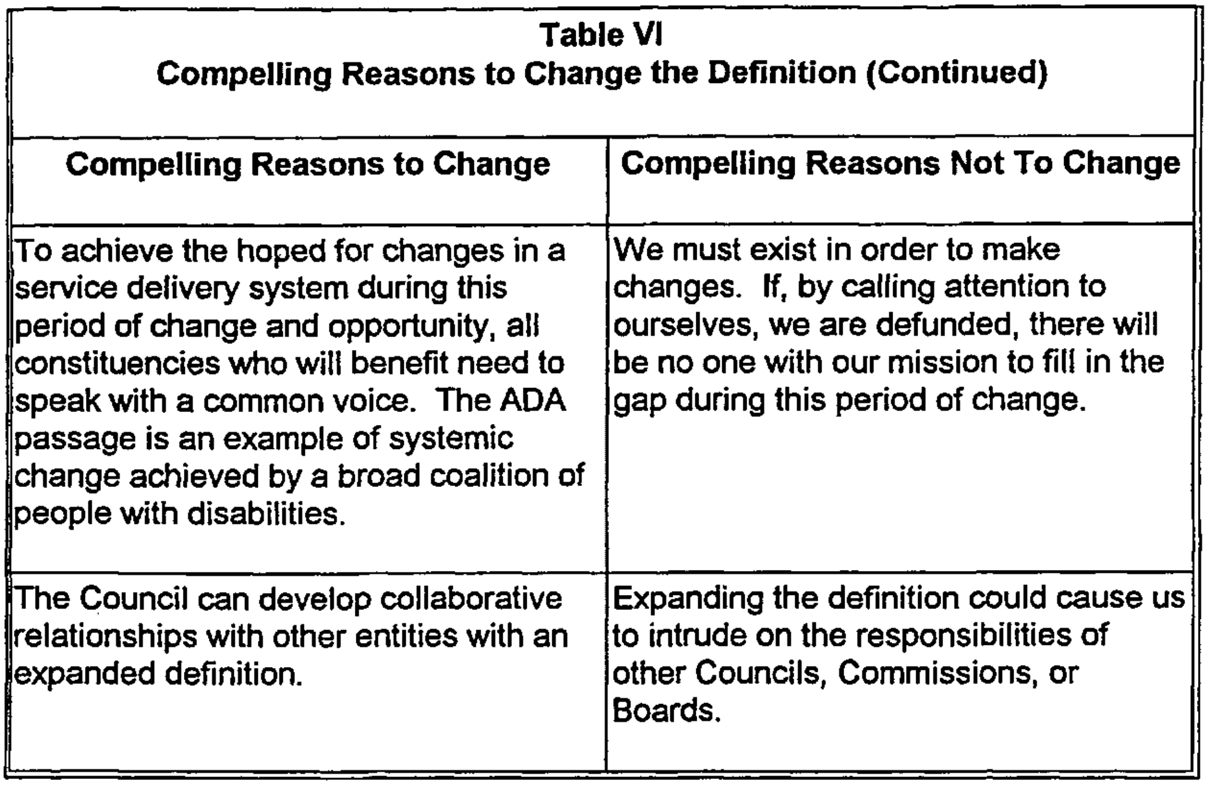

Table VI
Compelling Reasons to Change the Definition (Continued)

Compelling Reasons to Change	Compelling Reasons Not To Change
To achieve the hoped for changes in a service delivery system during this period of change and opportunity, all constituencies who will benefit need to speak with a common voice. The ADA passage is an example of systemic change achieved by a broad coalition of people with disabilities.	We must exist in order to make changes. If, by calling attention to ourselves, we are defunded, there will be no one with our mission to fill in the gap during this period of change.
The Council can develop collaborative relationships with other entities with an expanded definition.	Expanding the definition could cause us to intrude on the responsibilities of other Councils, Commissions, or Boards.

Recommendations

In the November 1995 Council meeting a brief discussion was held and the Council voted to recommend a change in the developmental disabilities definition eliminating the age of onset. The Council also voted not to recommend a change in the definition reducing the number of functional limitations from three to two.

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Appendix A

Focus Group Report

Focus Group Report

Introduction

The following is a report of the results from the Focus Group discussions held as an activity of the study. The Focus Group discussions focused on the supports, needs and life issues of persons with severe, chronic disabilities. In this study, focus groups were used as a data collection technique in order to obtain in-depth interview data from individuals with severe, chronic disabilities, their families, and their advocates. These focus groups consisted of a heterogeneous group of individuals across the state of Texas who would be impacted by the changes in the Council's proposed definition.

Research Questions

Focus Group research questions were formulated by the study work group. In particular, the work group targeted the following questions as primary in this study:

1. What are the service and support needs of persons with severe chronic disabilities?

2. What issues, barriers and opportunities exist currently in the lives of persons with severe chronic disabilities?

These questions were selected by the work group to determine whether the service and support needs of individuals with disabilities varied given the age of onset of the disability or the number of functional limitations demonstrated by the individual with disabilities.

Participants

Six communities across the state of Texas were chosen as sites for focus group meetings. The communities selected differed from those proposed in the study application. The work group advised that Lubbock be substituted for Amarillo, Tyler for Dennison and McAllen for Laredo. These substitutions were based on Work Group knowledge of active advocacy groups in the substituted cities. One of the intentions in selecting these communities was to provide a sample that was culturally diverse. Communities that represented geographically varied areas of Texas, as well as urban and rural populations, also were included.

Once the six communities had been selected, paid advocates and service providers in these communities were consulted to identify possible participants. However, paid advocates and service providers were asked not to participate as it was the belief of the researchers and Work Group that their presence would inhibit the candidness of responses from the other participants. In actuality, it was the case that many individuals with severe disabilities or their family members also were employed in advocacy or service capacities. In these cases, participants were asked to take part in the focus group from their vantage point as an individual with a severe disability or as a family member, rather than from the vantage point of a paid professional.

The individual participants who attended the six focus groups, as had been desired, represented a wide array of areas of disability, as well as a variety of ethnic and cultural groups. These participants also represented areas of chronic disability that occur across the life span and thus were not solely representative of those disabilities acquired prior to age 22. Each individual focus group consisted of individuals with severe disabilities, family members, or unpaid advocates. Each focus group was limited to 12 to 15 participants in order to facilitate fluid group discussion. Table I illustrates demographic data from the individuals who participated in these focus groups.

Table I

Participants	
Family Members	36
Individuals	31
Cultural Groups	
Native American	3
Asian American	3
African American	2
Hispanic	15
Anglo	46

Areas of Disability Represented:

Alzheimer's, Cerebral Palsy, Cystic Fibrosis, Deaf, Diabetes, Mental Health, Polio, Mental Retardation, Mobility Impaired, Multiple Sclerosis, Seizure Disorder, Traumatic Brain Injury, Visual Impairment.

Prior to each focus group meeting, an area coordinator from a local support group was selected to identify possible participants and to facilitate setting the location for the meeting. Potential participants were contacted initially by the area coordinator who provided a brief description of the study. Interested potential participants then were sent a packet of information by the researchers, which contained a letter of introduction, an overview of the entire project, an agenda for the meeting day, and a copy of the consent form. Packet information was provided in audio tape or Braille if requested by the individual. Interpreters for people who were deaf or Spanish speaking were provided as needed. Accommodations needed by the participants were identified so that attendance at and participation in the focus group could take place.

Procedure

Each focus group meeting was held between the months of February and April of 1995. Meetings consisted of a session from 9:00 a.m. to 2:30 p.m. with an hour break for lunch. Specific meeting sites in each community were chosen based on accessibility, required accommodations for participants, and general recommendations given by area coordinators. All focus group sessions were audio-taped for later transcription and analysis.

Focus group discussions centered on three questions presented by the researcher and followed by several probes. These questions and probes were:

1. What helps you live the way you want and manage your own life?
   Probe: If I could wave a magic wand and you had the help you needed to live the way you want and manage your own life, what would that help look like?

2. How are you getting the help you need right now?
   Probe: What or who is helping you now? When you need support, where do you turn?

3. If the TPCDD were to represent all of you here today, how might they help you?

Focus group meetings were well attended with 85% of those who had been invited to participate in attendance. The majority of the participants actively contributed in each focus group. Participant response to the initial focus group question often resulted in a lively two hour long discussion in which they shared their personal experiences and built on the stories and issues shared by other members of the group. Often the role of the focus group facilitator became one of a participation monitor who guided the group discussion so that every participant would have an opportunity to share. As such, the role of the focus group leader was minimized while the contributions from the group participants was maximized. During the lunch break, although the focus group was not formally convened, participants continued to share stories and information as they shared their meal. By the time the afternoon session took place, the meeting took on the characteristics of a support group. Many participants exchanged information and suggested strategies for future self-advocacy activities; occasionally offering and gathering each other's names and telephone numbers for future reference. This active, intensive participation of focus group participants resulted in a rich source of information concerning the lives of family members and individuals with severe chronic disabilities.

Analysis

The focus group format provided an efficient method by which to gather a large amount of interview data from a wide variety of participants. The discussion format often stimulated responses from a large proportion of the participants who brought forward their individual experiences that related to the questions raised by the researcher. Questions were explored from numerous individual points of view as participants gave examples of how a particular issue related to their life. The lively interaction between group members not only provided a rich array of viewpoints on particular issues but also provided a framework of important issues that were consistent across group meetings

Audiotapes from each focus group meeting were transcribed and read within two weeks of the meeting. A total of 25.5 hours of tape were transcribed, which produced a total of 568 pages of data. Each focus group generated between 4 to 4.5 hours of taped conversation rendering 62 to 114 pages of transcripts. Initial overall impressions of the groups and general issues brought forward by participants were written in field notes immediately following each meeting. Facilitator probes used in earlier focus groups were critiqued in order to refine the probes used in subsequent meetings.

After the initial reading, transcripts of the focus group meetings were analyzed using a grounded theory methodology developed by Strauss and Corbin (1990). Following this methodology, each transcript was examined line by line and then coded with conceptual labels during the open coding stage of analysis. In open coding, ideas and themes generated by participants are categorized conceptually. This process was intermingled with the ongoing data collection, in that open coding took place as later groups were conducted. Conceptual categories emerging from open coding were constantly compared and analyzed. Such analysis allowed the researcher to generate and verify emerging theoretical constructs concerning central issues in the lives of individuals with severe chronic disabilities. This theory generating activity is often referred to as "the constant comparative method of analysis" (Glaser & Strauss, 1967) in that the activities of participant data collection, coding and analysis are interwoven.

Emerging concepts resulting from open coding were then classified and grouped into categories which were hierarchically arranged. Characteristics or properties of each of these categories were examined. After the transcripts from the first three focus group meetings were coded, categories across these transcripts were compared in order to determined overall patterns in participant responses. These categories became the initial conceptual units from which the central phenomena later emerged. The central phenomena was the central event or idea around which the conceptual categories could be organized. During the coding of the last three focus groups, codes and categories were verified and refined. Individual participant stories were examined closely to understand how categories interacted.

Once open coding of all focus group transcriptions was complete and the classification of concepts into emerging categories had begun, the data were analyzed using axial coding. In this process, connections between categories and resultant subcategories are examined. Several main categories or phenomena were identified which formed an overall theoretical view of central issues in the participant data. These categories were examined, as suggested by Strauss & Corbin (1990), in light of their causal conditions, strategies, intervening conditions, context, and consequences. Causal conditions are those events which lead to the development of a phenomena. The phenomena itself occurs within a particular set of conditions or context. Intervening conditions facilitate or constrain the manifestation of the phenomenon, while strategies are those action/reactions made in order to manage the phenomenon. Consequences are the outcome of the effect that these variables have upon the central phenomenon.

