

STANDARD MEASUREMENT TOOLS FOR
IDENTIFYING THE DEVELOPMENTALLY DISABLED POPULATION

by

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P R E F A C E

The functional definition of developmental disabilities has been perplexing to the developmental disabilities community since it became part of the Mental Retardation Facilities and Community Health Centers Construction Act in 1978. As illustration of the perplexing nature of the functional definition of developmental disabilities, a Chairperson of a Developmental Disabilities Planning Council once asked this author, "How do I explain who is developmentally disabled under this definition?" The answer to the question is laborious at best and complicated to communicate unless an individual is familiar with the vernacular used in describing individuals who are disabled. Communicating to the general public the meaning of developmental disabilities is difficult.

Because of the complexity of the functional definition and because it is a significant change from the categorical definition which preceded it, there have been few attempts within or outside of the developmental disabilities community to operationalize the definition and identify the developmental disabilities population within a state.

However, if the present project of Counting the Developmentally Disabled Population in the State of Arkansas is going to be accomplished, then exact identification of individuals identified to be developmentally disabled must be accomplished. In order to accomplish the task of identification, some objective measures must be employed which are universally in application and discriminating among handicapping conditions so that individuals may be consistently identified as being either developmentally disabled or not developmentally disabled.

The contents of this report include the analysis used in identifying objective measurement instruments through which one can identify the developmentally disabled population. The report also contains an examination of the eligibility criteria of all programs which involve individuals who are handicapped. These criteria are examined to ascertain wherein all or part of the population could be developmentally disabled. The last section of the report contains an analysis of Individual Plans and a proposed composite plan which would allow comprehensive programming across all service agencies.

While the author of this work takes responsibility for its contents, I cannot take credit for the ideas and knowledge displayed herein. Many people have contributed to its formulation and development. I must thank Dr. Elizabeth M. Boggs, who provided critical guidance and displayed her vast experience during the writing of *A Numerical and Functional Description of the Developmental Disabilities Population* through which she introduced this author to the complexities and problems of identifying the developmental disabilities population. Dr. Boggs' guidance and patience with me during that time provided me with the knowledge base necessary to write this report.

Also, I must thank all the Directors and Commissioners of agencies in Arkansas who so patiently described the eligibility criteria used within their agencies and organizations. These busy administrators have taken time to diligently explain to me the eligibility criteria and, most important, their application in identifying individuals for services in their respective programs.

Expecially I want to thank Mr. John Knopp and Mr. Jim Moreland who spent time with me describing tests and testing practices used in the State of Arkansas. These gentlemen were kind enough to share with me manuals and testing information necessary for this report.

Finally, I must thank Mrs. Pat Huber, Planner for DDPC, and Mrs. Floydene Gillihan, Research Assistant to DDPC, for their assistance in gathering eligibiilty criteria and standards from a multitude of sources. Their assistance in this effort is greatly appreciated. Also, I would like to thank the DDPC members for funding the project which allowed this important planning document to be created. without the project to count the developmental disabilities population there would have been no need to identify objective measurement tools for identifying the developmental disabilities population.

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FOREWORD

- "The term 'developmental disability' means a **severe, chronic** disability of a person which--
- (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
 - (B) is manifested before the person attains age twenty-two;
 - (C) is likely to continue indefinitely;
 - (D) results in substantial functional limitations in three or more of the following areas of major life activity:
 - (i) self-care,
 - (ii) receptive and expressive language,
 - (iii) learning,
 - (iv) mobility,
 - (v) self-direction,
 - (vi) capacity for independent living, and
 - (vii) economic **self-sufficiency**; and
 - (E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated."

PL 95-602, Section 102(7)

The definition of developmental disabilities is intended to identify the individuals who have substantial functional limitations in major life activities and need social intervention for basic necessities of life. However, many individuals ask the same questions about the definition of developmental disabilities that the little girl asked about the song entitled "Do-Re-Mi" in the play "The Sound of Music" when she inquired, "But what does it mean?"

There have been articles written describing the historical development of the definition. There have been articles written identifying problems with operationalizing the definition. There have been articles written questioning the practicality of the definition.

A definition is descriptive by nature. We describe a person, place or thing when we use a definition. The dictionary defines definition as "a statement of what a thing is." Therefore, when we read the definition of developmental disabilities we should know what person in society or group of people in society are developmentally disabled. However, it is not quite that simple, as is demonstrated by the confusion existing within the professional community over the functional definition of developmental disabilities.

It is reasonable to assume that if the developmental disabilities definition is descriptive of individuals who are handicapped, then one should be able to recognize such individuals. The question which needs to be resolved is whether one creates new measurement tools to identify the individuals who are developmentally disabled or one adapts existing measurement tools to identify individuals who are developmentally disabled. Certainly, the latter method, if appropriate, would be cost effective and create less confusion.

This report displays the existing measurement tools, eligibility requirements and Individual Plans which have been adapted for use in identifying the developmentally disabled population in Arkansas in order to be able to accurately count the individuals who can appropriately be identified as developmentally disabled in the population.

The report demonstrates the appropriateness of using existing measurements to identify the developmentally disabled population within the existing service system. This approach also permits the Developmental Disabilities Planning Council to constantly update its enumeration of the developmentally disabled population through cooperative agreements with agencies providing services to individuals who are handicapped, without the creation of new and/or duplicative measurement tools.

INTRODUCTION

The term 'developmental disabilities' is a concept term rather than a descriptive term in the sense that the term was coined in 1970 to represent a concept concerning a population of disabled individuals in the United States. The developmental disabilities legislation of 1970 replaced legislation enacted in 1963. The 1963 legislation provided federal assistance for the construction of facilities "primarily for the mentally retarded." Therefore, the name of the 1963 legislation was the "Mental Retardation Facilities and Community Health Centers Construction Act of 1963." This title still remains the title of legislation which is now cited as the "Developmental Disabilities Assistance and Bill of Rights Act."

In the 1963 Regulations which accompanied the first act, the phrase "primarily for the mentally retarded" was interpreted to mean that more than 50 percent of the people who use the service housed in the facility would be mentally retarded. In practice, it was found that such facilities were usually built to accommodate persons who were moderately, severely or profoundly retarded.

The mildly retarded individuals, even in the 1960's, were more generally accommodated in buildings and programs which were at least partially integrated with other people. The mildly retarded individuals usually received services in the education and/or rehabilitation service system. The reason for the 1963 legislation was that, at that time, the existing service systems were not addressing the needs of the most severely handicapped individuals.

The Mental Retardation Planning Amendments of 1963 addressed the needs of those persons who, because of their mental retardation and related disorders, would benefit from ongoing programming involving different agencies and professional services.

Mental retardation is, by definition, a disabling condition which begins early in life. It is a developmental disorder, interfering with normal development. There are, of course, a variety of other handicapping conditions experienced by children which interfere to some extent, either directly with their development, or indirectly with their schooling and social experiences as children. Not all of these handicapping conditions persist as substantial handicaps into adult life.

The most widely used definition of mental retardation is that by the American Association of Mental Deficiency, which states that mental retardation is "substantially subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period."

It has been argued over the years that developmental disabilities are different in effect on one's life than are disabilities which occur after the developmental period. The adult who is

disabled by a stroke, for example, has need for rehabilitation programs in which he or she relearns activities which have been lost because of the stroke. However, the individual who has a condition at birth or early in life must learn skills and activities in concert with a disabling condition. Therefore, a developmental disability is age specific for onset of the condition which causes the disability. The condition must have onset before the individual reaches age 22 in order to be considered developmentally disabled under the present definition.

Recently professionals have challenged the appropriateness of the age requirement of the definition. The question has been asked, "if a 50 year old stroke victim who must regain the ability to function independently is any different in quality or quantity of problems which he or she experiences than a 50 year old cerebral palsied individual whose experiences are associated with growing up handicapped?" It may be argued that with the functional definition, no matter at what age in life the individual's disability is manifested, the limitations in life activities are the same, therefore the habilitation/rehabilitation program should be the same.

The argument against having an age specific definition may have merit. However, it must be remembered that the individual who becomes disabled after age 22 years did not have to learn to survive with the disability in the developmental years. These individuals were not the participants in special education programs and were not the participants in the special programs which help the developmentally disabled compensate for their disability and attain maximum potential, depending upon the severity of the disability. There remains a place for legislation which targets those individuals who have special needs during and after the developmental years, not so much because they have different functional limitations when they attain adulthood, but because their developmental process was different and there should be continuity of service programming for them throughout life. By definition, the disability is one that will last for a long time or lifetime for an individual who is developmentally disabled. The circumstances of life are different for an individual who is developmentally disabled both in the formative years and later in life than for a person who experiences a developmental period without a disability and becomes disabled after the conclusion of the developmental period. Therefore, the age specific nature of the developmental disabilities definition is not obsolete.

It has become apparent that the conditions which contribute to the disability of an adult and which are of early onset are quite different from those conditions experienced by adults who become disabled after they are adults. It is apparent that the conditions which contribute most to adult disabilities originating in childhood are mental retardation; childhood emotional difficulties, such as childhood psychoses; orthopedic impairments, including cerebral palsy; other health impairments, including epilepsy, autism, spina bifida, etc.; and children who are multihandicapped.

The above cited conditions account for 80% of persons who become entitled to Social Security benefits as a result of disabilities originating in childhood and almost 100% of all children evaluated for special education programs in Arkansas who are identified as developmentally disabled. Many of the disabilities cited do not occur as discrete entities but frequently occur together or in combination with other impairments and disorders such as sensory limitations in sight, hearing, language, etc.

It was because of the complexity of the conditions that in 1970 the term 'developmental disabilities' was first introduced into federal law. The term 'developmental disabilities' was defined as 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, 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."¹

States did not respond to the phrase "or other neurological handicapping conditions of an individual found to be closely related to mental retardation or to require treatment similar to that required by mentally retarded individuals," but identified the service clientele as those individuals who were mentally retarded, cerebral palsied, or epileptic or a combination thereof. In 1975, Congress added autism to the list of conditions for the service population contained under the term of 'developmental disabilities.'

There was growing concern within the community of individuals concerned with persons who are handicapped and subsequently with members of Congress that instead of having a definition of developmental disabilities which was flexible and encompassed individuals with a variety of disabilities with the emphasis on the severity of the disability, there seemed to be an endless number of groups representing conditions which requested to be added to the growing list of conditions included under the definition of developmental disabilities.

It was a cause of growing concern that individuals who could appropriately be served under the Developmental Disabilities Program were being left out because of the strict interpretation of the definition instead of a flexible interpretation.

A task force was formed and subsequently recommended the definition incorporated into Public Law 95-602 in 1978. The definition carefully avoids identifying cause of the disability or naming the disability but goes to length to describe the effects of the disability on the functional ability of the individual.

The functional definition accents the concept of substantiality and severity of the handicapping condition. There appears to be an equation between the severity of disability for purposes of the definition with the presence of several limitations related to different specific life functions. The functional definition appears to be a common sense approach to identifying and planning for a specific population of handicapped individuals.