At this point in the analysis, it was felt by the researcher that a verification of the initial categories and analysis was necessary. A second researcher, familiar with grounded theory methodology, was contracted to examine and verify the initial stages of analysis. As such, the role of the second researcher was to perform an audit of the methodology and to confirm the categories and preliminary results of the first researcher. Open

coding was again conducted on transcripts from all focus groups. Resultant codes and categories were listed. Categories were compared to those obtained by the first researcher. Jointly, the two researchers compared their obtained conceptual categories and agreed upon a working set of categories. Axial coding was then conducted separately by the researchers on those categories with richest source of properties or characteristics. From these categories, the researchers identified a phenomenon around which all categories from the focus groups were related.

In the final stage of analysis, selective coding was used to systematically relate all categories to the central phenomena and to validate those relationships. The central phenomenon was defined in terms of its properties and dimensions as well as the context within which it resided. The emergent theoretical model was validated again against the data and story-lines emerging from each focus group.

Results

All six focus groups meetings provided a rich source of information from individuals with severe chronic disabilities and family members. Participants appeared comfortable when responding to focus group questions, which resulted in lengthy detailed discussions. Participants often shared personal experiences as well as their general views of the issues. Participants emphasized similarities in their experiences as they discussed particular issues raised by the group. By the afternoon session, focus groups took on a supportive nature in that the participants shared resource information and often suggested strategies to help other individual participants.

Central Theoretical Issue

A central theoretical construct emerging from the focus group data centered on what the participant's themselves labeled as the "Qualifying Game."

> "It's all a game. The game of qualifying"..."I think your idea of a game board is excellent. What would we call this? The game of qualifying? The game of services?"..."The game of life. The game of a disabled life."

Participants shared that constant change and turmoil is a primary feature of the "game." Entry requirements, rules for qualifying and information concerning these rules is difficult for consumers to obtain.

> "The rules change as the person you talk to changes. The joke is call (agency) three times and get three different answers."

However, consumers are not the only players confused by the game. Service providers often are confused as well resulting in misinformation being provided to the public.

> "I called (agency) to inquire about their PASS Program which I was told there was no such thing. They didn't know what I was talking about. I was reading this out of one of their brochures and they still argued with me. So I hung up and called back and got a different person who knew exactly what I was talking about and mailed me the information...."

Consumers of services often see themselves as ultimately responsible for making sense of the game. The burden of acquiring accurate information lies with the individual seeking services. This burden places them at the "mercy" of service providers. When conceptualizing this process of acquiring services as a game, participants shared that there exists rules and strategies which appear to help. Valuable information concerning services must include information of how to play the "qualifying game."

Participants shared that the "qualifying game" is synonymous with the "game of life with a disability." In addition to knowing and accepting that an individual needs support, individuals must know the right questions to ask, the answers to the questions in order to frame the question appropriately and the language of the service agency. The participants' need to play the qualifying game results from the complexity and difficulty of accessing needed information about services and supports and their frustration with agencies and agency personnel.

This concept of the "qualifying game" is described best as a sociological contract that is, in actuality, designed by society. The "qualifying game" exists primarily because resources are scarce and difficult to obtain and because the service system is fragmented, duplicative, and, at the same time, incomplete. The service system has developed as a result of attempts to meet needs of individuals on a categorical basis, that is, based on diagnoses, ages, and other criteria, rather than a functional need basis.

Yet this "game" is the only process by which individuals with severe chronic disabilities and their families can obtain the necessary services to meet basic life supporting needs. Councils' activities in systems change are directed, in part, to eliminating or minimizing the effects of the qualifying game. When individuals gain information about the "qualifying game," this helps them "play" the game more skillfully. Individuals develop strategies because of the rules of the game and in response to the experiences of the "qualifying game." However, a function of the "game" is that the rules are complex. Making the game complex means that fewer individuals then have knowledge or access to services. Thus the "qualifying game" limits access to services which already are insufficient to meet the needs of those qualified to obtain them. This game-like nature of service provision includes constantly changing criteria for entry into the game, making the rules of qualifying difficult to comprehend, making accurate information difficult if not impossible to disseminate, and causing interminable waiting lists.

> "What it is, is it's not qualifying for respite care but it is the waiting list. A lot of the facilities have only certain amounts of slots or certain amount of children at a time that they can serve. And they are in need of some respite care. In many situations, it is an emergency need. It's not planning a vacation or planning to get away-it's something comes up within the family and they need time to go and deal with those situations and there is no service that we have been able to find where it's an immediate need for some sort of respite care. In dealing with some of the agencies, many times what we have found is, again, the waiting list. Even for day-care facilities, for sheltered workshops, for other agencies throughout the Valley here. It's a waiting list and many times our parents, our children, are not able to get in."

An outline form of the model for this theoretical concept of the "Qualifying Game" is presented in Table II. This model serves as an overview of the process by which individuals come to acquire services or at least gain more knowledge about acquiring services. Participants stressed that although their ultimate goal was to acquire services, this goal was based on basic survival needs. Even when the ultimate consequence of playing "the game" was additional information on how to play, the participants felt that this information alone allowed them to feel more personal control over their lives. Personal control, a sense of independence and being included in their communities were seen by participants as basic survival needs.

Table II
"Qualifying Game" Model

A) Causal Condition

Presence of a disability in the family

Properties

- of disability
  - duration; chronic
  - course; stable vs. degenerative
  - personal limitations; severe
  - type of impairment; sensory, mobility, cognitive
  - when occurred (birth vs. later onset)
- of family
  - family size
  - need for services

B) Central Phenomenon

Goal of Acquiring Services

Dimensions

- Intensity of Goal
- Duration of Goal

C) Context

Set by the characteristics of the Social Security Delivery System

Under conditions where the goal of acquiring services is based on intense need and on a continuing basis, then:

D) Intervening Conditions

(may facilitate or constrain strategies used)

- Gatekeepers
- Level of knowledge
- Accessibility and availability of services
- Economic status
- Presence of a family caretaker
- Communication
- Perception of disability

Action/Interaction Strategies

- Being assertive
- Gaining knowledge
- Moving to obtain services
- Changing economic status
- Attendant services

E) Consequences

Increased knowledge of the "qualifying game."

Acquire services (leading to inclusion in the community as well as economic and emotional stress relief).

Another defining characteristic of families in which a severe or chronic disability is present is the need for support services to meet often overwhelming limitations and barriers that the disability presents. The primary issues and concerns presented in the table below, were consistently shared as an important focus in all the focus groups. Regardless of area of disability or age of onset, these common issues remained the same and were a central focus in the family's life.

Causal Condition

Among all participants, the presence of severe and chronic disability served as an entry point to the "qualifying game." These factors were seen as the presence of a severe and chronic disability in the family. The presence of a disability in the family was seen as personally limiting and the limitations to personal freedom were severe. Across areas of disabilities, individuals talked about the personal loneliness and desperation that resulted from being socially isolated.

> "It's desperation as well. It's frantic despair. Sometimes you think, I can't do this another day. I just can't do it."

The characteristics or properties of both the family and the nature of the disability are important. In this study, a broad definition of the term "family" was chosen based on the way in which the participants presented the concept of "family." Participants shared that a family may be seen as only one person but if that person has a severe, chronic disability, it is the "family as a unit" that is impacted. In families with more than one member, others appeared to "take on" the identity of being disabled.

> "We really forget that when we are talking about disabilities, we are not necessarily talking about one individual with a disability. The whole family becomes an aspect of having a disability."

Another defining characteristic of families in which a severe and chronic disability is present is the need for support services to meet the often overwhelming limitations and barriers that the disability presents. The primary issues and concerns presented in the table below, consistently were shared as an important focus in all the focus groups. Regardless of area of disability or age of onset, these common issues remained the same and were a central focus in the family's life.

Participants shared that the individual drive to meet these needs came from the basic need for the individual and the family to survive. It was expressed among all participants that without these basic supports, individual and family health, ability to earn a livelihood, and independence were all compromised.

> "And families don't always have the resources to provide this themselves. In fact, we don't because we've had to give up so many other areas of our lives-

> sometimes our jobs. We don't have that income because sometimes, at that point, we just lost our will to fight it any further."

Although all individuals and families with disabilities may experience the issues and concerns mentioned above, participants shared that a severe disability was marked by multiple limitations in daily functioning. Even when the area of disability may exist within a single diagnostic category, "severity" appears to exist as an extreme along a continuum of functional limitations. As the number of limitations to independent, individual functioning increases, the level of severity of the disability increases. Individual functioning appeared to cross life areas and included psychological as well as physiological factors. In fact, at every focus group meeting, participants pointed out that the "most severe" disabilities are those acquired later in life. When a person is older, the psychological issues of personal grief and loss often were seen as overwhelming for the individual and thus made it more difficult for them to recognize or acquire necessary new coping strategies.

Just as every individual with a severe chronic disability and family are unique so the constellations and priorities of needs for that individual are unique. However, there exists a consistency in the patterns of needs across areas of disability. Family members and individuals with a severe chronic disability cited often the need for information and requested repeatedly for one central location to obtain this service. In those instances when the disability was episodic (in the case of mental illness) or progressive (in the case of Alzheimer's) in nature, needed supports appeared to be more difficult if not impossible to predict and provide. Accurate diagnosis and information concerning the nature of the disability was primary to planning strategies for future life. Participants presented a consistent picture of needs which are fundamental in the lives of all persons with a severe chronic disability. It is the drive for personal survival which leads the family to search actively for services, supports and accommodations to meet these needs.

Central Phenomenon

At every focus group meeting, the central issue of the entire group discussion related to the goal of acquiring services. Gaining services which included gaining supports and accommodations in the community were portrayed as a daily survival issue which overshadowed any other issue or concern in their life.

> "I filled out four identical six page questionnaires to four different agencies asking me the same questions. I've been fighting it for two years. I still don't have any extra money. I still don't have Medicaid. I still don't have anything. I have no place to put the boy. That boy is deteriorating everyday like you say. We're just both deteriorating. Just being locked up at home. And fighting the bureaucracy and the agencies and the incompetency and the endeavors."

The goal of acquiring services is comprised of the unique constellation of needs of individuals and their families. However, the nature of this goal must be viewed within a larger framework. The goal of acquiring services is impacted greatly by the interaction between the individual and the service delivery system. In this way, the central phenomena must be viewed within the context in which it resides.

Context

While the goal of acquiring services was the central issue of focus group discussion, the backdrop for this phenomenon was the overall context of the social service delivery systems. Support services were reported as scarce and expensive.

> "The attendant care-I would like to say affordable attendant care. Which we do not have, I feel, at this point and time. Those of us who are working are taking a beating and we end up suffering. A lot of people out there are not working because they can't get insurance or can't afford attendant care. It's just a major problem."

In addition, accessing services was described as difficult and dependent on the ability of the individual or family member to physically contact the service agency.

> "Transportation for a lot of our families to even get to an agency, if they get an agency, they can't even get to the agency. Transportation is a major problem for a lot of them. We don't have a lot of adaptive bus lines. Grand ADA**'S** out there but it's like it's non-existent."

The social service delivery system was described by participants as a very closed system in which individual service agencies lacked awareness and information about what other providers were doing. Referrals to other agencies were rare or nonexistent and this lack of knowledge enhanced the fragmentation of service delivery that was found often in the system.

> "And no one would tell me that, even though I asked about 15 individuals from both agencies before I even went out there. None of them give you that information. They probably didn't know themselves."

The process of qualifying for services is fragmented among the different agencies as well. Different agencies use a variety of checklists and definitions for providing services. Participants noted that each agency appears to have its own criteria for describing a disability.

Participants report that overall, the system focus is low in empathy for individuals with a severe disability and their families. Exceptions were offered by sharing exemplary cases in which the attention and caring of an individual service provider opened a life of more independence for an individual. However, participants reported at every focus group meeting a general negative or apathetic attitude among service providers.

> "Everything doesn't cost money. It takes understanding and caring, and we don't have that in the people who provide services."

Intervening Variables

Eight different categories that emerged from the discussions of the focus groups affected how readily individuals with disabilities and their families were able to acquire services. These categories function as intervening variables in that they facilitated or constrained the strategies that the participants used in order to acquire services. In many cases, these variables may be seen as "barriers" to acquiring services. However, within the "qualifying game" process, these same barriers may at times become "opportunities" if the individual understands the nature of the "game."

Gatekeepers

Participants in the focus groups made repeated references to individuals who functioned as "gatekeepers" to needed services. These gatekeepers were individuals who played a vital decision making role within the service delivery system. Roles of the described gatekeepers were to decide whether or not a person qualified for services or to supply additional information about services that might be available.

One primary gatekeeper described by focus group members was the physician, whose diagnosis is used by other service providers to determine if the individual with disabilities qualifies for certain services. Focus group members reported that physicians had little information to offer them concerning available services. A common frustration shared by participants was that physicians tended to focus primarily on what the individual with the disability could not do, rather than what they could do, with the appropriate supports.

Direct service providers were also described by focus group participants as being gatekeepers that kept them from needed services, protecting access to their individual services, rather than helping individuals search for services. Forging A New Era: The 1990 Reports on People with Developmental Disabilities (National Association of Developmental Disabilities Council, May, 1990) (1990 Reports) referred to this phenomenon as the need for case management services, assuming that case managers have knowledge of the broader system and can coordinate service delivery. Again, participants saw service providers as using a dysfunction model for determining eligibility for service as service providers focused on limitations of the individual to determine eligibility. Consumers and family members indicated that at times it seemed that service providers exercised arbitrary discretionary powers to determine an individual's eligibility.

Level Of Knowledge

Participants in the focus groups described how they needed to obtain knowledge in a number of key areas in order to obtain services. First, they needed knowledge about the disability that they themselves had or that their family member had. The less knowledge they had, the more difficult it was to determine where to begin their search for services. Second, they needed knowledge about agencies and organizations that provided services to individuals with disabilities. Most of the participants in the focus groups shared information with each other concerning where to obtain services. The belief of the participants was that the more knowledge they had about available services, the more likely they were to be able to obtain those services. Third, they needed knowledge about the criteria for eligibility for these services so that they could better access services. If they were not aware of the "game" that had to be played with a particular agency, they might unwittingly disqualify themselves or their family. Finally, they needed knowledge about their legal rights to access to services. Those individuals in the focus group who insisted on their legal rights believed that they were more successful in receiving the services to which they were entitled. Participants in the 1990 Reports focus groups reported similar experiences and expressed their needs for civil rights information in order to gain access to services.

Accessibility And Availability Of Services

One of the primary constraints that prevented individuals with disabilities and their families from obtaining services was that services were inaccessible because of long waiting lists or unavailable because they simply did not exist. These constrains were described by the participants as resulting from lack of funding, or in some cases, from the low pay that service providers received for their work.

While a common barrier to obtaining services was the lack of information about services, focus group participants felt that access to services that were available was extremely limited and that they often were faced with long waiting lists.

Economic Status

The economic status of the family limited the services that they received. All of the participants in the focus group discussed how services for individuals with disabilities were expensive and that they were unable to privately finance services an adequate amount of services. Those families who had more financial resources reported that they often then did not qualify for public assistance programs, while those families who did qualify for these programs reported they had to limit how much they earned so that they did not lose benefits.

Presence Of Family Assistance

A family assistant was described by the participants as the primary person that assisted the individual with the disability with personal care, supervision, or interpretation services. In the focus groups that were part of this study the family caretaker was usually the parent, spouse, or child of the individual with the disability, although it was occasionally a sibling.

The presence of a family caretaker affected the extent to which individuals with disabilities needed attendant or assistive care or an interpreter. Those without a family caretaker had to finance attendant care so that they could function independently. Those family caretakers who participated in the focus groups also had to assist in seeking support services for the individual with the disability. Ironically, the presence of a family caretaker was seen as limiting the amount of additional assistive care that an individual received. If a family caretaker was available to offer support services to the individual with the disability, it was often the case that the individual would not be eligible for additional assistant care. The family member was then responsible for providing the services that an attendant, in home or in an institution, would offer. The dependence on the family member for personal assistance care created an intense need for respite services. Respite services were viewed as providing relief for the family member from stress and allowing the family member to conduct necessary business. Assistant services were also cited as necessary for the family to participate in recreational activities.

Perception Of Disability

How others, particularly service providers, viewed the family or individual with the disability affected the ability of the family to obtain services. The perception most disturbing to those participating in the focus groups was when others emphasized what the individual with the disability could not do, rather than what they could do. Individuals whose perceptions affected the ability to obtain services were parents, educators, and the community members at large. These perceptions were usually discussed as ones that constrained the individual with disability, or their family, from obtaining services and from functioning independently.

Communication

Communication was usually a factor that directly affected the individual with the disability directly. When the individual with the disability might have difficulties in communicating, for example, because of speech impairments, deafness, or limited English, he or she was also severely limited in obtaining services. Either a caretaker or an interpreter was needed to help the individual obtain services.

An element of communication that affected all focus group members we using the technical vocabulary of service providers to inquire about and discuss services. If an individual did not know what particular questions to ask a gatekeeper, or could not understand explanations of the complex service system, their ability to seek services from that agency was severely limited.

Strategies

Focus group participants described common strategies that they used to obtain needed services. These strategies were actions that the individuals and family members took in their attempts to acquire services, or responses they made in reaction to barriers that they encountered during their search for services. Five categories of strategies were predominately discussed by participants; being assertive, changing their economic status, moving to an urban area that had needed services, gaining information about how to play the "qualifying game," and enlisting the help of attendants or caretakers to acquire services. These strategy categories are described in the following section.

Being Assertive

Participants discussed how it was necessary for them to be extremely assertive in order to obtain services in their communities. This assertiveness was used to obtain information about available services and to advocate for disability rights. Family members as well as individuals with disabilities felt they had to learn assertive behaviors. "I learned that with my daughter, you have to be an aggressive parent. Because no one else is going to do it for you." Agencies that existed for the purpose of offering services to individuals with disabilities were often viewed as entities that had to be confronted in order to obtain information and services rather than organizations that offered support.

Community services that did not provide access to individuals with disabilities also had to be confronted. Participants gave examples where they had to be assertive and educate agencies about the rights of individuals with disabilities. Participants described that it was difficult to change both community services and the service system for individuals with disabilities, but that one strategy for possibly doing so was through organizing together to campaign for legislative action. This type of organizing was seen as a type of group assertiveness and advocacy.

Despite extensive agreement among the participants that assertiveness was necessary in order to receive services, some participants pointed out that they had some fear of doing so.

Gaining Knowledge

Participants indicated that knowledge about the service system was important to obtain services. Participants believed that the more knowledge they had about how to qualify for services, the more likely they were to obtain services, and the more knowledge they had about what services were available, the more successful they would be at qualifying for services. In part, knowledge about services was used to circumvent the gatekeepers who were seen as preventing access to these services. Service providers were viewed as not forthcoming with information that would help families become more educated about the service system. Instead, other individuals with disabilities or their family members were seen as being reliable and helpful sources of information about the system.

> "I also checked into that program. The first time I called I was given incorrect information that there was a resource limit, and I was over the resource limit so I couldn't apply."
>
> "So you didn't apply because you were told that you were over the resource limit?"
>
> "Right. And I later checked that program and they said they don't have a resource limit."

Agencies seemed uninformed about what services were available from other agencies and often did not properly refer families, nor give them information about how to qualify for available services in their own agency.

> "But no one agency tells you about the other programs. (Agency), if you called for client management, you're only going to find out about client management they're going to say you don't qualify-oh, is there anything else that I qualify for-I don't think so, no, because the only program they know is the one they're working on. So you think you've already talked to (agency), you've found out about all their programs and therefore you don't qualify. And there's several of them out there that would fit you just perfect so you're up a creek. It took anywhere from two to three years to understand this and I've worked extremely hard. I've been at a lot of meetings. A lot of training to even come close to understanding the ins and outs and then that's not to count on whatever the deception is that's going on."

Participants talked about networking to obtain badly needed information about available services and how best to provide support for their family member with a disability:

> "You make every meeting, you're everywhere, you're talking to anyone. If you see someone in the grocery store you tell them your story. You hope someone gives you a piece of information that someone hadn't. You chase every false lead, you know, where some people say you're paranoid, you're obsessed. No, you're desperate."

> "And that's really been the key is agencies that help us connect up with other parents, whether they be the same age, older or younger, to our own network. ...we've gotten most of our information from consumers, not the professionals. Some of us do have dual roles and I think that's because we saw a lack of experts giving us information that we could use or appropriate information. So what has really helped us is being able to connect up with other parents or consumers and getting information from those people...and we've maintained that anything that we have found out have not been from the 'experts'."

Moving To Obtain Services

Individuals with disabilities and their families who lived in rural areas spoke about the difficulty in obtaining services, particularly skilled attendant care. Many families had chosen to relocate to cities where these services were available.

> "And actually I moved away from Houston for about four years. I moved to West Texas and I came back to Houston because Houston has the services that I need."

Others traveled long distances to obtain services that were needed intermittently. Participants from the McAllen focus group spoke about the lack of trained professionals, including teachers, doctors, and translators for people who are deaf in South Texas. They also shared that it was not unusual to travel to San Antonio for services.

Changing Economic Status

Participants repeatedly discussed the high costs of services needed by individuals with disabilities and their difficulties in obtaining services through public agencies. Families had to carefully monitor their income as a change in economic status might mean the loss of services. Some families consciously chose to impoverish themselves in order to qualify for a wider range of services. All participants recounted stories of economic struggle, while many told stories of financial ruin.

> "We didn't have any Medicare or anything... and one day one of the twins got real sick and we didn't have any insurance or anything so we were afraid to take them to the hospital so we took him to the doctor and he said, 'Well, this kid's is almost dying.' And we took him to the hospital-we made arrangements with the hospital to make payments little by little but it was so hard for us because we didn't have any insurance or anything. So finally...after two and a half years by ourselves, you know, paying the bills and all that. We finally got Medicaid-but sometimes my husband has a chance to go to college or do something better than his job but we say wait a minute--if you get a better job we're going lose our Medicaid and everything now."

Being dependent on public programs was not seen as a positive choice because participants understood that it placed the entire family at economic risk. Managing these financial challenges was made more difficult by the lack of information and its complexity about qualifying economically for services.

Finding respite or attendant services that would allow family members to work while someone cared for the family member with the disability was difficult. Families often had to make choices that might place their family member with a disability at risk.

> "...you sometimes have to make the choice: Do I work or do I take care of my child's needs? Do I go on welfare and food stamps and SSI? Or do I sacrifice my child's need and I go in and draw a paycheck? ...we shouldn't have to decide between employment and the well-being of our children. And as a group we are having to do that."

Economic support seemed to be particularly difficult for individuals who were not classified as having a developmental disability and did not yet qualify for services designed for the elderly.

> "The problem right now is that kids basically 1-22 have got resources. The older people from 64 on up have resources. I'm over 23 and I'm under 64 and I don't have anybody to talk to."

Attendant Services

Attendant care was one of the types of services that individuals with disabilities and their families sought. Attendants, in turn, were used to obtain other services. Deaf individuals particularly pointed out, that without an interpreter, they were often unable to obtain basic health and transportation services. Individuals with disabilities discussed their need for attendant services in order to pursue employment opportunities and to participate in social and recreational activities.