The common sense approach rests on the fact that if a person has a disability which limits his or her functional ability in three of seven major life activities, then this individual needs and should have appropriate intervention by society to assist the individual in overcoming, blunting or accommodating the disability to the extent that the individual can attain maximum participation in society.

It is apparent that the developmental disabilities population will be a heterogeneous population because of the variety of conditions which cause the disabilities and the variety of major life activities in which a person is limited. However, the Developmental Disabilities Act provides for a group of concerned citizens, the Developmental Disabilities Planning Council, to make sure that this heterogeneous population of individuals with severe, chronic disabilities are identified, planned for and provided coordinated, comprehensive, appropriate services throughout their lifetime or as long as the condition remains which causes the functional limitations in major life activities.

To operationalize the functional definition of developmental disabilities, one must seek out that subgroup of each population of individuals with handicaps who have multiple functional limitations in life activities and whose condition manifested itself prior to age 22.

Functional limitations can be measured by adaptive behavior scales since the adaptive behavior scales identify limitations in the functions of individuals. Many programs use the results of adaptive behavior scales to plan the program activity and measure program achievement in specific areas of activity for individuals who are handicapped. Adaptive behavior scales are widely used in planning and evaluating programs for individuals who are handicapped. Therefore, if it is possible to equate items, parts or whole adaptive behavior scales, with functional achievements (or limitations) in the seven major life activities in the definition of developmental disabilities, then there would be objective measures for identifying the individual who is developmentally disabled within the universe of individuals who are handicapped. The next section of this report, entitled "Tests", identifies those adaptive behavior scales most widely used in the State of Arkansas and identifies those elements which identify the functional activities in the seven major life activities listed in the definition of developmental disabilities.

A method which can be used to ascertain if, in fact, a program is serving individuals who are developmentally disabled in its service population is to examine the program's eligibility requirements for participants. Many times one must also examine the application of the eligibility requirements in order to determine if, in fact, the developmentally disabled are being screened in or screened out of the program.

In order to count the developmentally disabled population in Arkansas, the eligibility requirements for each program which provides services to individuals with handicaps in the State were examined. The results of this examination are contained in the section of this report entitled "Eligibility Requirements."

The last section of this report is included as a personal bias of the author since it is an area which has caused countless problems for the individuals who are developmentally disabled throughout the nation. As long as eligibility requirements were under examination, it was easy enough to examine the requirements for Individual Plans at the same time. Therefore, the last section of this report includes a discussion of individual service, program, education and other plans for individuals who are handicapped.

There are several programs which, by statute, require an Individual Service Plan be written for each program participant. The Developmental Disabilities Act requires that an Individual Habilitation Plan be written for each individual in a program which receives funds from this act. This same mandate is written into many other laws which provide services to individuals who are handicapped.

Historically, there is little effort to write a coordinated Individual Plan between service agencies even though the same person may be participant in two, three or four programs. In order to facilitate the activity of producing a common Individual Plan for individuals who are developmentally disabled, the last section of this report contains a discussion of the several Individual Plans now required in the State of Arkansas and suggestions as to how one plan might meet all statute requirements and facilitate a coordinated service program between agencies for each individual who is developmentally disabled.

It is possible to identify the individuals who are developmentally disabled according to the functional definition. One of the features of our present society is that we count and measure skills, functions and activities for each person more times in his or her lifetime than at any other time in our history. Using available data to identify and plan for the developmentally disabled population is both cost effective and insures comprehensive application of the Developmental Disabilities Act in the State of Arkansas.

Eighty percent of the individuals who are identified as developmentally disabled of the school age population in the State of Arkansas are diagnosed as mentally retarded. Special Education in the State of Arkansas defines mental retardation as:

"Significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which adversely affects a child's educational performance."²

The Program Standards also contain a list of possible referral characteristics of a person who is mentally retarded. The Performance Standards indicate that:

"From the definition cited above, it would appear that an obvious consistency exists in the identification and programming of mentally handicapped individuals. After all, the definition addresses two major characteristics, subaverage general intellectual ability and deficits in adaptive behavior. It would appear that mentally retarded individuals have approximately the same developmental pattern and basically the same needs. However, as one becomes involved in working with these individuals it becomes apparent that their behavioral characteristics are extremely diverse and cover a wide range of performance."³

It is apparent that for individuals who are mentally retarded, both the general intellectual ability and the adaptive behavior are taken into consideration in identification and planning for their education program.

The definition of developmental disabilities before 1978 focused on the "subaverage general intellectual ability" in identifying individuals who made up the major part, about 80%, of the developmental disabilities population in the nation. The functional definition, implemented in 1978, now focuses on the "adaptive behavior" of the individual without reference to the degree to which the individual has "subaverage general intellectual ability." Adaptive behavior, or the ability of the individual to perform functions in identified major life activities, has become the focal point in identifying and planning for individuals who are developmentally disabled.

In selecting objective measurement tools which can be used to identify individuals who are developmentally disabled our attention must turn to adaptive behavior tests, since it is in this realm of functional capacity that the developmental disabilities community wants to measure a person's functional capacity in major life activities.

In researching the tests used for adaptive behavior measurement in the State of Arkansas, it was found that there are four adaptive behavior tests most widely used throughout the State. The four adaptive behavior tests used are:

AAMD Adaptive Behavior Scale
Vineland Social Maturity Scale
Denver Developmental Screening Test
Bayley Scales of Infant Development

The following narrative contains a brief description of each of these adaptive behavior tools and an **adaption** of each test equating selected items and parts of the tests with the seven major life activities listed in the definition of developmental disabilities. These adaptation tables for each of the adaptive behavior tests permit individuals to use these standard measurements to identify individuals who are developmentally disabled, that is, individuals who have substantial functional limitations in at least three of seven major life activities.

It must be pointed out that individuals, in order to be identified as developmentally disabled, must also meet the qualifications of the other parts of the **definition** of developmental disabilities. The other parts of the **definition** are that the disability is a severe, chronic disability of a person which--

"(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
(B) is manifested before the person attains age twenty-two;
(C) is likely to continue indefinitely;
(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."⁴

When one uses an adaptive behavior scale one is measuring only the functional limitations for Part D of the definition. Part D of the definition of developmental disabilities is:

"(D) results in substantial functional limitation 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."⁵

The adaptive behavior measurement is used to identify those individuals who have substantial functional limitations in three

or more of the areas of self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and/or economic sufficiency.

It is important that there be some understanding of each of the seven major life activities before descriptions of the adaptive behavior tests are presented. The descriptions of the functional limitations in each of the seven major life activities used in the approved Developmental Disabilities State Plan for Arkansas are those presented in the work entitled A Numerical and Functional Description of the Developmental Disabilities Population by Dr. Elizabeth M. Boggs and Dr. R. Lee Henney. The descriptive definitions for functional limitations in each of the seven major life activities are:⁶

1. SELF-CARE

The definition for an individual who has a substantial functional limitation in SELF-CARE is:

A person who has a long-term condition which requires that person to need significant assistance to look after personal needs such as food, hygiene and appearance. Significant assistance may be defined as assistance at least one-half of the time for one activity or a need for some assistance in more than one-half of all activities normally required for self-care.

2. RECEPTIVE AND EXPRESSIVE LANGUAGE

The definition for an individual who has a substantial functional limitation in RECEPTIVE AND EXPRESSIVE LANGUAGE is:

A person who has a long-term condition which prevents that person from effectively communicating with another person without the aid of a third person, a person with special skill or with a mechanical device, or a long-term condition which prevents him/her from articulating his thoughts.

3. LEARNING

The definition for an individual who has a substantial functional limitation in LEARNING is:

A person who has a Long-term condition which seriously interferes with cognition, visual or aural communication, or use of hands to the extent that special intervention or special programs are required to aid that person in learning.

4. MOBILITY

The definition for an individual who has a substantial functional limitation in MOBILITY is:

A person who has a long-term condition which impairs the ability to use fine and/or gross motor skills to the extent that assistance of another person and/or a mechanical device is needed in order for the individual to move from place to place.

5. SELF-DIRECTION

The definition for an individual who has a substantial functional limitation in SELF-DIRECTION is:

A person who has a long-term condition which requires that person to need assistance in being able to make independent decisions concerning social and individual activities and/or in handling personal finances and/or protecting his/her own self-interest.

6. CAPACITY FOR INDEPENDENT LIVING

The definition for an individual who has a substantial functional limitation in CAPACITY FOR INDEPENDENT LIVING is:

A person who has a long-term condition that limits the person from performing normal societal roles or which makes it unsafe for that person to live alone to such an extent that assistance, supervision or presence of a second person is required more than half the time.

7. ECONOMIC SELF-SUFFICIENCY

The definition for an individual who has a substantial functional limitation in ECONOMIC SELF-SUFFICIENCY is:

A person who has a long-term condition which prevents that person from working in regular employment or which limits his or her productive capacity to such an extent that it is insufficient for self-support.

With the above conceptual framework clearly in mind, let us now examine the four adaptive behavior tests and adaptations thereof permitting the consistent and universal measurement of substantial functional limitation in each of the seven major life activities contained in the definition of developmental disabilities.

AAMD ADAPTIVE BEHAVIOR SCALE

Table 1 contains an adaption of the AAMD Adaptive Behavior Scale showing equivalent items for major life activities listed in the definition of developmental disabilities. "The AAMD Adaptive Behavior Scale is a behavior rating scale for mentally retarded, emotionally maladjusted, and developmentally disabled individuals, but can be used with other handicapped persons as well. It is designed to provide objective descriptions and evaluations of an individual's adaptive behavior. The term 'adaptive behavior' was introduced and defined by the American Association of Mental Deficiency in the first edition of its Manual on Terminology and Classification in Mental Retardation and retained in the new revision. The term primarily refers to the effectiveness of an individual in coping with the natural and social demands of his or her environment."⁷

It is clear from the definition of 'adaptive behavior' used in this introduction to the AAMD Adaptive Behavior Scale that the authors of this test are seeking to establish standard measurements for functional activities related to a person's ability to function in life. If the authors of the test have succeeded in establishing such standards to the satisfaction of the professionals in the field, and if it is possible to relate the items in the AAMD Adaptive Behavior Scale in part or in all to functional activities required for self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and/or economic sufficiency, then it is possible to use this test or parts thereof to identify individuals who have substantial functional limitations in three or more of the major life activities listed in the definition of developmental disabilities as contained in PL 95-602, Section 102(7)(D).

The issue of identification of a person's intellectual capacity as contrasted to the person's functional capacities is referenced in the introduction to the AAMD Adaptive Behavior Scale in stating that, "While the IQ score has some value in evaluating the potential academic performance of average or above average persons from middle class communities, it does not provide a full description on the way an individual maintains his or her personal independence in daily living or of how he or she meets the social expectations of his or her environment."⁸ It is further underscored in the manual that the functional capacity of the individual is "crucial" to the type of training, education and habilitation program needed for the individual. Therefore, the adaptive behavior or functional definition for individuals who are developmentally disabled is of more benefit to planners and implementors of programs than is the simple listing of the cause of the disability.