> "Well, I can't get up in the morning unless I have somebody who will come and help me get, up, get dressed. I can't get to work if I don't have transportation."

> "...as a disabled woman I find it very difficult to find a gynecologist who has an accessible office and or the staff that can get me up on the table and help me in positioning and whatever in order to get that kind of exam."

Attendant services were inevitably described as expensive by the participants in the focus groups.

Consequences

Participants shared that although the ultimate goal was to obtain needed services, acquiring information about the process was seen as a positive outcome in itself. Even when necessary services were unavailable or difficult to attain, knowledge of how to begin attaining them was enough to provide the individual with an increased sense of personal control. Some level of personal independence and control over their own lives were seen as equally vital to focus group participants as the needed services.

Often, the level of services an individual or family received directly correlated with the degree of inclusion that individuals experienced within their communities. These outcomes were seen as basic life goals and provided the driving emotional force behind the search for services.

Conclusions

Based on the analysis of the focus group meetings, a storyline emerges which illustrates how the issues, barriers and opportunities in the lives of individuals with a severe chronic disability impact these participants' lives. This storyline may be seen as follows:

What is true about all of these groups is that having a disability creates a need for services that are scarce and costly. Financial assistance is needed to obtain these services. People, at first, know very little about how to obtain services. They begin going to doctors, agencies, social workers, and teachers, none of whom are particularly satisfactory in either providing them with services, referring them for services, or in being empathetic about the needs of the individual with the disability. Often, these entities are seen as being uninformed, inept, insensitive, or unhelpful. Nevertheless, they are the gatekeepers to the services that the person with the disability need. They have the power to order services or to refer the individual to services. It also means they usually make a "yes" or "no" decision regarding the individual's eligibility and do so based on how their agency defines "disability."

This definition is a microcosm of how much of society perceives individuals with a disability, i.e.,. by what they cannot do rather than what they can do. Persons with a disability and their families have to become educated, assertive, and persistent to obtain services that are controlled by gatekeepers. They understand the nature of their disability, the need to network with other parents/individuals with disabilities, the need to educate themselves about services available, and the need to educate themselves about their rights. It also means that they may have to withhold information from the gatekeepers or misconstrue what resources, both economic and personal, the individual with a disability has.

Depending on how well this game is played the family and individual with the disability may obtain needed services. However, once a person qualifies they may not receive services because of shortages or long waiting lists. The the level of services received are correlated to the degree of inclusion that the individual has in the community. The ability to receive services also influences the level of stress (economic and emotional) experienced by the family and/or the individual with the disability.

Participants of the focus groups identified five primary categories of concerns with subcategories under two of the primary concerns. The five categories of concerns are: personal care services with subcategories of attendant care, assistant care and respite care, education with subcategories of parents and family members, professionals, and the community at large, transportation, information, and acquiring individual assertive behaviors. (See Table III below.) In addition, participants identified that these needs must be satisfied before other needs such as individual and family health, ability to earn a livelihood and independence could be met.

The concerns, frustrations and strategies they described are reminiscent of those identified in the 1990 Reports that were prepared by DD Councils to meet a requirement in the 1987 reauthorization of the Act (P.L.
The function of
these needs in the lives if the participants call for the strategies assigned to DD Councils by the Act, that is, systems change, capacity building, and advocacy.

Table III

Primary Categories of Concerns

Across age of onset or nature of disability, the primary categories of concerns included:

Personal Care
  Attendant Care
  Assistant Care
  Respite Care

Education of:
  Parents and family members
  Professionals
  Community at large

Transportation

Information
    Acquiring individual assertive behaviors

Appendix B

Work Group Membership

Appendix B

Work Group Membership

Dave Sloane, *Assistant Director,* Advocacy, Inc.
(The Texas Protection and Advocacy Agency)

Penny Seay, Ph.D., *Director,* The Texas University Affiliated Program

Bob Kafka, *Director,* Institute for Disability Access
Belinda Carlton, *Executive Director,* Coalition for Texans with Disabilities;
Personal Assistance Services Task Force

Patricia Anderson, *Executive Director,* United Cerebral Palsy of Texas

Mike Bright, *Executive Director,* The Arc of Texas

Eldon Baber, *Executive Director,* Texas Alliance for the Mentally Ill

Stella Mullins, *Executive Director,* Mental Health Association in Texas

Kevin Tracy, *Self-Advocacy Program Coordinator,* Texas Advocates

Barbara Ellis, *Program Specialist,* Texas Department on Aging

Rita Handley, *Associate Director,* Texas Dept. of Mental Health/Mental Retardation

Steve Schoen, *Program Specialist,* Texas Rehabilitation Commission

Andres Alcantar, *Planner,* Texas Health and Human Services Commission

Bill Agnell, *Program Specialist,* Texas Commission for the Blind

David Meyers, *Commissioner,* Texas Commission for the Deaf and Hearing Impaired

Appendix C

Disability Statistics

Disability Statistics

Introduction

"It is clear to most of us within the disability research community that there is a serious need for more and better data about people with disabilities in the United States. We need better information about the nature of disabling conditions and their social and economic consequences, both to guide policy and programmatic decisions as well as to enrich our understanding of disability. We need to know more about demographic trends, the impact of impairments on employment and the range of life functions, the ways in which people with disabilities participate (or not) in public and private programs, and the values and attitudes of disabled and nondisabled people about disability."[1]

How many people with a disability are there in Texas? How many Texans have one, two or three functional limitations? These are not easy numbers to estimate.

Some Texas Demographics

The population in Texas continues its rapid growth. According to projections provided by the Texas State Data Center, Texas, with a 1995 population of 18.6 million, is now the second most populous state in the nation. According to these projections, the state's population will grow from 17.0 million in 1990 to 20.3 million in the year 2000.

Using these population projections, three prevalence rates can be used to estimate and project the total number of Texans with developmental disabilities under the current definition. These prevalence rates, developed by the Governor's Planning Council on Developmental Disabilities, Minnesota State Planning Agency, provide a range — low, middle, high — for estimating the number of people with developmental disabilities. The low prevalence rate provides projections based on the assumption that the number of Texans with developmental disabilities accounts for 1 % of the state's general population. The middle and high prevalence rates are 1.6% and 2.4%, respectively.

The estimates show that Texas has experienced substantial growth in the number of Texans with developmental disabilities. Using the lowest prevalence rate, it is estimated that there will be at least 203,182 Texans with developmental disabilities in the year 2000 (Table I). If high prevalence rates are applied, it is estimated that there could be as many as 487,638 Texans meeting the current definition.

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[1] Richard L. Scotch, "The Politics of Disability Statistics." In Zola (Ed.), Disability Studies Quarterly, Summer 1990, Vol. 10, No. 3.

Table I
Estimated Prevalence of Developmental Disabilities

Year	Texas Population	Low DD Prevalence	Middle DD Prevalence	High DD Prevalence
1,995	18,617,441	186,174	297,879	446,818
1,996	18,950,549	189,505	303,208	454,813
1,997	19,286,597	192,865	308,585	462,878
1,998	19,626,206	196,262	314,019	471,028
1,999	19,969,937	199,699	319,518	479,278
2,000	20,318,262	203,182	325,092	487,638

Source: Texas population estimates and projections, 1.0 Growth scenario. Prepared by the Texas State Data Center, Texas A&M University

Estimates for the Texas population with developmental disabilities are based on the prevalence rates developed by the Governor's Planning Council on Developmental Disabilities, Minnesota State Planning Agency, taken from A New Way of Thinking, University of Minnesota, January 1987.

Consistent with national trends, a larger proportion of the Texas population will be older. Longer life expectancy, the aging "baby boomers" and lower birth rates all contribute to the growing elderly population. The Texas population 65 years and over is projected to reach 2.0 million (Table II) by the year 2000.

Table II
Estimated Texas Population 65 Years and Over

Year	Projection
1,995	1,885,972
1,996	1,921,517
1,997	1,946,652
1,998	1,975,304
1,999	2,001,597
2,000	2,034,367

Source: Texas population estimates and projections, 1.0 Growth scenario. Prepared by the Texas State Data Center, Texas A&M University

The frail elderly are defined as elderly persons unable to perform one or more activities of daily living (ADLs) without help. The Texas Department of Aging has estimated that of 608,000 elderly persons with disabilities in the state, 329,000 or 54% met this definition for the frail elderly.

Even though the number of elderly in Texas continues to grow, the proportion of children to adults in Texas is larger than the nation as a whole. The number of children is projected to grow by about 10% by the year 2000.

The state is also becoming more ethnically diverse. Persons of Hispanic origin are the fastest growing ethnic group in the state. The Hispanic population is projected to grow to 6.3 million (Table III) by the year 2000.

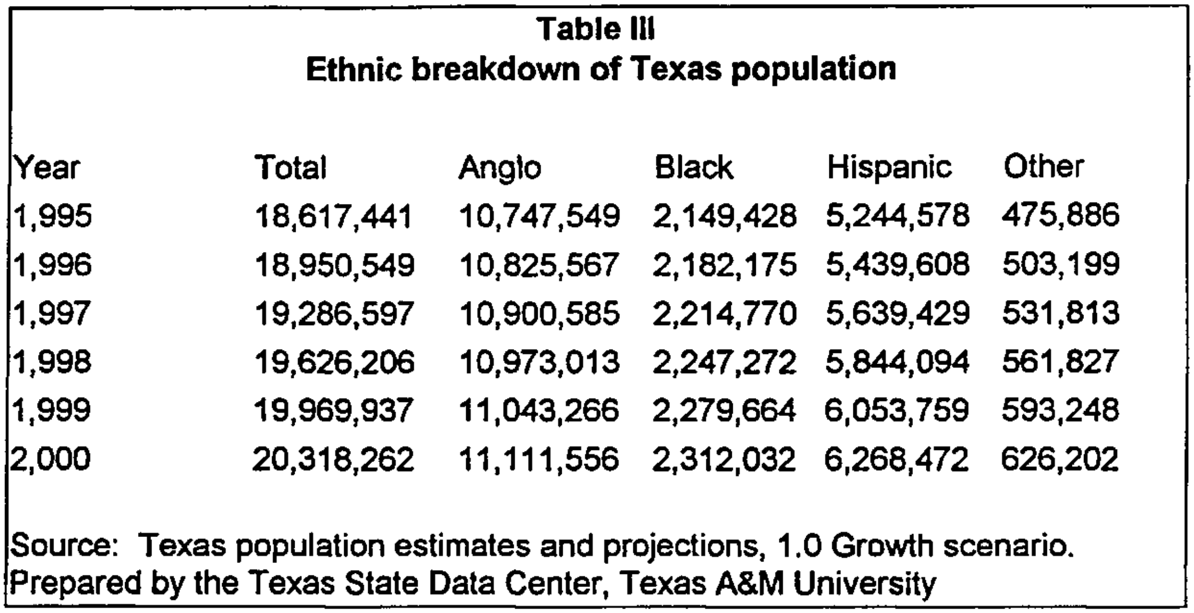

Table III
Ethnic breakdown of Texas population

Year	Total	Anglo	Black	Hispanic	Other
1,995	18,617,441	10,747,549	2,149,428	5,244,578	475,886
1,996	18,950,549	10,825,567	2,182,175	5,439,608	503,199
1,997	19,286,597	10,900,585	2,214,770	5,639,429	531,813
1,998	19,626,206	10,973,013	2,247,272	5,844,094	561,827
1,999	19,969,937	11,043,266	2,279,664	6,053,759	593,248
2,000	20,318,262	11,111,556	2,312,032	6,268,472	626,202

Source: Texas population estimates and projections, 1.0 Growth scenario.
Prepared by the Texas State Data Center, Texas A&M University

According to the 1989 Special Texas Census, the number of persons with disabilities, without regard to age, is projected to grow from 2.1 million in 1993 to 2.4 million (Table IV) by the year 2000. However, precise estimates on the number of people with specific disabilities in Texas are currently not available. The definitions used to identify many of these populations have played a key role in this deficiency.

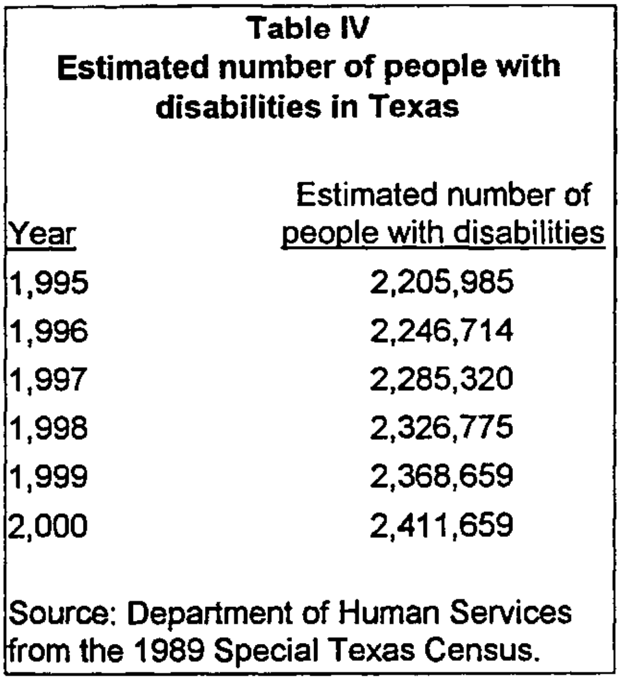

Table IV
Estimated number of people with disabilities in Texas

Year	Estimated number of people with disabilities
1,995	2,205,985
1,996	2,246,714
1,997	2,285,320
1,998	2,326,775
1,999	2,368,659
2,000	2,411,659

Source: Department of Human Services from the 1989 Special Texas Census.

A Matter of Definitions

Researchers and demographers have had difficulty estimating the number of people with specific disabilities because there is no simple way to answer the many possibilities. Statisticians, who often depend on program statistics serving specific populations, are hindered in estimating the size of specific disability populations by the differing definitions used.

There is no common definition of disability. The concept measured by a given survey or administrative data system may be limitation of activity, limitation in function, need for personal assistance, a chronic condition, or others.

The definitions have impacted the ability of statisticians to estimate the number of people with a disability, chronic or other. It is also very difficult to determine the number of individuals in the state with one, two or three functional limitations.

The definition used for any program is crucial in determining who will ultimately receive services. As such, definitions have been carefully written to target services to specific groups with specific disabilities and needs. The differing definitions of disability have had a significant impact on public policy. Over time, definitions have evolved into a budget tool to manage the growth of the system of services. They have also contributed to the complexity of the system, increased the levels of fragmentation within the system and created barriers to accessible services. The definitions of disability have in many instances become a handicap in the lives of individuals with disabilities needing services.

World Health Organization. The World Health Organization (WHO) defines disability as "any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner, or in the range, considered normal."[2] Disability involves many areas of functioning including physical, emotional, and mental functioning.[3]

WHO has developed a conceptual framework for disability as part of the International Classification of Impairments, Disabilities and Handicaps (ICIDH). The ICIDH was developed as an extension of the International Classification of Diseases (ICD), and provides a classification system for three concepts: impairments, disabilities, and handicaps.[4]

Under the ICIDH the three concepts are defined as follows:

1. Impairments are concerned with abnormalities of body structure, organ or system function, and appearance;
2. Disabilities reflect the consequences of the impairment in terms of functional performance;
3. Handicaps are concerned with the disadvantages experienced by an individual as a result of impairments and disabilities and the interaction of the individual with his or her surroundings.[5]

A disability should be viewed as a functional limitation within the individual caused by physical, mental, or sensory impairments, and a handicap should be viewed as the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.[6] Thus, "an understanding of the role of the environment (the extent to which physical and social barriers exist) is critical to any attempt to define disability or handicap."[7]

Again, a single meaning and measure of disability cannot fit the range of data sources attempting to measure the prevalence of disabilities. While definitional complexities and inconsistencies do exist and this makes enumeration difficult, it also demonstrates the multi-dimensional nature of disability and the corresponding need for separate statistics on the various types of limitations.[8]

Given the varying definitions of disability, the focus of many disability studies is not on the conditions themselves (medical perspective), but on the functional capacity

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[2] Digest of Data on Persons with Disabilities, p.5

[3] Digest of Data on Persons with Disabilities, p.5

[4] Americans With Disabilities, 1991-92, p.1.

[5] Americans With Disabilities, 1991-92, p.1.

[6] The Chairman of Disabled People International in Americans With Disabilities, 1991-92,p.3.

[7] Americans With Disabilities, 1991-92, p.3.

[8] Digest of Data on Persons with Disabilities, p.5.

and need of the individuals involved (non-medical perspective).[9]

Number and Characteristics of Persons with Disabilities

A precise estimate of the number of Texans with disabilities is currently not available. It is also difficult to precisely estimate the number of individuals with specific disabilities. This is due to "the differing operational definitions of disability, divergent sources of data, and inconsistent survey methodologies, which together make it impossible to aggregate much of the data that are available.[10]

Several national surveys, conducted by federal agencies, provide much of what is available about population statistics on disability. Surveys such as the National Health Interview Survey, the Survey of Income and Program Participation, and the Current Population Survey provide some of the most reliable figures.

In addition to the differing definitions of disability, the two major approaches used to count the number of people with disabilities can also lead to confusion. As has been stated, federal statistical agencies measure and report on the prevalence of disabilities using many different definitions. Activity limitation and functional limitation are the most general measures of disability used. On the other hand, measures of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) limitations pertain to individuals with severe long-term personal assistance needs and describe disability in both household and institutional settings.[11] In addition, many national studies focus on particular health conditions and distinguish between the household population and those living in institutions and among demographic groups such as children and the elderly.[12]

Most data on disability show prevalence at only the national level because most sample sizes from the various disability-related surveys are too small to allow state-level estimates. However, the 1990 Census provides limited state level data on persons with disabilities, and several surveys also contain state-level data. Unfortunately, they do not provide the specific estimates needed for the expansion populations in this study.

National Health Interview Survey (NHIS). NHIS is a nationwide sample of households conducted by the National Center for Health Statistics (NCHS). It surveys the civilian, noninstitutionalized population of the United States on its health. For disability purposes, it is concerned with activity limitations and chronic conditions. Each weekly sample is representative of the target population and is additive with other weekly samples. Sampling is done throughout the year, thus

[9] Digest of Data on Persons with Disabilities, p.6.

[10] Toward Independence, p. 3.

[11] Digest of Data on Persons with Disabilities, p.13.

[12] Digest of Data on Persons with Disabilities, p.13.

preventing seasonal bias.

The NHIS defines disability as "long-term reduction in activity resulting from chronic disease or impairment."[13] The NHIS describes an activity limitation in terms of the major activity it considers usual for an individual's age group: 1) ordinary play for children under 5 years of age, 2) attending school for those 5-17 years of age, 3) working or keeping house for persons 18-69 years of age, and 4) capacity for independent living for persons after age 69.

The NCHS determines the severity of disability by asking respondents whether they are able to perform their major activity, or, if they can, whether they are limited in the amount or king of major activity. Individuals not able to perform their major activity are classified as having a severe disability.[14] If persons are not limited in their major activity, NCHS asks whether they are limited in other ways, which it terms 'non-major' or 'outside' activity. Also, for those persons 18-69 years of age who keep house, and those persons 70 years of age and over, working is included as a category of 'outside activity'.

Using these definitions, NCHS estimates that 14.1% of the population of the U.S. have an activity limitation. This includes 4.1% who are unable to perform their major activity, 5.4% who are limited in the amount or kind of major activity, and 4.5% who are limited in non-major activity.[15] Of the total noninstitutionalized population in the United States, 34.2 million (14.1%) were limited in activity due to a chronic health condition in 1989.

The NHIS has found that limitation in activity increases with age. Of the population aged 70 and over, 7.5 million (39%) were limited in activity while 3.4 million (5.3%) children under 18 years of age were limited in activity.

The Americans With Disabilities Act population size of 43 million was taken from the NHIS survey count of the total number of noninstitutionalized individuals with impairments. It is estimated that an additional 1.5 to 2 million individuals, most of whom have disabilities, reside in nursing homes, mental hospitals, residential facilities and mental retardation facilities.

1990 Census. The 1990 U. S. Census of Population and Housing measured the disability status of non-institutionalized persons above the age of 15. Children with disabilities and persons with disabilities living in institutions were not measured by the survey. The 1990 Census estimated 575,641 non-institutionalized persons (16 years or older) in Texas with "self-care" limitations. Self-care limitation was defined as a physical or mental condition which has existed for at least 6 months and which makes it difficult for an individual to take care of his or her personal

[13] Digest of Data on Persons with Disabilities, p.6.

[14] Digest of Data on Persons with Disabilities, p.6.

[15] Digest of Data on Persons with Disabilities, p.7.

needs, such as dressing, bathing, or getting around inside the home.[16]

The 1990 Census also estimated 504,237 non-institutionalized persons with a mobility limitation in Texas. A mobility limitation was defined as a physical or mental condition which has existed for at least 6 months and which makes it difficult for an individual to independently leave his home.[17]

The 1990 Census also estimated 831,145 non-institutionalized people in Texas, 16 years or older, with mobility or self-care limitations, or both.

Current Population Survey (CPS). The CPS is a monthly survey conducted by the Bureau of the Census for the Bureau of Labor Statistics. The CPS sample is selected from census files covering all 50 states and the District of Columbia. The sample is continuously updated. Questions relating to labor force participation are asked of all members in a household who are 14 years or older. In March, supplementary questions are asked about income and work disability. People are classified as having a work disability if they:

1. have a health problem or disability that prevents them from working or limits the kind or amount of work they can do,
2. have a service-connected disability or ever retired or left a job for health reasons,
3. did not work in the survey week because of long-term physical or mental illness or disability that prevents the performance of any kind of work,
4. did not work at all in previous year because of illness or disability,
5. are under 65 years of age and are covered by Medicare, or
6. are under 65 years of age and a recipient of Supplemental Security Income (SSI).

The 1988 CPS reported 13.4 million people with a work disability. Of these, 31.6% were in the labor force and 14.2% were unemployed.

The Survey of Income and Program Participation (SIPP). The Census Bureau provides another measure of disability in its Survey of Income and Program Participation (SIPP). SIPP is a longitudinal survey conducted by the Bureau of the Census. Core areas are covered at every survey period, while specific areas of interest are done in one period. As with the NHIS, the SIPP covers the noninstitutionalized population of residents living in the United States. The same households are interviewed every 4 months for two and a half years. A cycle of four interviews covering the entire sample, using the same questionnaire, is called a wave.

In the report entitled, ***Americans With Disabilities: 1991-92. Data from the Survey of***

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[16] 1990 U.S. Census of Population and Housing.

[17] 1990 U.S. Census of Population and Housing.