The AAMD Adaptive Behavior Scale consists of two parts. Part One of the Scale is designed to evaluate all of the individual's skills and habits in ten behavior domains. The ten behavior domains are:

TABLE 1. ADAPTION OF AAMD ADAPTIVE BEHAVIOR SCALE SHOWING EQUIVALENT SCALE ITEMS FOR M E
MAJOR LIFE ACTIVITIES LISTED IN M E DEFINITION OF DEVELOPMENTAL DISABILITIES

Major Life Activity	AAMD Adaptive Behavior Scale Domain	Objective Measurement for Substantial Functional Limitation
Self-Care	Part I - Independent Functioning Domain	Score less than the 75th percentile
Receptive and Expressive Language	Part I - Physical Domain	Score 1 or less on either Vision or Hearing Subdomain
	Part I - Language Development Domain	OR Score for 8 years and over, 29 or less; Age 7, 26 or less; Age 6, 23 or less; Age 5, 20 or less; Age 4, 17 or less; Age 3, 14 or less
Mobility	Part I - Physical Domain	Score 13 or less on Motor Development Subdomain
Self-Direction	Part I - Self-Direction Domain	Score below the 60th percentile
		OR
	Part I - Responsibility Domain	Score 3 or less
		OR
	Part I - Socialization Domain	Score 50th percentile or less
		OR
	Part I - Economic Activity Domain	Score 80th percentile or less
Learning	Part I - Language Development Domain	Score for 8 years and over, 29 or less; Age 7, 26 or less; Age 6, 23 or less; Age 5, 20 or less; Age 4, 17 or less; Age 3, 14 or less
Capacity for Independent Living	Part I - Domestic Activity Domain	Score 65th percentile or below
		OR
	Part I - Economic Activity Domain	Score 80th percentile or below
Economic Sufficiency	Part I - Vocational Activity Domain	Score 65th percentile or below

The above adaption of the AAMD Adaptive Behavior Scale is a modification of the adaption of the Scale that was originally used in the Linberg and Putman study, which is described in the report entitled The Developmentally Disabled Of West Virginia, A Profile of the Substantially Handicapped Who Are Not In Institutions.

I	Independent Functioning
II	Physical Development
III	Economic Activity
IV	Language Development
V	Numbers and Time
VI	Domestic Activity
VII	Vocational Activity
VIII	Self-Direction
IX	Responsibility
X	Socialization

Part Two of the Scale is designed to measure maladaptive behavior related to personality and behavior disorders. Part Two is divided into fourteen domains. The fourteen domains are:

I	Violent and Destructive Behavior
II	Antisocial Behavior
III	Rebellious Behavior
IV	Untrustworthy Behavior
V	Withdrawal
VI	Stereotyped Behavior and Odd Mannerisms
VII	Inappropriate Interpersonal Manners
VIII	Unacceptable Vocal Habits
IX	Unacceptable or Eccentric Habits
X	Self-Abusive Behavior
XI	Hyperactive Tendencies
XII	Sexually Aberrant Behavior
XIII	Psychological Disturbances
XIV	Use of Medications

The AAMD Adaptive Behavior Scale can be reliably used for several purposes, according to its authors. Two of the general purposes for which the Scale can be used are:

- To identify areas of deficiency that individuals or groups have, in order to facilitate proper and useful assignment of curricula and placement in training programs.
- To provide a common medium of information exchange within, as well as between, organizations through a standardized reporting system.⁹

These two purposes fit well into the need for adaptive behavior information concerning individuals and groups in identifying individuals who are developmentally disabled and evaluating programs designed for individuals who are developmentally disabled. There is a need to identify areas of deficiency or functional limitations in the seven major life activities in order to identify individuals who are developmentally disabled. Equally as important to the identification is the establishment and maintenance of a standardized reporting system between and among service providers to ascertain if developmental process is being made as a result of program participation. Therefore, adapting the AAMD Adaptive Behavior Scale enabling one to identify functional limitations in the seven major areas of life activity contained in the definition of developmental disabilities can be helpful in meeting the needs of the developmental disabilities community for a standard measurement tool to measure functional limitations.

VINELAND SOCIAL MATURITY SCALE

Table 2 contains an adaption of the Vineland Social Maturity Scale placing equivalent items from the Scale in categories which correspond to the seven major life activities identified in the definition of developmental disabilities, providing an objective measurement tool by which substantial functional limitations in each of the major life activities may be identified.

TABLE 2 ADAPTION OF VINELAND SOCIAL MATURITY SCALE SHOWING EQUIVALENT SCALE ITEMS FOR THE MAJOR LIFE ACTIVITIES LISTED IN ME DEFINITION OF DEVELOPMENTAL DISABILITIES

Major Life Activity	Under 5 years of age 2 or more consecutive - (minus) indicates functional limitations	5 years to 10 years of age 2 or more consecutive - (minus) indicates functional limitations	10 years to 20 years of age 2 or more consecutive - (minus) indicates functional limitations	Over 20 years of age 2 or more consecutive - (minus) indicates functional limitations
Self-Care	Balances head Rolls over Sits unsupported Pulls self upright Drinks from cup , assisted Pulls off socks Drinks from cup unassisted Eats with spoon Asks to go to toilet Removes coat or dress Eats with fork Gets drink unassisted Dries own hands Puts on coat or dress Buttons coat or dress Washes hands unaided Cares for self at toilet Washes face unassisted Dresses self	Uses table knife for spreading Bathes self assisted Goes to bed unassisted Uses table knife for cutting Combs or brushes hair Bathes self unaided Cares for self at table	Exercises complete care of dress	Same as 10-20 years
Receptive and Expressive Language	Crows: laughs Talks: imitates sounds Uses names of familiar objects Talks in short sentences	Prints simple words Uses pencil for writing Reads an own initiative	Writes occasional short letters Makes telephone calls Answers ads: purchases by mail Enjoys books, newspapers, magazines Communicates by letter Follows current events	Same as 10-20 years
Mobility	Walks about room unattended Walks upstairs unassisted Walks downstairs one step per tread	Goes about neighborhood unattended Goes to school unattended Goes about home town freely	Goes to nearby places alone Goes to distant points alone	Same as 10-20 years

TABLE 2 (Continued)

Major Life Activity	Under 5 years of age 2 or more consecutive - (minus) indicates functional limitations	5 years to 10 years of age 2 or more consecutive - (minus) indicates functional limitations	10 years to 20 years of age 2 or more consecutive - (minus) indicates functional limitations	Over 20 years of age 2 or more consecutive - (minus) indicates functional limitations
Self-Direction	Not appropriate for this age	Is trusted with money Makes minor purchases	Is left to care for self or others Buys own clothing, accessories Goes out unsupervised daytime Has own spending money Buys all own clothing Looks after own health Goes out nights unrestricted Controls own major expenditures	Assumes personal responsibility Uses money providently Provides for future Purchases for others
Learning	Reaches for familiar objects Demands personal attention Plays with other children Plays cooperatively at kindergarten level Performs for others	Plays competitive exercise games Plays simple table games Disavows Jitterbug Santa Claus Participates in pre- adolescent play	Plays difficult games Engages in adolescent group activities	Assumes responsibility beyond own need Contributes to social welfare Inspires confidence Promotes civic progress Shares community responsibility Advances general welfare
Capacity for Independent Living	Not appropriate for this age	Is trusted with money Makes minor purchases	Is left to care for self or others Buys own clothing, accessories Goes out unsupervised daytime Has own spending money Buys all own clothing Looks after own health Goes out nights unrestricted Controls own major expenditures	Assumes personal responsibility Uses money providently Provides for future Purchases for others Assumes responsibility beyond own need Contributes to social welfare Inspires confidence Promotes civic progress Shares community responsibility Advances general welfare
Economic Sufficiency	Not appropriate for this age	Uses skates, sled, wagon Uses tools or utensils Does routine household tasks	Does small remunera- tive work Does simple creative work Performs responsible routine chores Has a job or continues schooling	Performs skilled work Engages in beneficial recreation Systematizes own work Supervises occupa- tional pursuits Directs or manages affairs of others Performs expert or professional work Creates own opportunities

The foreword of the **Vineland** Social Maturity Scale manual identified the division between identifying individuals because of the cause of their disability, such as mental retardation, or by the effects of their disability, such as functional limitations in mobility. "It is increasingly evident that the ultimate goal of each individual is social competence, and that helping him (her) to attain that goal is the purpose of schools and other societal agencies."¹⁰

The **Vineland** Social Maturity Scale was first proposed in 1935. It was developed at The Training School at Vineland, New Jersey, and has been used worldwide for more than forty years. "The scale provides a definite outline of detailed performances in respect to which children show a progressive capacity for looking after themselves and for participating in those activities which lead toward ultimate independence as adults."¹¹

It is interesting that the items on the **Vineland** are arranged in order of increasing average difficulty and are identified as to the functional activity which is being measured. The items on the scale measure functional abilities in self-help, self-direction, locomotion, occupation, communication and social relations. There are 117 items in the **Vineland** Social Maturity Scale. "The central purpose of each item of the scale is to represent some particular aspect of the ability to look after one's own practical needs."¹² The items are presented in maturation order to reflect progressive freedom from need of assistance, direction or supervision on the part of others, in other words, to eliminate the need for social intervention and provide the individual with maximum freedom to fulfill his or her own needs.

DENVER DEVELOPMENTAL SCREENING TEST

Table 3 contains an adaption providing equivalent items from the Denver Developmental Screening Test in five major life activities listed in the definition of developmental disabilities.

The Denver Developmental Screening Test was developed to standardize the "developmental deviations in young children", according to the information contained in the introduction of the manual of instructions for the test.¹³ This standardization is designed to aid the health provider in detecting potential problems.