Income and Program Participation. Current Population Reports, P70-33, a person was considered to have a disability if the person was identified by any of the questions described in 12 possible categories. In the same survey, persons were categorized as having a severe disability if they were described by the following statements:

- Persons 15 years old and over who used a wheelchair or who had used a cane, crutches, or a walker for 6 months or longer.
- Persons 15 years old and over who were unable to perform one or more functional activities or who needed the help of another person with an Activity of Daily Living (ADL) or with and Instrumental Activity of Daily Living (IADL).
- Persons 16 to 67 years old who were prevented from working at a job or business.
- Persons 16 years old and over who were prevented from doing work around the house.
- Persons 15 years old and over with mental retardation, a developmental disability such as autism or cerebral palsy, or Alzheimer's disease, senility, or dementia (either measured directly or cited as a condition causing a limitation or disability).
- Persons 0 to 21 years old with autism, cerebral palsy, or mental retardation (cited as a condition casing a limitation or disability).[18]

Based on these responses, it was estimated that the number of persons with a severe disability was 24.1 million, or 9.6% of the total population.[19]

According to the 1991-92 SIPP Report, the chances of having a disability increase with age. While persons age 65 and over were estimated to comprise 12% of the general population, it was estimated that they comprise 34% of persons with disabilities and 43% of persons with severe disabilities.[20] Some other SIPP findings:

- 48.9 million persons were counted as having a disability based on the 12 categories.

- Of the 195.7 million persons 15 years old and over, 17.5% had difficulty with one or more functional activities and 7.8% were unable to perform one or more activities.

- Relatively large numbers of persons were identified as having difficulty with physical activities. In all, 16.2 million persons (8.3%) had difficulty lifting and carrying a weight as heavy as 10 pounds, and 7.7 million (4.0%) could not perform this task at all.

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[18] Americans with Disabilities, 1991-1992, pp. 2-3.

[19] Americans with Disabilities, 1991-1992, p. 3.

[20] Americans with Disabilities, 1991-1992, p. 4

- The least prevalent of the six functional limitations was difficulty having one's speech understood. The number identified as having difficulty with this functional activity was 2.3 million, or 1.2%; the number unable to have their speech understood at all was 0.2 million, 0.1%.

- Of the 34.2 million persons having difficulty with one or more functional activities, more than half had difficulty with more than one activity; 14.5 million had difficulty with one; 7.1 million had difficulty with two; and 12.6 million had difficulty with three or more.

- Among the 15.2 million persons who were unable to perform one or more functional activities, 7.0 million were unable to perform one activity, 4.0 million were unable to perform two activities, and 4.3 million were unable to perform three or more activities (the latter two figures are not statistically different).

- Persons were much less likely to have difficulty with an ADL than to have difficulty performing a functional activity. The number of persons 15 years old and over who had difficulty with one or more ADL's was 7.9 million, or 4.1%. Of this number, 2.0% of the population 15 years old and over required the assistance of another person with one or more of the basic six activities.

- Of the 7.9 million persons with an ADL limitation, 3.3 million had difficulty with one activity, and 4.6 million had difficulty with two or more. Of those needing assistance, 1.5 million needed assistance with one activity, and 2.4 million needed assistance with two or more.

- Among those needing assistance with an IADL were 6.0 million for going outside the home to shop or visit a doctor's office, 4.7 million for doing light housework, 3.7 million for preparing meals, and 3.4 million for keeping track of money and bills.

- Based on responses to the ADL and IADL questions, the number of persons needing assistance with one or more activities was 9.2 million, or 4.7% of the population 15 years old and over.

There were several items on the questionnaire that attempted to identify persons with a mental or emotional disability. In this study, a person 15 years old and over was considered to have a mental or emotional disability if the person:

1. was identified by one of the questions that asked if the person had a learning disability, had mental retardation, had Alzheimer's disease, senility, or dementia, or had any other mental or emotional condition;

2. had a functional, ADL, or IADL limitation or a work or housework disability that

was caused by any of four conditions including learning disability, mental or emotional problems or disorders, mental retardation, or senility, dementia, or Alzheimer's disease; or

3. had difficulty keeping track of money and bills.

Other Relevant Information

The number of persons 15 years old and over identified as having a mental or emotional disability was 6.9 million, or 3.5% of ail persons in this age group.

Another Census report supports SIPP Report findings of an increase in disability with age. In the January 1994 Statistical Brief "Americans with Disabilities" prepared by the Bureau of the Census, it is estimated that 19.4% of the general population has a disability and 9.6% have a severe disability. In the same brief, it is estimated that 56% of persons 65 and over have a disability, with 37.4% having a severe disability.[21]

- Needs assessments conducted by the Texas Area Agencies on Aging in 1994 indicate the broad range of needs for older Texans. Primary needs identified include: additional congregate and home delivered meals, transportation services, caregiver support services (such as respite care, adult day care and telephone reassurance), and services for the homebound elderly such as personal assistance, residential repair and assisted living.

- Texas Department of Health (TDH) estimates 73,000 persons in Texas living with the HIV virus in 1992.[22]

- TDH reports 8,975 persons living with AIDS in Texas in its *Texas AIDS Cases: Surveillance Report.*

- Texas Department of Mental Health and Mental Retardation (TXMHMR) estimates 2,553,641 persons with mental illness in Texas in 1991.

- TXMHMR estimates 474,299 Texans with a mild, moderate or severe form of mental retardation.

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[21] "Americans with Disabilities" Statistical Brief, Bureau of the Census, January 1994.

[22] Annual Report, HIV Services, p. 23-24.

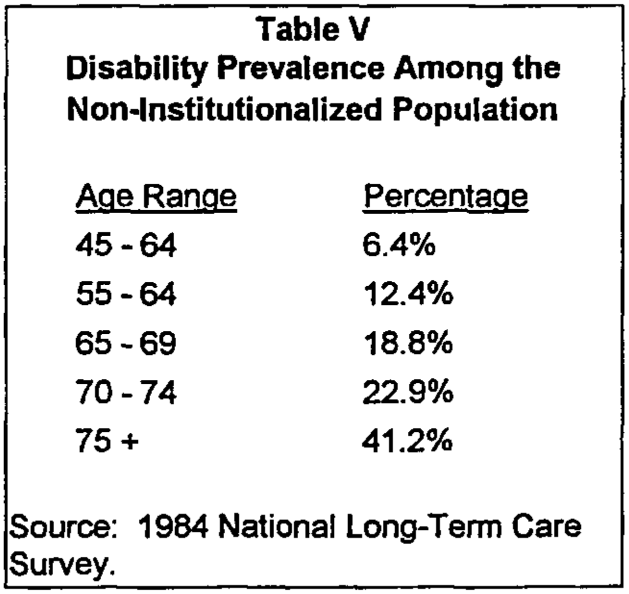

Table V
Disability Prevalence Among the Non-Institutionalized Population

Age Range	Percentage
45 - 64	6.4%
55 - 64	12.4%
65 - 69	18.8%
70 - 74	22.9%
75 +	41.2%

Source: 1984 National Long-Term Care Survey.

- The US Department of Health and Human Services statistics estimate that 35% of the general population have disabilities which impact their ability to live independently.

- The median age of the 1989 population was 34.20 years old versus a statewide average of 30.9 years and a national average 35.9 years.

Appendix C

Sources of Prevalence Statistics

Texas population estimates and projections, 1.0 Growth scenario, Texas State Data Center, Texas A&M University.

Fiscal Size Up, 1994-1995 Biennium, Texas State Services, Legislative Budget Board.

U.S. Data on Demand, s in Profile, 1993.

Texas Department of Health, *Texas Vital Statistics, 1992 Annual Report.*

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Appendix D

Grants Profile List

TEXAS PLANNING COUNCIL FOR DEVELOPMENTAL DISABILITIES

PROFILES OF GRANT PROJECTS

OCTOBER 1995

EMPLOYMENT PROJECTS

Local/Regional
Employment Systems Change Project
Project Period: January 1, 1993
December 31, 1997

Project Director: Tina Coy
Austin-Travis County MHMR Center
1430 Collier
Austin, TX 78704
512/483-5800

This project utilizes community integrated work settings to assess, train and employ individuals who are currently in a workshop or other congregate setting. Extensive consultation and training is being provided which will enhance the Center's capacity to develop community employment resources. Their system for employing individuals with severe disabilities will convert from day programming in congregate settings to support for jobs in regular community employment.

Local/Regional
Employment Systems Change Project
Project Period: December 1, 1992
May 31, 1997

Project Director: Paul Fagan
Junction Five-O-Five
4410 College Main
Bryan, TX 77801
409/846-3670

This project provides community integrated employment options by involving area businesses in the planning and promotion of employment for people with disabilities. An interagency cooperative (IAC) and a business advisory council are combining efforts and resources through regular meetings to maximize available community resources. The IAC brings together local agencies and organizations which assist with employment of people with disabilities.

Local/Regional
Employment Systems Change Project
Project Period: March 1, 1993
May 31, 1997

Project Director: Carolyn Shelton
Collin County MHMR Center
708 South College
P.O. Box 828
McKinney, TX 75069
214/542-8737

This conversion project is intended to result in the closure of the Collin County MHMR Center workshop. The project provides extensive training, consultation and technical assistance related to community inclusion to staff, consumers, parents, and community members. In year five, it is expected that all vocational services will be provided in the community. A conversion guide has been developed.

COMMUNITY LIVING PROJECTS

Texas Respite Resource Network	Project Director: Jennifer Cernoch, Ph.D.
Project Period: May 27, 1991	Santa Rosa Health Care
May 31, 1997	519 W. Houston
	P.O. Box 7330
	San Antonio, TX 78207-0330
	210/704-2794

Funded since 1985, the Texas Respite Resource Network has been instrumental in developing statewide and national awareness regarding respite issues. The project has worked on policy reform, legislative changes and statewide networking in order to develop a statewide respite system. Currently the project is monitoring the Home and Community Support Services Act rules development, supporting the Respite Task Force, and conducting training and information sessions. Five national conferences on respite have been convened by the project.

Child Care Services System Change Project	Project Director: Nancy Hard
	Dependent Care Management Group
Project Period: September 1, 1991	130 Lewis Street
May 31, 1996	San Antonio, TX 78212
	210/225-0276

This project promotes the development of a statewide system of inclusive child care services by implementing the recommendations of the "Planning Study on Integrated Child Care Options" that was funded by the Council. This systems change initiative is conducting regional "summits" which bring together the key components of the child care delivery system such as parents, child care centers, family day homes, and child care resource and referral agencies. The overall goal is to increase the availability of inclusive child care for children with disabilities. A video entitled "ABCs of Inclusive Child Care" was produced.

Personal Assistance Services Task Force	Project Director: Belinda Carlton
Project Period: December 1, 1991	Coalition of Texans with Disabilities
November 30, 1997	316 W. 12th Street, Suite 405
	Austin, TX 78701
	512/478-3366

The Personal Assistance Services Task Force (PASTF) provides a forum for identifying issues surrounding the provision of attendant services. The purpose of this project is to provide staff support for PASTF activities, to monitor PAS public policy issues, and to gather and disseminate information concerning attendant services. An implementation study, "Improving Personal Attendant Services in Texas," outlines action steps and recommendations about how to solve issues relating to recruitment, retention and training of personal care attendants. The project provides training, information, and network development in local communities.

Community Living Systems Change	Project Director: Liz Shelby
Project Period: January 1, 1993	Texas Department of Mental Health
May 31, 1996	and Mental Retardation
	P.O. Box 12668
	Austin, TX 78711-2668
	512/323-3256

This project promotes the development of permanent family supports for children with developmental disabilities. Intensive statewide training and consultation for professionals involved in permanency planning is being provided. A resource manual for family support staff is being developed by a statewide group of professionals involved in permanency planning.

Community Living Systems Change	Project Director: Patty Moore
Project Period: December 1, 1992	Community Options, Inc.
May 31, 1996	One Highland Center
	314 Highland Mall Blvd., Suite 306
	Austin, TX 78752
	512/459-7694

This project provides supports for people with severe developmental disabilities as they transition from institutional residency to community living. Circles of support are being developed using inclusion, personal futures planning, assistive technology, family supports and supported employment. Assistance with obtaining housing is provided.

All Children Belong Demonstration Project	Project Director: Vince Trevino
Project Period: January 1, 1993	Dallas County Mental Health
May 31, 1996	Mental Retardation Center
	1341 W. Mockingbird Lane, Suite 1000E
	Dallas, TX 75247-4942
	214/630-2952

This project demonstrates a model for reunifying children, who are in institutions, with their birth families. Foster families, adoptive families, case management, and other supports are provided in order for the child to return to their community.

Inclusive Education Systems Change
Project Period: January 1, 1993
May 31, 1997

Project Director: Rona Statman
The Arc of Texas
Inclusion Works!
P.O. Box 5368
Austin, TX 78763-5368
512/454-6694

This project provides statewide support to promote the inclusion of students with disabilities in neighborhood schools and regular classes. The project provides technical assistance and training to schools involved in inclusive education pilot projects. The project also monitors public policy issues that influence inclusive education. Partial funding for this project is provided by the Texas Education Agency for public information activities. Products include: a quarterly newsletter, a video on inclusive education and a resource library of inclusive education training materials. A statewide conference on inclusive education is held annually. A blueprint for inclusive education in Texas has been developed.

Inclusive Education Demonstration Project
Project Period: January 1, 1993
May 31, 1997

Project Director: Bessie Ford
Fort Bend ISD
16431 Lexington Blvd.
Sugar Land, TX 77479
713/980-1300

This inclusive education project includes students, pre-K through 12, in regular education classrooms. The program features a district-wide advisory committee with inclusive education teams on each campus.

Inclusive Education Demonstration Project
Project Period: January 1, 1993
May 31, 1997

Project Director: Imogene Gideon
Mansfield ISD
609 East Broad
Mansfield, TX 76063
817/473-5683

This inclusive education project is demonstrating methods for educating students with disabilities in regular classrooms in their neighborhood schools. The project also identifies critical elements needed by educators and parents to implement an inclusive education system. A training program to develop the skills needed to implement inclusion is conducted for all school personnel, community leaders, parents, volunteers and school board members.

Consumer-Controlled Housing Initiative
Project Period: June 1, 1994
May 31, 1997

Project Director: Lisa Tips
Diana McIver & Associates
500 Loop 360 N, Suite 6100
Austin, TX 78746
512/328-3232

This statewide project provides training and technical assistance to improve the knowledge of individuals and organizations about ways to develop affordable, consumer-controlled (owned, leased or rented) housing. Training and technical assistance is focused on enabling people with disabilities to secure, maintain and retain independent, self-controlled housing. A statewide task force provides guidance and direction for project activities and public policy recommendations.

Conference Coordination
Project Period: June 1, 1994
May 31, 1997

Project Director: Janet Morrow
Credentials, Inc.
4360 South Congress Ave., #102 LB-9
Austin, TX 75745
512/440-7606

This project provides support and assistance to the TPCDD staff for coordination of various training activities including a statewide best practices conference, regional seminars and a national Partners In Policymaking conference.

SYSTEM COORDINATION/COMMUNITY EDUCATION PROJECTS

Texas Transition Task Force
Project Period: October 1, 1987
August 31, 1997

Project Coordinator: Elliott Zirkle
Advocacy, Inc.
7800 Shoal Creek Blvd., #171-E
Austin, TX 78757
512/454-4816

This statewide project provides training to parents of children who have disabilities and are planning the transition from school to adult life. Training is coordinated through local Education Service Centers and advocacy groups.

Texas Disability Policy Consortium
Project Period: December 20, 1990
November 30, 1996

Project Coordinator: Nancy Epstein
Advocacy, Inc.
7800 Shoal Creek Blvd., #171-E
Austin, TX 78757
512/454-4816

The Texas Disability Policy Consortium is an organization of 20 statewide disability advocacy groups. The Consortium's mission is to identify, formulate positions on, and educate public officials regarding public policy issues of concern to persons with disabilities and their families. Member organizations have the opportunity to jointly endorse and publicly support such positions. The project provides administrative and professional staff support to assist the Consortium. Training is provided to local communities and individuals on effective legislative and advocacy skills. Grant products include: an electronic bulletin board system and a cross-disability legislative newsletter.

Support for Partners in Policymaking
Project Period: September 1, 1991
June 30, 1998

Project Coordinator: Frank Walsh, J.D.
The Walsh Company
3933 Steck Ave., Suite B-107
Austin, TX 78759
512/794-8485

This project provides administrative support for the Partners in Policymaking program. It assists the DD Council in coordinating training support activities necessary to implement the Partners program. Project staff manage resources, make arrangements for airline transportation, and reimburse individuals and speakers for the Partners in Policymaking sessions, advanced training and Partners testifying in Austin and/or attending other meetings.

ABLE KIDS: A Statewide Assistive Technology Program for the Early Childhood Intervention Program
Project Period: June 1, 1992
May 31, 1998

Project Director: Nancy Hellstrom
Children's Habilitation Center
2219 Babcock Road
San Antonio, TX 78229
210/614-1910

This project provides training and technical support in the use of assistive technology in ECI programs for children 0-3 years of age. Trainings will be held in 12 regions of the state including areas which are considered underserved. Key components of the project include a training video, team training at Education Service Centers, video consultation for ECI programs, video teleconferencing, and development of an assistive technology equipment catalogue.

Information and Referral Project
Project Period: September 1, 1991
November 30, 1997

Project Director: Peggy Garrison
Health and Human Services Commission
Texas Information & Referral Project
4807 Spicewood Springs Road, Bldg. #4
Austin, TX 78759
512/502-3200

The purpose of this project is to promote the development of a statewide network of information and referral (I&R) services which are coordinated through local "Hub" providers. The project implements recommendations of "Information and Referral in Texas: A Plan to Improve Services" that was completed with funding by the Council. The project establishes regional networks of I&R programs, provides technical assistance in attaining professional standards in I&R and is developing an automated health and human services information clearinghouse. Grant products include: "Finding Help in Texas - A Directory of I&R Providers," "Texas Health and Human Services Dictionary of Terms," and the State Information and Referral System (SIRS) database.

Technology Learning Collaboration Project Assistance	Project Director: Elizabeth Tucker
Project Period: January 1, 1994	United Cerebral Palsy of Texas
December 31, 1996	900 Congress Ave., #220
	Austin, TX 78701
	512/472-8696

The Technology Learning Collaboration National Outreach Project (TLC) is funded by the U.S. Department of Education to conduct training for parents and practitioners on how to access and integrate readily-available technology into early childhood intervention programs. Council funds are used to provide support to the TLC Project including: printing of training materials, travel expenses of parents attending training sessions, a 1-800 phone line, computer equipment for project training, and project personnel.

Quality Living Study	Project Director: Celia S. Feinstein
Project Period: January 1, 1994	CFA, Inc.
May 31, 1999	350 West Mount Airy Ave.
	Philadelphia, PA 19119
	215/204-6561

This study is evaluating community placement outcomes for Texans with developmental disabilities who are moving out of state schools. The project will measure longitudinally the impact of community placement on key areas including: adaptive behavior, challenging behavior, health status, inclusion, independence, productivity or contribution, consumer satisfaction, family satisfaction, and services and supports received. Data will be collected prior to movement whenever possible and at intervals of six and 12 months after moving the consumer out of the state school.

Local Transportation Coordination Models	Project Director: Christine Janek
Project Period: October 1, 1995	Health and Human Services Commission
May 31, 2000	Office of Client Transportation Services
	4807 Spicewood Springs Road, Bldg. #4
	Austin, TX 78759
	512/502-3277

The Office of Client Transportation Services (OCTS) will develop five local transportation coordination models that each have a local coordinator and local coordination team. These teams will include agencies responsible for transportation funding, planning and implementation, as well as local advocates of transportation, including people with disabilities. Each coordinator and team will develop and implement a plan that will assure full access to services for people with disabilities, and will maximize the use of

resources. OCTS will evaluate the models for statewide applicability and establish a consolidated planning process for funding and delivery of transportation services.

PROJECTS COORDINATED BY COUNCIL STAFF

Partners in Policymaking

An innovative educational and leadership-training program, the first annual Partners in Policymaking class started in August 1990. Partners in Policymaking is designed for adults with developmental disabilities and parents of young children with developmental disabilities. Participants from across the state meet two days a month, for eight months, to explore current developmental disabilities issues, best practices, and the policymaking and legislative processes in order to strengthen self-advocacy skills and increase personal empowerment. The outcome of this project, managed directly by Council staff, is to increase the ability of participants to interact with public officials, to influence the development of public policy, and to obtain the most appropriate state-of-the-art services for themselves and others. For further information, contact Jopie Smith at 512/483-4089 or Susan Murphree at 512/483-4095.

Consumer Stipends

This project provides stipends which enable consumers and families without organizational support to attend conferences, workshops, meetings and other events. Funds of up to $5,000 are awarded to organizations sponsoring events in Texas that promote consumer empowerment and involvement in activities that enhance independence, productivity and community integration for people with developmental disabilities. Organizations must apply for stipends at least 120 days before an event. For more information about stipend applications, contact Lester Sanders, Grants Management Director, at 512/483-4084. Since the project began in late 1989, 79 stipend grants have been awarded.

Appendix E

Disability Policy Consortium Membership List

Appendix E

Disability Policy Consortium

Advocacy, Inc.

The Arc of Texas

Coalition of Texans with Disabilities

Directors Association of Texas Centers for Independent Living (DATCIL)

Epilepsy Coalition of Texas

The Institute for Disability Access

Mental Health Association in Texas

Spina Bifida Association of Texas

Texas Advocates

Texas AIDS Network

Texas Alliance for the Mentally Ill

Texas Association for the Deaf

Texas Deaf-Blind Association

Texas Head Injury Association

Texas Planning Council for Developmental Disabilities

Texas Society for Autistic Citizens

United Cerebral Palsy of Texas

Appendix F

Individual Profiles

Person # 1

Age 15, Diagnoses; autism, profound deafness, mild mental retardation

Is non-verbal, but communicates with American Sign Language

Periodically, shows bizarre, sometimes assaultive behavior
    Displays perseverative self-stimulating behavior
    If angered will strike others
    Unpredictable

Does not understand money management or the value of money

Types very well

Has poor judgment and may undertake actions that are dangerous to herself or others

Has problems learning, and understanding complex thought

Cannot be assumed to understand nutritional needs or how to maintain good nutrition

Provides own personal care with direction

Does not drive a car and needs transportation

Care given by relative who expresses need for respite and opportunities for family activities both including and excluding person

Is not self-medicating

Isolated socially

Person # 2

Age 86; diagnoses; senile dementia, hypertension, chronic fatigue

Medically frail

Mobility impaired, but ambulates slowly without assistance

Does not know how to write checks, keep a check register

Requires assistance with personal care

Without assistance does not maintain nutrition

Has poor memory and cannot follow complex discussion or thought

Does not drive a car and needs transportation

Has chronic medical conditions

Is self-medicating with reminders

Isolated socially

Person # 3

Age 85; Diagnoses; stroke at age 60, mild heart failure

Has limited expressive language although understands spoken language

Has chronic medical conditions

Is self-medicating with reminders

Provides own personal care with occasional checks and reminders

Socially integrated

Does not drive a car and needs transportation

He has little or no cognitive limitations, but thought processes and verbal expressions are concrete

Understands conditions and can participate in care

Is stubborn and has been known to "lie" and agree to limitations and then exceed them

Has minor motoric problems (tremor in right hand in certain positions, balance disturbance)

Person # 4

Age 45; diagnoses; post-polio syndrome (age 3), chronic severe respiratory distress

Uses electric wheel chair

Severe medical problems

Uses respirator at night and oxygen during day

Declining health-not expected to live more than five years

Socially integrated, but becoming less so

Needs assistance with all personal care

Self-medicating with physical assistance in opening containers

Understands conditions and can direct assistance

Does not drive and needs transportation

No cognitive limitations

Person # 5

Age 35; Diagnoses, progressive neuro-muscular disease

Degenerative medical condition resulting in motor and health problems; condition expected to be terminal