The Denver Test is designed to be used "with children from birth to six years of age and is administered by asking a child to perform various tasks appropriate for his (her) age."¹⁴ The test is administered to apparently 'well' children in order to sort out those children who have a high probability of being developmentally impaired. The authors of the test indicate that there are three reasons that this test is valuable to the health provider:

TABLE 3. ADAPTION OF DENVER DEVELOPMENTAL SCREENING TEST SHOWING EQUIVALENT TEST ITEMS FOR FIVE MAJOR LIFE ACTIVITIES LISTED IN THE DEFINITION OF DEVELOPMENTAL DISABILITIES

Major Life Activity	Indicates limitation at 1 year of age if child fails 2 or more of the items	Indicates limitation at 3 years of age if child fails 2 or more of the items	Indicates limitation at 6-1/2 years of age if child fails 2 or more of the items
Self-Care	Regards face Smiles responsively Smiles spontaneously Feeds self cracker Resists toy pull Works for toy out of reach Initially shy with strangers	Plays pat-a-cake Plays ball Indicates wants (not crying) Drinks from cup Imitates housework Uses spoon, spilling little Helps in house Puts on clothing	Washes and dries hands Plays interactive games Separates from mother easily Dresses with supervision Buttons up Dresses without supervision
Receptive and Expressive Language	Responds to bell Vocalizes - not crying Laughs Squeals Turns to voice Da-da or Ma-ma, nonspecific Imitates speech sounds	Da-da or Ma-ma specific 3 words other than above Combines 2 different words Points to one named body part Names one picture Follows directions	Uses plurals Gives first and last name Comprehends cold, tired, hungry Comprehends prepositions Recognizes colors Opposite analogies Defines words Composition of things
Mobility	Lifts head Head up 45° Head up 50° Chest up, arm support Sit - head steady Rolls over Put up sit, no head lay Bear some weight on legs Sits without support Stands holding on Pulls self to stand Gets to sitting	Walks holding on furniture Stands momentarily Stands alone well Stoops and recovers Walks well Walks backwards Walks up steps Kicks ball forward Throws ball overhead Balance on 1 foot 1 second Jumps in place Pedals tricycle	Broad jump Balance 1 foot 5 seconds Balance 1 foot 10 seconds Hops on 1 foot Heel-to-toe walk Catches bounced ball Backward heel-to-toe walk
Self-Direction	Not applicable at this age	Puts on clothing Points to one named body part Dumps raisin from bottle spontaneously Dumps raisin from bottle demonstrated	Plays interactive games Dresses without supervision Defines words Composition of things Imitates bridge Imitates <input type="checkbox"/> demonstrated Draws man - 5 parts Draws man - 6 parts
Learning	Grasps rattle Regards raisin Reaches for object Sits, looks at yarn Sits, takes 2 cubes Passes cube hand to hand Bangs 2 cubes held in hands	Helps in house Points to one named body part Names one picture Follows directions Puts on clothing Scribbles spontaneously Tower of 2 cubes Tower of 4 cubes Tower of 8 cubes Imitates vertical lines Dumps raisin from bottle	Dresses without supervision Recognizes colors Opposite analogies Defines words Composition of things Imitates bridge Picks longer line Copies 0 Imitates <input type="checkbox"/> demonstrated Copies + Draws man - 3 parts Copies <input type="checkbox"/> Draws man - 6 parts
Capacity for Independent Living	Not Applicable for this age		
Economic Sufficiency	Not Applicable for this age		

- (a) to screen asymptomatic children for possible problems,
- (b) to confirm intuitive suspicions with an objective measure, and
- (c) to monitor high risk children such as those who have experienced perinatal difficulties.¹⁵

The Denver Developmental Screening Test form is made up of 105 tasks, or items, written in the range of accomplishments of children in the age span from birth to six years. These items are arranged on the test form in four sectors:

- 1. Personal-Social - That is, tasks which indicate the child's ability to get along with people and to take care of himself (herself)
- 2. Fine Motor-Adaptive - That is, the child's ability to see and to use his hands to pick up objects and to draw
- 3. Language, - That is, the child's ability to hear, to understand, and to use language
- 4. Gross Motor - That is, the child's ability to sit, walk and jump¹⁶

Since the Denver is designed to test children only from birth to six years of age, it is limited for use in identifying individuals who are developmentally disabled to those individuals who are of preschool age. The number of areas in which a preschool child has demonstrated skills in major life activities listed in the definition of developmental disabilities is reduced from the seven listed in the definition to five. A preschool child is not expected to be required to demonstrate functional ability in either economic sufficiency or a capacity for independent living at this stage in life. However, the preschool child can certainly demonstrate some proficiency in the major life activities of self-care, receptive and expressive language, learning, mobility and self-direction. Since these five major life activities are crucial to the developmental process and especially fundamental to success in the school experience, the lack of functional ability in these areas certainly limits the success of the child in the school environment, thereby restricting opportunities as an adult.

It is equally important, if not more important, to identify children, especially in the first year of life, who have diagnosed functional limitations in the five major life activities listed above. Early intervention has been demonstrated to be more productive in blunting or eliminating the effects of functional impairments during the first year of life than at any other time

in the child's formative years. Therefore, early diagnosis and subsequent early intervention activities will greatly reduce the developmental disabilities of many, if not most children. For this reason, it is important to use a standardized objective measurement tool to identify those children who demonstrate developmental delay during the preschool years.

BAYLEY SCALES OF INFANT DEVELOPMENT

Table 4 contains an **adaption** of the **Bayley** Scales of Infant Development, placing equivalent items from the Scales in categories which correspond to five of the seven major life activities identified in the definition of developmental disabilities, providing an objective measurement tool by which substantial functional limitations in each of the five major life activities may be identified. Only five major life activities are used in this **adaption** since the infant from birth to two years of age is not expected to demonstrate skills in either capacity for independent living or economic sufficiency.

The **Bayley** Scales of Infant Development are a popular standard measurement tool used in the State of Arkansas to measure infant development. "The Scale is designed to provide adequate measurement of developmental progress of infants both for clinical and research use."¹⁷

The **Bayley** Scales of Infant Development are made up of two separate Scales. The Mental Scale consists of 163 items and the Motor Scale consists of 81 items.

It is important that high risk infants in danger of developmental delay and/or developmental disabilities are diagnosed early and provided intervention programs as early as possible in their life for maximum benefit and productivity in blunting and/or overcoming the effects of the delay and/or disability.

In the first year of life, the child has no 'set' for following directions and solving problems at the request of the examiner, therefore special methods must be used to determine developmental progress and progression for infants early in life. "The **Bayley** Scales of Infant Development are designed to provide a tripartite basis for the evaluation of the child's developmental status in the first two and one-half years of life."¹⁸

"The Mental Scale is designed to assess sensory-perceptual activities, discriminations and the ability to respond to these; the early acquisition of 'object constancy' and memory, learning, and problem-solving ability; vocalization and the beginnings of verbal communication; and early evidence of the ability to form generalizations and **classifications**, which is the basis of abstract thinking."¹⁹

TABLE 4. ADAPTION OF BAYLEY SCALES OF INFANT DEVELOPMENT SHOWING EQUIVALENT PARTS OF THE SCALES FOR FIVE MAJOR LIFE ACTIVITIES IN THE DEFINITION OF DEVELOPMENTAL DISABILITIES

Major Life Activity	Indicates limitation at 1 year of age if child fails 2 or more of the items	indicates limitation at 2-1/2 years of age if child fails 2 or more of the items
Self-Care	Visual and manual behaviors Responses to bell and rattle	Mirror
Receptive and Expressive Language	Vocalization	Vocalization and words
Mobility	Turning Sitting Gaining vertical position Upright progress to walking	Gaining vertical position-furniture Stands up from floor alone Walking skill - pull toy Balance Stairs Walking board Jumping from floor Walks on line Jumping from height
Self-Direction	Not applicable at this age	Spoons Pellet
Learning	Cubes	Manipulative behavior
Capacity for Independent Living	Not Applicable for this age	
Economic Sufficiency	Not Applicable for this age	

"The Motor Scale is designed to provide a measure of the degree of control of the body, coordination of the large muscles, and finer manipulatory skills of the hands and fingers."²⁰

The administration manual for the Bayley Scales indicates that the Infant Behavior record provides the clinician with a comprehensive evaluation of an infant's development and a means of comparing him (her) with his (her) peers.

The Scales also provide criteria for the early detection of mental retardation. There is reported research evidence which indicates that there are specific items in the Bayley Scales which successfully differentiate the infants who are suspected of having neurological handicaps from infants who have no such handicaps.

It is important that once developmental problem(s) are recognized, treatment must be geared to the child's developmental age and diagnosis. It is important that an individual specific treatment and training program be planned for each infant. The importance of the Individual Plan is underscored by the requirement in Developmental Disabilities for an Individual Habilitation Plan for each program participant. The Individual Plan requirement has been initiated by several other programs which provide services to children and adults with handicaps, including Special Education programs.

Since the Bayley Scales are designed to test children only from birth to 2-1/2 years of age, they are limited for use in identifying individuals who are developmentally disabled to those individuals who are in the first two years of life. However, they do provide a comprehensive measurement scale for early intervention programs in the first two years of life. The Bayley Scales provide an excellent objective evaluation tool for early intervention programs supported by Developmental Disabilities funds in order to assure progress for program participants.

Certainly the item equivalents in each of the preceding tables are opinion in assignment. Each researcher or program implementor will have his or her own opinion as to which discrete item belongs under each of the seven major life activities for each of the adaptive behavior scales. However, the tables do illustrate the fact that it is possible to adapt each of the scales to be used in identifying individuals with substantial functional limitations in specific major life activities, thereby providing the developmental disabilities community with objective measurement tools with standardized norms for identification and evaluation purposes.

It is also apparent from the discussion herein included that the functional definition of developmental disabilities which focuses on functional limitations in seven major life activities has many proponents in the developers of the adaptive behavior scales and other professionals in a variety of disciplines.

INTELLIGENCE SCALES

It would not be appropriate to conclude this section of the report without identifying the tests used in Arkansas for measuring the intellectual capacity of individuals. As has been stated previously in this section, mental retardation for Special Education in the State of Arkansas "means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which adversely affects a child's educational performance." Mental retardation is usually identified by the administration of one of five intelligence scales in the State of Arkansas. "Intelligence Tests are psychometric devices, that is, sets of standardized questions and tasks for assessing an individual's potential for purposeful and useful behavior."21

The results of an intelligence test are translated into an Intelligence Quotient, or IQ. The term 'IQ' was first used by Wilhelm Stern in 1912 to describe a method of comparing one child's score on the Binet Intelligence Scale with the performance of average children of the same age.

Subaverage .general intellectual .functioning denoting a person who is mentally retarded means the person's IQ test score is at least two standard deviations below average, that is, an IQ score of approximately 70 or below. As can be seen from the following graph and table from the Stanford-Binet Intelligence Scale Manual for Adminstration, the Mean of the test results for the experimental group is 101.8, and the Standard Deviation is 16.4. The table containing the distribution shows that a score of 70-79 indicates a person is "borderline defective" and that a score of below 70 indicates the person is "mentally defective" or mentally retarded.

The Stanford-Binet Intelligence Scale is used in the State of Arkansas by some professionals to test individuals. However, the four Wechsler Scales are the most popular intelligence tests used in the State of Arkansas. The four Wechsler Scales are:

- Wechsler Preschool and Primary Scale of Intelligence (WPPSI)
(for 4 to 6-1/2 year olds)
- Wechsler Intelligence Scale for Children - Revised (WISC-R)
(for 6 to 16 years of age)
- Wechsler Adult Intelligence Scale (WAIS)
(for 16 years of age and above)
- Wechsler Adult Intelligence Scale - Revised (WAIS-R)
(for 16 years of age and above)

The Wechsler Adult Intelligence Scale - Revised (WAIS-R) is composed of eleven tests, six verbal and five nonverbal. When the eleven tests are administered together, the tests yield a Full Scale IQ. The verbal tests may be administered separately to yield a verbal score and the nonverbal may be administered separately to yield a performance score. The nonverbal tests permit use of the Wechsler with those individuals who are not able to comprehend or manage language.22

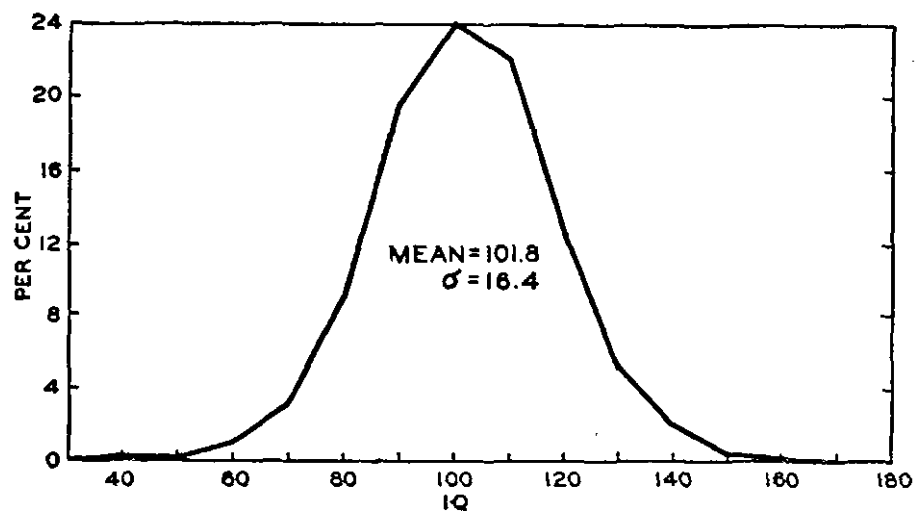


Figure 1. Distribution of Composite IQ's of 1937 Standardization Group²³

TABLE 5. DISTRIBUTION OF M E 1937 STANDARDIZATION GROUP²⁴

IQ	Per Cent	Classification
160-169	0.03	Vary superior
150-159	0.2	
140-149	7.1	
130-139	3.1	Superior
120-129	8.2	
110-119	18.1	High average
100-109	23.5	Normal or average
90-99	23.0	
80-89	14.5	Low average
70-79	5.6	Borderline defective
60-69	2.0	Mentally defective
50-59	0.4	
40-49	0.2	
30-39	0.03	

CONCLUSION

The whole question of the functional definition of developmental disabilities or the categorical definition, in the opinion of this author, comes down to the question of what does society want to do with a person after it has labeled the person developmentally disabled. Society has been labeling individuals developmentally disabled since 1970 when the term was coined in the Developmental Disabilities Act of 1970. Society has been labeling individuals mentally retarded since the term 'mentally defective' was coined in 1912. The label means nothing unless something happens to the person to maximize the person's potential.

It is a conclusion from this presentation on Tests that society knows more about the person and what he or she can do in relationship to his or her environment if society knows the functional limitations of the person. Society knows very little about the functional aspects of the individual, other than assumption, if the instrument used to measure the person's ability tells society only that he or she is intellectually performing at a level corresponding to persons younger than himself or herself. Therefore, the functional definition, apparently, requires society to be more active in its developmental programs and enables society to focus on the functional limitations in those areas of greatest deficits for individuals who are identified as developmentally disabled than did the categorical definition. The functional definition is a step in the direction of humanity in labeling individuals in our society, in the opinion of this author.

ELIGIBILITY REQUIREMENTS

The Developmental Disabilities law requires the Developmental Disabilities Planning Council to define its population and the service system according to a statement in the approved State Plan for Arkansas.²⁵ The authors of the State Plan admitted this to be a reasonable request by asking the question, "Who other than the DDPC should know and be able to find their population as it receives services through the state?"²⁶ The contents of the plan continue to establish the importance of the identification of the population which is developmentally disabled:

"It is important for the DDPC to know its population, identify the services being provided, and spend money to fill the gaps in the service network. The privilege of serving requires the responsibility of reporting. Unless we know who we serve, how many we serve, and how well they are served, there might come the time when we will no longer have the privilege of serving those individuals who so desperately need assistance."²⁷

In the preparation of the State Plan, many service agencies were reviewed to ascertain the number of individuals served and the type of services provided. The dilemma experienced by the plan preparers in identifying the developmentally disabled in each of the service agencies is expressed in the following: "Granted the definition of an individual with developmental disabilities in Public Law 95-602 will require some interpretation, deliberation and decision as to who are the severely handicapped individuals who have a substantial functional limitation in three of the seven major life activities..."²⁸

The agencies selected for identification of the developmentally disabled population for construction of the State Plan are identified in the following:

"Many of the major public agencies which have been included in the DD State Plan fall under the aegis of the Department of Human Services (DHS). The DHS agencies primarily responsible for serving the developmentally disabled population are: Mental Health Services, Mental Retardation-Developmental Disabilities Services, Office of Title XX, Office of Aging, Rehabilitation Services, and Social Services Division, which has the programs for Public Assistance, Social Services, Crippled Children's Services, and Medical Assistance. The remaining major public agencies with responsibility for the DD population are: Arkansas Department of Education, Arkansas Health Department, and State Health Planning and Development Agency."²⁹

It was this list of agencies which provided the starting point for the counting of the developmental disabilities population in the State of Arkansas. The essential question which was

asked for each of these agencies was: "What exists in the eligibility requirements of each of these agencies that would indicate individuals which can legitimately be identified as developmentally disabled who are part of its service population?" For those agencies wherein one or more individuals can be identified as developmentally disabled in their service population, a second question was asked: "How many of the individuals served by the agency can be identified as developmentally disabled using the functional definition of developmental disabilities contained in PL 95-602?" The last question to be asked of each agency which, by its own eligibility requirements, was found to be able to include one or more individuals identified as developmentally disabled was: "How many individuals who are developmentally disabled are presently being served by the agency?" The results of the answers to these questions are contained in the work entitled The Developmentally Disabled Population Registry for Arkansas.

The purpose of this section of the report is to provide an audit trail identifying the decision points made in relation to each service program to include or exclude its population or some portion thereof from the count of the developmentally disabled population in Arkansas. The examination of the eligibility requirements of each of the agencies and the program decisions resulting therefrom provide the DDPC and its staff with the information necessary to continually update the count of the developmentally disabled population in the State of Arkansas. If the DDPC is responsible for the coordination and evaluation of services provided to the developmentally disabled population as indicated in the State Plan, then this section of the report will be most helpful in future years to be used in achieving this goal.

The method used in evaluating the eligibility requirements was a threefold process in which the author met with the Commissioner or representative thereof asking an explanation of the eligibility requirements for individuals to receive services, requesting and reviewing written eligibility requirements, and comparing the agency's eligibility requirements with the definition of developmental disabilities contained in PL 95-602. The results of this three step process provided information by which decisions can be made as to: (1) can any of the individuals served by the agency be identified as developmentally disabled? (2) if yes, can all of the individuals served by the agency be identified as developmentally disabled?, or (3) if not all of the population can be identified as developmentally disabled then what portion of the individuals served by the agency can be appropriately identified as developmentally disabled?

The following narrative contains the presentation of the eligibility requirements for each of the agencies for which eligibility requirements were reviewed and decisions made concerning inclusion or exclusion of its population or portion thereof in the count of the developmentally disabled population in the State of Arkansas. Total population figures for each of the agencies are given in order to provide the reader with some reference as to the

number of Arkansas residents being served by each of the agencies reviewed in the count of the developmentally disabled population in the State.

The agencies and programs for which eligibility has been reviewed and which are presented in this section of the report are:

- Supplemental Security Income (SSI)
- Medicaid
- Medicare
- Aid to Families of Dependent Children
- Special Education
- Maternal and Child Health
- Mental Health
- Developmental Disabilities Services
- Title XX
- Crippled Children
- Head Start
- Rehabilitation Services
- Long Term Care
- Office on Aging

SUPPLEMENTAL SECURITY INCOME (SSI)

Supplemental Security Income (SSI) is monthly benefits paid to individuals who are aged, blind or disabled according to federal regulations relevant to the Social Security Act. The SSI population contains individuals who are developmentally disabled and SSI is the main economic support for many of the developmentally disabled within the State of Arkansas.

The basic definition of disability used to determine eligibility for benefits under the Supplemental Security Income (SSI) section of the Social Security Act is:

"The law defines disability as the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. To meet this definition you (the recipient of the benefits) must have a severe impairment which makes you unable to do your previous work or any other substantial gainful activity which exists in the national economy. To determine whether you are able to do any other work, we (the federal government) consider your residual functional capacity and your age, education and work experience. We will use this definition of disability if you are applying for a period of disability, or disability insurance benefits as a disabled worker, or child insurance benefits based on disability before age 22."³⁰

It is readily identifiable from the definition of disability used to determine eligibility for SSI benefits that the person must have a "severe disability" and that the disability must have long-term ramifications. Also, it is clear from the definition that individuals under the age of 22 years can receive SSI benefits, therefore some of the population receiving SSI benefits will have disabilities which are manifested prior to age 22. Therefore, some part of the SSI recipient population meets four of the five requirements contained in the definition of developmental disabilities. Some number of the SSI recipients have a disability which (a) is attributable to a mental or physical impairment; (b) is manifested before the person attains age twenty-two; (c) is likely to continue indefinitely; 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.

A further examination of the Rules for Determining Disability and Blindness for Supplemental Security Income benefits indicates that some of the recipients who receive SSI benefits as disabled individuals will have functional limitations in three or more of the seven major life activities contained in the definition of developmental disabilities. The Rules for Determining Disability and Blindness contain two listings of impairments. The first listing is contained in Appendix 2, Part A, and provides "criteria applicable to individuals age 18 and over and to children under age 18 where criteria are appropriate." ³¹ This section of the rules presents impairments under 13 classifications of impairments. The 13 classifications are:

- 1.00 Musculoskeletal System
- 2.00 Special Senses and Speech
- 3.00 Respiratory System
- 4.00 Cardiovascular System
- 5.00 Digestive System
- 6.00 Genito-Urinary System
- 7.00 Hemic and Lymphatic System
- 8.00 Skin
- 9.00 Endocrine System
- 10.00 Multiple Body Systems
- 11.00 Neurological
- 12.00 Mental Disorders
- 13.00 Neoplastic Diseases, Malignant

A close examination of the etiologies of the conditions contained under each of the above identified classifications shows that SSI determination is based not only on the condition but on the functional limitations imposed by that condition. Chronicity, for example, is defined under many of the classifications as "persistence of the condition for at least 3 months." There are no conditions just because of their etiology which make an individual automatically eligible for Supplemental Security Income

benefits. Individuals must have functional limitations caused by the disability which last over a long period of time.