Uses wheel chair

Marginally integrated socially

Provides own personal care

Self-medicating

Understands conditions and can direct assistance

No cognitive limitations

Drives and provides own transportation

Person #6

Age 70, Diagnosis; Alzheimer's

Is verbal, but speech may not be meaningful

Periodically, shows bizarre, sometimes assaultive behavior
  If angered will strike others
  Unpredictable

Does not understand money management or the value of money

Has poor judgment and may undertake actions that are dangerous to herself or others

Has problems with memory, learning, and understanding complex thought

Cannot be assumed to understand nutritional needs or how to maintain good nutrition

Needs assistance with all personal care-incontinent

Does not drive a car and needs transportation

Does not understand condition and is not able to participate in self-care

Care given by relative who expresses need for respite

Socially isolated

Person # 7

Age 35; Diagnosis; closed head injury

Has cognitive limitations

Provides own personal care

Needs assistance with self-direction due to memory and judgment limitations

Self-medicating with reminders

Does not drive **a** car and needs transportation

Maintains good nutrition

Understands condition and participates in care

Person # 8

Age **40-Diagnosis; psychosis**

Has cognitive limitations

Provides own personal care

Needs assistance with self-direction due to memory and judgment limitations

Self-medicating with reminders

Drives a car and does not need transportation

Maintains good nutrition

Understands condition and participates in care

Periodically, displays "off the wall" behavior which calls attention to itself

Appendix G

Council Grant Projects

Appendix G
COUNCIL GRANT PROJECTS
As of OCTOBER 1995
Analysis of Eligibility For Current Council Grants With Elimination of Age of Onset

Grant/ (Grantee)	Grant Profile	Impact of Eliminating Age of Onset
EMPLOYMENT PROJECTS		
Local/Regional Employment Systems Change Project/ (Austin-Travis County MHMR Center)	This project utilizes community integrated work settings to assess, train and employ individuals who are currently in a workshop or other congregate setting. Extensive consultation and training is being provided which will enhance the Center's capacity to develop community employment resources. Their system for employing individuals with severe disabilities will convert from day programming in congregate settings to support for jobs in regular community employment.	Members from expansion populations could benefit from this type of grant activity. Individuals between the ages of 23-65 with severe disabilities would benefit if they were in the Austin-Travis County MHMR Center.
Local/Regional Employment Systems Change Project/ (Junction Five-O-Five)	This project provides community integrated employment options by involving area businesses in the planning and promotion of employment for people with disabilities. An interagency cooperative (IAC) and a business advisory council are combining efforts and resources through regular meetings to maximize available community resources. The IAC brings together local agencies and organizations which assist with employment of people with disabilities.	Members from expansion populations have indirectly benefited from the strategies employed by grant funded project. Individuals between the ages of 23-65 are benefiting from this unique initiative.

Grant/ (Grantee)	Grant Profile	Impact of Eliminating Age of Onset
Local/Regional Employment Systems Change Project/ (Collin County MHMR Center)	This conversion project is intended to result in the closure of the Collin County MHMR Center workshop. The project provides extensive training, consultation and technical assistance related to community inclusion to staff, consumers, parents, and community members. In year five, it is expected that all vocational services will be provided in the community. A conversion guide has been developed.	Members from expansion populations benefit from this grant funded activity. Individuals between the ages of 23-65 with severe disabilities can directly benefit from the grant's activities.
COMMUNITY LIVING PROJECTS		
Texas Respite Resource Network/ (Santa Rosa Health Care)	Funded since 1985, the Texas Respite Resource Network has been instrumental in developing statewide and national awareness regarding respite issues. The project has worked on policy reform, legislative changes and statewide networking in order to develop a statewide respite system. Currently the project is monitoring the Home and Community Support Services Act rules development, supporting the Respite Task Force, and conducting training and information sessions. Five national conferences on respite have been convened by the project.	Families of individuals in the expansion populations already benefit from the success of this Council funded network. It serves and benefits individuals of all ages and with different numbers of functional limitations. It is an excellent example of outcomes possible through the successful implementation of Council strategies focused on improving the functionality of the system of services.

Grant/ (Grantee)	Grant Profile	Impact of Eliminating Age of Onset
Personal Assistance Services Task Force/ (Coalition of Texans with Disabilities)	The Personal Assistance Services Task Force (PASTF) provides a forum for identifying issues surrounding the provision of attendant services. The purpose of this project is to provide staff support for PASTF activities, to monitor PAS public policy issues, and to gather and disseminate information concerning attendant services. An implementation study, "Improving Personal Attendant Services in Texas," outlines action steps and recommendations about how to solve issues relating to recruitment, retention and training of personal care attendants. The project provides training, information, and network development in local communities.	This grant's mission focuses on improving a priority need identified by expansion population members --- personal attendant services. This grant benefits expansion populations and their family members.
Community Living Systems Change/ (Community Options, Inc.)	This project provides supports for people with severe developmental disabilities as they transition from institutional residency to community living. Circles of support are being developed using inclusion, personal futures planning, assistive technology, family supports and supported employment. Assistance with obtaining housing is provided.	This grant funded project would benefit expansion population members. This project would assist expansion group members in meeting their desire to live, eat, work and play in their communities.
All Children Belong Demonstration Project/ (Dallas County Mental Health)	This project demonstrates a model for reunifying children, who are in institutions, with their birth families. Foster families, adoptive families, case management, and other supports are provided in order for the child to return to their community.	This grant targets children. Expansion population members would not benefit from this grant funded activity.

Grant/ (Grantee)	Grant Profile	Impact of Eliminating Age of Onset
Inclusive Education Systems Change/ (The Arc of Texas)	This project provides statewide support to promote the inclusion of students with disabilities in neighborhood schools and regular classes. The project provides technical assistance and training to schools involved in inclusive education pilot projects. The project also monitors public policy issues that influence inclusive education. Partial funding for this project is provided by the Texas Education Agency for public information activities. Products include: a quarterly newsletter, a video on inclusive education and a resource library of inclusive education training materials. A statewide conference on inclusive education is held annually. A blueprint for inclusive education in Texas has been developed.	This grant targets children and adolescents. Expansion population members would not benefit from this grant funded activity.
Inclusive Education Demonstration Project/ (Fort Bend ISD)	This inclusive education project includes students, pre-K through 12, in regular education classrooms. The program features a district-wide advisory committee with inclusive education teams on each campus.	This grant targets children and adolescents. Expansion population members would not benefit from this grant funded activity.
Inclusive Education Demonstration Project/ (Mansfield ISD)	This inclusive education project is demonstrating methods for educating students with disabilities in regular classrooms in their neighborhood schools. The project also identifies critical elements needed by educators and parents to implement an inclusive education system. A training program to develop the skills needed to implement inclusion is conducted for all school personnel, community leaders, parents, volunteers and school board members.	This grant targets children and adolescents. Expansion population members would not benefit from this grant funded activity.

Grant/ (Grantee)	Grant Profile	Impact of Eliminating Age of Onset
Conference Coordination/ (Credentials, Inc.)	This project provides support and assistance to the TPCDD staff for coordination of various training activities including a statewide best practices conference, regional seminars and a national Partners In Policymaking conference.	This project provides support for a Council activity that would serve expansion population members.
SYSTEM COORDINATION/COMMUNITY EDUCATION PROJECTS		
Texas Transition Task Force/ (Advocacy, Inc.)	This statewide project provides training to parents of children who have disabilities and are planning the transition from school to adult life. Training is coordinated through local Education Service Centers and advocacy groups.	This Council grant targets individuals exiting the public school system. This age group is not representative of the expansion populations. This grant does not benefit expansion population members.
Texas Disability Policy Consortium/ (Advocacy, Inc.)	The Texas Disability Policy Consortium is an organization of 20 statewide disability advocacy groups. The Consortium's mission is to identify, formulate positions on, and educate public officials regarding public policy issues of concern to persons with disabilities and their families. Member organizations have the opportunity to jointly endorse and publicly support such positions. The project provides administrative and professional staff support to assist the Consortium. Training is provided to local communities and individuals on effective legislative and advocacy skills. Grant products include: an electronic bulletin board system and a cross-disability legislative newsletter.	This grant funded activity includes representation from expansion populations and addresses all the issues identified by expansion group members in this study. It does and will continue to benefit expansion group members, directly and indirectly.

Grant/ (Grantee)	Grant Profile	Impact of Eliminating Age of Onset
ABLE KIDS: A Statewide Assistive Technology Program for the Early Childhood Intervention Program/ (Children's Habilitation Center)	This project provides training and technical support in the use of assistive technology in ECI programs for children 0-3 years of age. Training will be held in 12 regions of the state including areas which are considered underserved. Key components of the project include a training video, team training at Education Service Centers, video consultation for ECI programs, video teleconferencing, and development of an assistive technology equipment catalogue.	This grant targets children. Expansion population members would not benefit from this grant funded activity.
Technology Learning Collaboration Project Assistance/ (United Cerebral Palsy of Texas)	The Technology Learning Collaboration National Outreach Project (TLC) is funded by the U.S. Department of Education to conduct training for parents and practitioners on how to access and integrate readily-available technology into early childhood intervention programs. Council funds are used to provide support to the TLC Project including: printing of training materials, travel expenses of parents attending training sessions, a 1-800 phone line, computer equipment for project training, and project personnel.	This grant targets children. Expansion population members would not benefit from this grant funded activity.

Grant/ (Grantee)	Grant Profile	Impact of Eliminating Age of Onset
Quality Living Study/ (CFA, Inc.)	This study is evaluating community placement outcomes for Texans with developmental disabilities who are moving out of state schools. The project will measure longitudinally the impact of community placement on key areas including: adaptive behavior, challenging behavior, health status, inclusion, independence, productivity or contribution, consumer satisfaction, family satisfaction, and services and supports received. Data will be collected prior to movement whenever possible and at intervals of six and 12 months after moving the consumer out of the state school.	This study focuses directly on the outcomes for people with developmental disabilities. The findings of this study should benefit all people with disabilities by identifying areas in the system of services needing improvement.
Local Transportation Coordination Models/ (Health and Human Services Commission)	The Office of Client Transportation Services (OCTS) will develop five local transportation coordination models that each have a local coordinator and local coordination team. These teams will include agencies responsible for transportation funding, planning and implementation, as well as local advocates of transportation, including people with disabilities. Each coordinator and team will develop and implement a plan that will assure full access to services for people with disabilities, and will maximize the use of resources. OCTS will evaluate the models for statewide applicability and establish a consolidated planning process for funding and delivery of transportation services.	This Council funded project addresses a key issue identified by expansion group members--transportation. It will benefit expansion population members.

Grant/ (Grantee)	Grant Profile	Impact of Eliminating Age of Onset
PROJECTS COORDINATED BY COUNCIL STAFF		
Support for Partners in Policymaking/ (The Walsh Company)	This project provides administrative support for the Partners in Policymaking program. It assists the DD Council in coordinating training support activities necessary to implement the Partners program. Project staff manage resources, make arrangements for airline transportation, and reimburse individuals and speakers for the Partners in Policymaking sessions, advanced training and Partners testifying in Austin and/or attending other meetings.	This project provides support for a Council activity that would serve expansion population members.
Consumer Stipends	This project provides stipends which enable consumers and families without organizational support to attend conferences, workshops, meetings and other events. Funds of up to $5,000 are awarded to organizations sponsoring events in Texas that promote consumer empowerment and involvement in activities that enhance independence, productivity and community integration for people with developmental disabilities. Organizations must apply for stipends at least 120 days before an event.	Expansion population group members would be eligible to apply for this Council activity.