For example, a person with epilepsy qualifies for benefits based on the type, frequency, duration and sequence of seizures. Likewise, an individual with cerebral palsy must have: (A) IQ of 69 or less; or (B) abnormal behavior patterns such as destructiveness or emotional instability; or (C) significant interference in communication due to speech, hearing or visual defect; or (D) disorganization of motor function.

One last illustration of the requirement of functional limitation before an individual can receive SSI benefits is contained in the requirements for a person who is mentally retarded. Mental retardation must be manifested by the following in order for an individual to receive SSI benefits:

- A. Severe mental and social incapacity as evidenced by marked dependence upon others for personal needs (e.g., bathing, washing, dressing, etc.) and inability to understand the spoken word and inability to avoid physical danger (fire, cars, etc.) and inability to follow simple directions and inability to read, write, and perform simple calculations; OR
- B. IQ of 59 or less; OR
- C. IQ of 60 to 69 inclusive and a physical or other mental impairment imposing additional and significant work related limitation of function.³²

The point of the three illustrations is that in all requirements for eligibility for SSI benefits a person must have functional limitations in major life activities in order to qualify for such benefits. Therefore, it can be assumed that any persons, especially children, who are receiving SSI benefits probably have functional limitations in at least three of the seven major life activities listed in the definition of developmental disabilities.

If the above assumption is correct, then the task which remains is to identify those individuals who receive SSI benefits whose disability manifested itself prior to age 22 years. At least it has been demonstrated that some portion of the individuals who receive SSI benefits are individuals who can be appropriately identified as developmentally disabled according to the functional definition of developmental disabilities.

There were 75,473 individuals in the State of Arkansas receiving Supplemental Security Income in September, 1981 according to a report contained in the Social Security Bulletin for January, 1982. Of this population, 33,700 were receiving SSI benefits

because of a disability.³³ We can break down the population even further in a report on the SSI recipients in December, 1980 which indicates that 3,656 children were receiving SSI benefits because of a disability in December, 1980.³⁴ As has been described, the disabled child who receives SSI benefits probably can appropriately be identified as developmentally disabled according to the functional definition of developmental disabilities. Some portion of the adult population, those adults whose disability manifested itself prior to age 22 years, who are recipients of SSI benefits because of a disability, probably can also appropriately be identified as developmentally disabled.

MEDICAID

Title XIX of the Social Security Act was passed July 30, 1965 in Public Law 89-97. This Title of the Social Security Act brought into existence the Medicaid Program. The Medicaid Program provides reimbursement for health services for:

"(1) Medical assistance on behalf of families with dependent children (AFDC) and of aged, blind, or permanently and totally disabled individuals (SSI recipients), whose income and resources are insufficient to meet the costs of necessary medical services (medically needy)...."³⁵

Eligibility for medical services is basically dependent upon an individual being eligible for other federal/state programs. Individuals who are determined to be eligible for SSI benefits, herein defined, are automatically eligible for Medicaid. Individuals who are determined to be eligible for AFDC benefits are also automatically eligible for Medicaid. The individuals who become Medicaid eligible under the medically needy portion of the statute must meet income and need requirements in order to receive reimbursement for medical services.

When an individual is determined to be eligible for SSI benefits, then the Medicaid Office in the Division of Social Services is automatically notified that the individual is Medicaid eligible also.

Some of the types of medical services for which individuals may receive reimbursement under Medicaid are:

- Inpatient hospital services
- Outpatient hospital services
- X-ray services
- Skilled nursing home services
- Physicians' services
- Medical care
- Private duty nursing services
- Clinic services
- Dental services
- Prescribed drugs

The above is only a partial list as illustration, but not an exhaustive list of the type of medical services for which reimbursement is made under the Medicaid program.

There were 256,828 individuals eligible for Medicaid in fiscal year 1981 in the State of Arkansas. This number is divided among 108,099 who were Medicaid eligible because of being SSI recipients and 148,729 who were AFDC recipients.

The SSI recipients are further divided as follows: aged (65 and over) 62,674; blind, 1,771; disabled, 43,654.

The AFDC Medicaid eligible of 148,729 are further divided as follows: AFDC, 128,731; under 21 years, 17,031; foster care, 2,967.

MEDICARE

Title XVIII of the Social Security Act was passed at the same time as the Medicaid Program came into existence. Medicare is an insurance program for individuals age 65 and over who are entitled to retirement benefits from the Social Security Act and for individuals who are disabled. In order to be eligible for benefits from Medicare a person must be receiving Social Security benefits or must be disabled.

Some of the medical services which are reimbursable under the Medicare Program are:

- Inpatient hospital services
- Post-hospital services
- Outpatient hospital diagnostic services

The Medicare Program is handled through a contract with Blue Cross and Blue Shield, Inc. in the State of Arkansas. The Medicare Program is incidentally involved with the disabled since individuals can receive Medicare medical services if they are disabled. However, the majority of the individuals on Medicare rolls are those individuals 65 years of age and older, therefore Medicare rolls do not provide a particularly fruitful data base for finding the developmentally disabled within a state.

AID TO FAMILIES OF DEPENDENT CHILDREN (AFDC)

Aid to Families of Dependent Children (AFDC) is one of the oldest programs in existence in the United States. The program was originally authorized in the first writing of the Social Security Act of August 14, 1935. Title IV of that act was entitled Grants to States for Aid to Dependent Children. The original program was to provide financial assistance to 'needy' children in each state in the United States. The term 'dependent child' was defined as follows in 1935:

"(a) The term 'dependent child' means a child under the age of sixteen who has been deprived of parental support or care by reason of the death, continued absence from the home, or physical or mental incapacity of a parent, and who is living with his father, mother, grandfather, grandmother, brother, sister, stepfather, stepmother, stepbrother, stepsister, uncle, or aunt, in a place of residence maintained by one or more of such relatives as his or their own home."³⁶

Since this early beginning, the AFDC has been the basic welfare program which has provided basic support to millions of dependent children over the years. The basic purpose of the program has not changed. The age of eligibility has increased to 21 years. The same basic eligibility remains as a child who "has been deprived of parental support" for whatever reason. AFDC benefits are in the form of monthly payments which are to be used for the basic support of the dependent child or children.

In fiscal year 1981 there were a total of 148,729 individuals eligible for AFDC benefits in the State of Arkansas.

SPECIAL EDUCATION

There are two laws which provide assistance for Special Education programs within the State of Arkansas. The two laws are Public Law 89-313 and Public Law 94-142.

PL 89-313 was enacted on November 1, 1965 and was an amendment to PL 815 and PL 874. These amendments provided financial assistance in the construction and operation of public elementary and secondary schools in areas affected by a major disaster, eliminated inequities in the application of PL 815 in certain military base closings, and made uniform eligibility requirements for school districts in PL 874.

The last section of PL 89-313 contained financial assistance for Special Education programs for handicapped children who were the direct responsibility of a State Agency and not subject to the jurisdiction of a school district. The eligibility for Special Education funds from PL 89-313 is as follows:

"In the case of a State Agency which is directly responsible for providing, on a non-school-district basis, free public education for handicapped children (including mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, crippled, or other health impaired children who by reason thereof require special education), the maximum basic grant which that agency shall be eligible to receive under this title..."³⁷

The other law which provides funds for Special Education programs is PL 94-142, which is entitled The Education For All Handicapped Children Act. The purpose of the law is assuring:

"that all handicapped children have available to them, within the time periods specified in section 612(2)(B) a free appropriate public education which emphasizes special education and related services designed to meet their unique needs, to assure that the rights of handicapped children and their parents or guardians are protected, to assist States and localities to provide for the education of all handicapped children, and to assess and assure the effectiveness of efforts to educate handicapped children."³⁸

PL 94-142 requires that:

"all children residing in the state who are handicapped, regardless of the severity of their handicap, and who are in need of special education and related services are identified, located, and evaluated, and that a practical method is developed and implemented to determine which children are currently receiving needed special education and related services and which children are not currently receiving needed special education and related services."³⁹

The implementation of PL 94-142 assures the citizens of the state that every effort will be made to locate and provide an appropriate education for every child with a handicap within the state. The law also requires every effort to be made to educate handicapped children with children who are not handicapped. This heterogeneous educational structure applies not only to handicapped children in regular school classrooms but also handicapped children in public or private institutions or other care facilities within the state. If it is not possible to educate handicapped children with children who are not handicapped, then the law requires:

"that special classes, separate schooling, or other removal of handicapped children from the regular education environment occurs only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."⁴⁰

Not only does PL 94-142 mandate the state to assure the citizens of the state that all children with handicaps are sought out and provided a free appropriate public education, but the law requires that each local educational agency take the responsibility for identification and evaluation of the children with handicaps in their district. Section 614(a) of PL 94-142 requires:

"A local educational agency or an intermediate educational unit which desires to receive payment under section 611(d) for any fiscal year to provide that all children residing within the jurisdiction of the local education agency or the intermediate education unit who are handicapped, regardless of the severity of their handicap, and are in need of special education and related services will be identified, located, and evaluated."41

Therefore, it is not only possible to identify the number and classification of children with handicaps at the state level, but because PL 94-142 is specific to each educational district, it is possible to identify the number and classification of children with handicaps in each school district.

Special Education has developed one of the most specific sets of definitions of any program which provides services to a population with special needs for eligibility. It is stated in the Program Standards that:

"A child is determined eligible when the child has been evaluated in accordance with state and federal regulations and has been determined to be mentally retarded, hearing impaired, speech/language handicapped, visually handicapped, seriously emotionally disturbed, orthopedically handicapped, other health impaired, deaf-blind, severely/profoundly handicapped, or to have specific learning disabilities, and who because of those impairments and the adverse effect on his/her educational performance is determined eligible for special education and related services."42

It can be argued that every individual who is eligible for Special Education could be legitimately defined as developmentally disabled with the exception that not every individual who is eligible for Special Education has a handicapping condition which "results in substantial functional limitations in three or more of the seven major life activities."

A person who is eligible for a Special Education program certainly has a handicap which is "attributable to a mental or physical impairment or combination of mental and physical impairments", which is the first requirement in the definition of developmental disabilities in PL 95-602.

A person who is eligible for a Special Education program certainly has a handicapping condition which "is manifested before the person attains age twenty-two." The age of eligibility for Special Education programs is at least 5 - 21 years of age in all states and 3 - 21 years of age in most states.

It may be argued that not all handicapping conditions which make individuals eligible for a Special Education program are "likely to continue indefinitely."

Individuals who are handicapped because of being mentally retarded, hearing impaired, visually handicapped, orthopedically impaired, deaf-blind, multi-handicapped, and severely/profoundly handicapped most likely have handicaps which will continue indefinitely.

Individuals who are eligible for a Special Education program because they are speech/language handicapped, seriously emotionally disturbed, other health impaired, with the exception of individuals who are autistic, and have a specific learning disability may not have a handicap which "is likely to continue indefinitely."

However, with the above question noted concerning the indefinite nature of some of the handicapping conditions, it is assumed in this report that all handicapping conditions which are listed in Special Education regulations meet the criteria in the definition of developmental disabilities that they are "likely to continue indefinitely."

Certainly each of the individuals who has a handicapping condition which makes him or her eligible for a Special Education program is in need of "a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifetime or extended duration and are individually planned and coordinated."

The Special Education services are not planned for a lifetime but are individually planned through an Individual Education Plan (IEP) for at least one year.

There is little question that individuals who are eligible for a Special Education program have a substantial functional limitation in learning.

The deficit in learning is mandatory for an individual to be eligible for a Special Education program. The Program Standards, in the list of definitions, record that eligibility for Special Education services requires:

"A student is determined eligible for special education services when a handicapping condition is present as defined in PL 94-142 that results in an educational deficit and the corresponding need for specially designed instruction."⁴³

The task which remains in order to accurately identify the developmentally disabled population which exists within the Special Education population is to identify those individuals who

have two or more additional functional deficits in the six remaining life activities listed in the definition of developmental disabilities. The task is to identify those individuals who are eligible for a Special Education program who have functional limitations in at least two of the following life activities: self-care, receptive and expressive language, mobility, self-direction, capacity for independent living or economic sufficiency.

A student in school who is between the ages of 3 through 21 probably will not demonstrate functional ability in the capacity for independent living or economic sufficiency to the degree that a person 22 years of age or older would demonstrate functional ability or functional limitation. Therefore, the major life activities in which the student may show functional limitations in order to be identified as developmentally disabled will be in self-care, receptive and expressive language, mobility, and/or self-direction.

Table 6 contains a discussion of the categories of individuals which can appropriately be identified as developmentally disabled who are enrolled in the Special Education program in the State of Arkansas. A discussion of the method used in identifying specific subgroups of the Special Education population as developmentally disabled and omitting other subgroups is presented in Report Number 3 of the Arkansas Series, entitled Decoding Special Education Statistics: Counting the Developmentally Disabled Population.⁴⁴

Just over 19% of the population of Arkansas attends school, according to the pupil enrollment count as of October 1, 1981. This count shows that 437,576 residents of Arkansas are enrolled in Arkansas elementary and secondary schools. Of this number, 49,747, or 11.4%, of the school population were enrolled in Special Education programs within the State.

There were 46,231 students enrolled in Special Education programs funded under PL 94-142 on December 1, 1981 and 3,516 students enrolled in Special Education programs funded under PL 89-313 on that date.

Using the method of identification contained in Table 6, there have been 6,480 participants in Special Education programs identified as developmentally disabled. The 6,480 represents 13% of the Special Education population and 1.5% of the entire school population in the State of Arkansas.

A complete report on the Special Education population in the State of Arkansas including the composition of the developmentally disabled population contained therein is contained in Report Number 3 of the Arkansas Series heretofore referenced.

TABLE 6. FUNCTIONAL LIMITATIONS IN MAJOR LIFE ACTIVITIES AND IDENTIFICATION OF THE DEVELOPMENTALLY DISABLED POPULATION IN THE SPECIAL EDUCATION POPULATION FOR INDIVIDUALS **DIAGNOSED** AS MENTALLY RETARDED, HARD OF HEARING, DEAF, SPEECH IMPAIRED, VISUALLY HANDICAPPED, SERIOUSLY EMOTIONALLY DISTURBED, ORTHOPEDICALLY IMPAIRED, OTHER HEALTH IMPAIRED, SPECIFIC LEARNING DISABLED, DEAF-BLIND AND MULTIHANDICAPPED

Classification of handicap	Functional limitation in major life activities	Identification of developmentally disabled
Mentally Retarded	Will have functional limitations in LEARNING. May have functional limitations in SELF-CARE, EXPRESSIVE AND RECEPTIVE LANGUAGE, and/or SELF-DIRECTION	Those individuals who are diagnosed as Mentally Retarded and assigned to separate classes, separate school facilities or other educational environments
Hard of Hearing	Will have functional limitations in LEARNING. May have functional limitations in EXPRESSIVE AND RECEPTIVE LANGUAGE	NONE
Deaf	Will have functional limitations in LEARNING. May have functional limitations in EXPRESSIVE AND RECEPTIVE LANGUAGE	NONE
Speech Impaired	Will have functional limitations in LEARNING and EXPRESSIVE AND RECEPTIVE LANGUAGE	NONE
Visually Handicapped	Will have functional limitations in LEARNING. May have functional limitations in EXPRESSIVE AND RECEPTIVE LANGUAGE	NONE
Seriously Emotionally Disturbed	Will have functional limitations in LEARNING. May have functional limitations in SELF-CARE, EXPRESSIVE AND RECEPTIVE LANGUAGE, and/or SELF-DIRECTION	Those individuals who are diagnosed as Severely Emotionally Disturbed and assigned to separate classrooms, separate school facilities or other educational environments
Orthopedically Impaired	Will have functional limitations in LEARNING and MOBILITY. May have functional limitations in SELF-CARE, EXPRESSIVE AND RECEPTIVE LANGUAGE, and/or SELF-DIRECTION	Those individuals diagnosed as Orthopedically Impaired and assigned to separate school facilities or other educational environments
Other Health Impairments	Will have functional limitations in LEARNING. May have functional limitations in SELF-CARE, EXPRESSIVE AND RECEPTIVE LANGUAGE, MOBILITY, and/or SELF-DIRECTION	Those individuals diagnosed as Other Health Impaired and assigned to separate classrooms, separate school facilities or other educational environments
Specific Learning Disability	Will have functional limitations in LEARNING	NONE
Deaf-Blind	Will have functional limitations in LEARNING. May have functional limitations in SELF-CARE, EXPRESSIVE AND RECEPTIVE LANGUAGE, MOBILITY, and/or SELF-DIRECTION	Those individuals who are Deaf-Blind and assigned to separate classrooms, separate school facilities or other educational environments
Multihandicapped	Will have functional limitations in LEARNING. May have functional limitations in SELF-CARE, EXPRESSIVE AND RECEPTIVE LANGUAGE, MOBILITY, and/or SELF-DIRECTION	Those individuals who are diagnosed as having Multiple handicaps and are assigned to separate classrooms, separate school facilities or other educational environments

MATERNAL AND CHILD HEALTH

Title V of the original Social Security Act was entitled Grants to States for Maternal and Child Welfare. The original Social Security Act was passed August 14, 1935. Part 1 of Title V established the Maternal and Child Health Services Program. The purpose of the program is stated as follows:

"For the purpose of enabling each state to extend and improve as far as practicable under the conditions in such state, services for promotion of the health of mothers and children, especially in rural areas and in areas suffering from severe economic distress..."⁴⁵

The primary purpose of the Maternal and Child Health Program has not substantially been changed over the years. Today, the Maternal and Child Health Program in the Department of Health operates several programs which focus on the health and delivery of a healthy baby. There are a few programs which provide medical services for critically ill infants and children in need. However, these services are usually short-term in nature and referrals are made to other agencies for follow-up or long-term care when such services are required. Each child and/or adult served in one of the Maternal and Child Health operated programs who can appropriately be identified as developmentally disabled can probably be counted from another service agency's rolls rather than ferreting out the person from the Maternal and Child Health Program rolls.

The following programs conducted by Maternal and Child Health are briefly summarized in the following narrative to identify the population served and eligibility requirements. The programs reviewed are:

- Home Health Program
- Intensive Care Nursery
- Maternity and Infant Care Project (M&I)
- Maternity Program
- Genetic Screening
- Hearing and Speech Services
- Hearing and Vision Screening Program
- Children and Youth Project
- Dental Services
- Early Periodic Screening, Diagnosis and Treatment Program
- Childhood Blood Lead Screening Program
- Family Planning Program
- Arkansas Regional Perinatal Program
- Special Supplemental Food Program for Women, Infants and Children (WIC)
- Arkansas Sudden Infant Death Syndrome Project

Home Health Program: This program is primarily engaged in providing skilled nursing services and other therapeutic services such as physical, speech or occupational therapy, medical social services, and home health aide services to patients who are

homebound due to illness or disability. Seventy-four of the seventy-five counties in Arkansas meet the conditions for participating as a Medicare-Certified Home Health Agency. The Home Health Care program is primarily for individuals who have a short-term illness or disability and the existence of help in the home will reduce the individual's time in the hospital or other institution. For those individuals who have long-term needs for home health care and have a disability manifested prior to age 22 years, they would reasonably be expected to receive additional benefits such as SSI, Medicaid, etc. and it would not be necessary to identify them from this program.

Intensive Care Nursery Project: This program certainly deals with infants who are at risk of developmental disabilities and/or developmental delay. The major purpose of this program is to provide intensive care for infants who are born at risk, who are potentially at risk, or who become at risk during the first year of life. The program provides inpatient hospital care, follow-up clinic programs, and transportation to other hospitals in the State when necessary.

This program is again a short-term, life saving program for those infants at risk. If the infant needs services over an extended period of time and the life threatening danger is past, then the infant will be referred to other programs in the State such as Crippled Children, Medicaid, Developmental Center and other services which provide extended developmental, educational and treatment programs for the infant.

Maternity and Infant Care Project (M & I): This is a geographical specific project providing services in two counties in the State of Arkansas. The project provides comprehensive multidisciplinary clinic services and medical care to maternity patients and infants in Pulaski and Jefferson Counties. The project provides inpatient hospital services during pregnancy and delivery to a small number of high risk, low income maternity patients from these two counties.

The program is based on the fact that there are a large number of women in low income families who are receiving poor or no prenatal care who have a high incidence of complications during pregnancy, who have a high mortality rate, and who deliver prematurely two to three times as frequently as the national average. The infants of these mothers are especially vulnerable to brain damage, neurological disability, mental retardation, and mortality. Since the program is sensitive to the pregnancy outcome, should the infant need additional assistance following birth it is assumed that the program staff would refer the infant to service agencies which provide early intervention and developmental services.

Maternity Program: This program is just what the title indicates. The program provides prenatal services from the initial visit to delivery in 54 clinics located in 34 counties.

Genetic Screening: This is a program which is the result of the Developmental Disabilities Program in the United States, since the PKU screening process was discovered at one of the University Affiliated Facilities in the United States. This program has as a goal the screening of all newborns in Arkansas for the presence of genetically transmitted diseases. At this time, screening services are limited to (PKU) phenylketonuria and hypothyroidism. However, when a positive case is found the infant is referred to the appropriate agency for an early intervention program and developmental services. The Genetic Screening Program is a diagnostic program.

Hearing and Speech Services: The goal of the Hearing and Speech Services Program is to provide hearing, speech and language evaluations to Arkansas children from birth to 21 years of age suspected of having a communication problem. The program is a referral program; many times the referral comes from the school system or other programs requesting information of impairment and diagnosis of the problem. The child or youth so diagnosed as having an impairment would be reported in the referral agency's clinic population.

Hearing and Vision Screening Program: This program is conducted in cooperation with the school system, especially in the kindergarten and elementary grades. Individuals diagnosed as having sensory problems would be included in the Special Education population within the school system if the severity of the impairment warranted such a specialized program.

Children and Youth Project: This project is designed to provide medical services to AFDC recipients at Children and Youth Clinics and other users under age 16 years, usually low income or individuals with special needs.

Dental Services: As part of the dental program, the Department of Health has a service contract with a clinic located at Central Baptist Hospital in Little Rock which provides dental services to Medicaid eligible children or children who are eligible for Pulaski County Health Unit Services. Individuals who are provided services through the dental program will appear both on Special Education rolls and on Medicaid rolls for the purposes of enumeration.

Early Periodic **Screening,Diagnosis** and Treatment Program: The purpose of this program is to provide ongoing preventive health care for Medicaid eligible children. Medical screening and outreach are the two components of the program. While there may be individuals served who could appropriately be identified as developmentally disabled in the program, these individuals would also appear on the Special Education and Medicaid rolls and very possibly on the Crippled Children rolls for the purposes of enumeration.

Childhood Blood Lead Screening Program: The purpose of the Blood Lead Screening Program is to screen children ages 1 through 5 to identify lead poisoning or potential lead poisoning. Certainly the relationship of lead poisoning as a cause of mental retardation has been well established in the last decade. Therefore, the population identified through this program could very well be developmentally disabled. However, individuals who are mentally retarded due to lead poisoning would also be found on the Crippled Children rolls, the Developmental Center rolls, and ultimately on the Special Education rolls.

Family Planning Program: This program provides education and services concerning family size, promoting the health of the mother and children, the merits of spacing children, and other information which contributes to effective and positive parenting.

Arkansas Regional Perinatal Program: This program focuses on presenting continuing education courses and seminars for health care professionals throughout the State. It was from this program that the statewide transportation system for critically ill newborns was established, which has been responsible for transporting over 700 critically ill babies in the past few years.

Special Supplemental Food Program for Women, Infants and Children (WIC): This program is designed to provide education concerning nutrition and nutritious food to women who are pregnant and women who are breastfeeding their infants. The program also provides nutritious food to infants and children to five years of age who are at nutritional risk.

Arkansas Sudden Infant Death Syndrome Project (SIDS): Counseling and information to families who have lost an infant due to sudden infant death syndrome are provided through this program. The program staff of the SIDS Project also provide educational information to health professionals regarding the handling of infant deaths due to Sudden Infant Death Syndrome.

As can be seen from the list of programs cited, the Maternal and Child Health Division in the Department of Health in the State of Arkansas is concerned with providing comprehensive, preventive health services to both the Arkansas children and their mothers both prior to birth of the infants and immediately following the birth of the infants. The programs and projects cover a wide variety of specialized activities which in the past have been and still are major health problems for expectant and new mothers and their offspring.

However, in seeking to identify the developmentally disabled in the State of Arkansas, the program participants in Maternal and Child Health programs do not provide a unique population which is not elsewhere presented on the rolls of other service agencies which also provide services to individuals who are disabled in the State. Therefore, the clinic population from Maternal and Child Health programs is not pursued in counting the developmentally disabled population. However, the Maternal and Child Health programs should be in the forefront of designing prevention and early intervention programs since many of the programs operated by the agency provide the first contact in society with the mother and the infant who is at risk of being developmentally disabled and/or developmentally delayed, as has been referenced in the heretofore cited programs.

MENTAL HEALTH

The Division of Mental Health Services functions as a part of the system within the Department of Human Services in the State of Arkansas. The division has as its clientele all individuals in the State of Arkansas who are in need of mental health services and/or individuals who are mentally ill. Mental illness is defined by the federal government as "an affliction resulting in a disturbance in behavior, feeling, thinking, or judgment to such an extent that a person requires or chooses to obtain care and treatment." It is necessary, in the State of Arkansas, for the individual to seek assistance and, in acute cases where hospitalization is necessary, to self-commit to the hospital, except for those individuals who are committed to the facility by court order.

The organization divisions of the Division of Mental Health Services provide the reader with an overview of the complexity and diversity of services and programs provided by the Division of Mental Health.

"The Division of Mental Health Services consists of nine organization divisions: The State Hospital at Little Rock, the Greater Little Rock Community Mental Health Center, the George W. Jackson Community Mental Health Center at Jonesboro, the Benton Service Center, the Forensic Psychiatry, Professional and Continuing Education and Quality Assurance, Children and Adolescent Treatment Services, Community Mental Health Services, and Administrative Services." 46

The philosophy of the Division of Mental Health is to provide mental health services in the closest proximity of the individual's home community as possible and to limit the number of

hospital days or residential treatment days as much as possible. The division works for the prevention of mental health problems and mental illness for all residents in the State, provides outpatient treatment programs where needed, and residential programs.

The mental health problems treated through the Division of Mental Health include alcohol disorders, drug abuse disorders, mental retardation, depressive affective disorders, schizophrenia, psychoses, disturbances of childhood and adolescence, social maladjustment, and other social and cultural adjustment conditions which cause an individual to be estranged from his or her social and/or family situation, emotionally, mentally and/or physically.

Acute, intensive psychiatric inpatient treatment programs are operated at the Arkansas State Hospital. The facilities at the Arkansas State Hospital include a specialized treatment program for youth 13 - 17 years of age. Services for children from 0 - 14 years of age are provided by Child Study Center of the University of Arkansas Medical Services.

The Benton Services Center Nursing Home is an intermediate care facility of 630 beds which provides long-term care for individuals suffering from chronic mental or physical disorders or those individuals who are mentally retarded or developmentally disabled and cannot be cared for at home. The Benton Services Center Program consists of three components, which are education, recreation, and occupational therapy. The curriculum is individually planned for each individual and is designed to help each individual become more self-reliant and a better family member or to allow the individuals to maintain themselves at their present level of functioning so that regression does not take place.

The Division of Mental Health has as its priorities for the five year period between FY '81 and FY '85 Services to the Chronically Mentally Ill, Services to Adolescents, and Services to the Elderly.

The Chronically Mentally Ill are individuals who, for the Division's programs, are defined as

An individual with a long term mental illness refers to a person, 18 and over who:

(a) Is severely impaired in at least two of the three following areas of behavioral functioning:

- (1) Social Role: The ability to function independently in the role of worker, student, or homemaker;
- (2) Daily living skills: The ability to engage independently in personal care (grooming, personal hygiene, etc.), and community living activities (handling personal finances, using community services, performing household chores, etc.) at an age-appropriate level;
- (3) Social acceptability; the ability to exhibit appropriate social behavior, the absence of which would result in the demand for intervention by the mental health and judicial system;

(b) Has experienced this impaired behavioral functioning for one year or longer, or, if less than one year, carries a diagnosis of a mental illness that is likely to result in seriously impaired behavioral functioning for one year or longer.

It is interesting to note that the definition of chronically mentally ill is defined in functional limitation terms much the same as the areas of functional limitations contained in the definition of developmental disabilities. It is apparent that individuals who are chronically mentally ill and have functional limitations in three or more of the life areas which are in the definition of developmental disabilities and whose condition is manifested prior to age 22 must be appropriately identified as developmentally disabled. Therefore, part of the chronically mentally ill served by the Division of Mental Health can appropriately be identified as developmentally disabled.

A task force selected in 1978 addressed the issue of services to emotionally disturbed children and youth. As a result of the deliberations of this task force, the Division of Mental Health set forth as one of its major priorities the development of a comprehensive system of care for the emotionally disturbed children and youth throughout the State.

The comprehensive system of care contains five levels of service. Level I is the diagnostic and evaluation service. Level II is the prevention of mental illness for those children and youth who are identified to be victims of family and situational crises which impair or could impair their mental health. Level III is for those moderately dysfunctioning youth who have problems brought to the attention of the community, school, and in some cases the court. Level IV is for the severely disturbed youth who are unable to cope with daily living realities and their intense maladaptive behaviors require a restrictive placement. Level V is for the acutely dysfunctioning youth who are an obvious danger to themselves and others.

It is certainly easy to see that all youth in Levels IV and V programs can appropriately be identified as developmentally disabled. Some of the individuals in Level III could be developmentally disabled, depending upon the severity of the dysfunctioning.

The youth who are severely emotionally disturbed are probably already identified in the Special Education program prior to their being referred and placed in one of the adolescent programs operated by the Division of Mental Health. However, it is important to underscore the existence of this comprehensive program for the emotionally disturbed adolescents and the priority it is given by Mental Health.

The other major priority is services to the elderly. The Division of Mental Health is making an effort to provide mental health services to individuals in nursing homes and aged individuals in rural areas. Probably this group, the elderly mentally ill, will not contain a significant number of individuals who could be appropriately identified as developmentally disabled. The fact that most of this population has illness which causes functional limitations in major life activities which manifest themselves after age 22 years eliminates most of the population from being considered developmentally disabled.

The Division of Mental Health coordinates its program activities and relies on funding therefor from many other programs in the State of Arkansas. Major coordination efforts are arranged with Health Planning, Titles XVIII, XIX and XX of the Social Security Act, the Vocational Rehabilitation Act, Community Development Act, and Older Americans Act. The division also works cooperatively with the Department of Education, Division of Special Education in providing diagnostic and evaluation services and providing treatment programs when necessary.

The Division of Mental Health provided services through its CMHC's in FY '80 to 46,956 individuals. Some of these individuals could appropriately be identified as developmentally disabled, depending upon the severity of the impairment. High on the list of probability of individuals being developmentally disabled are the 996 individuals diagnosed as mentally retarded and the 2908 individuals diagnosed as having disturbances of childhood and adolescence.

In order to ascertain the exact number of individuals served by the Division of Mental Health who could appropriately be identified as developmentally disabled, the reader is referred to Report Number 1 of the Arkansas Series entitled The Developmentally Disabled Population Registry for Arkansas.

DEVELOPMENTAL DISABILITIES SERVICES

The Division of Developmental Disabilities Services is located in the Department of Human Services in the State of Arkansas. The division is responsible for providing operating, licensing and/or funding programs for selected individuals identified as developmentally disabled. Eligibility for services in the division is based on a definition of developmental disabilities which differs from the definition of developmental disabilities contained in PL 95-602. The eligibility criteria for services used by the division are as follows:

"Criteria. Eligibility for services is restricted to persons who have been diagnosed as being developmentally disabled under the legal definition of Act 513, exhibit impairment in adaptive behavior to such an extent that the ability to function with peers is substantially limited, and who require services available from Developmental Disabilities Services or its licensed affiliates. A developmental disability is established by the following evidence during the developmental years and/or prior to the chronological age of 18 years:

a. Mental Retardation - scores of intelligence which fall two or more standard deviations below the mean of a standardized test of intelligence administered by a licensed psychological examiner; **Infants/Preschool** - developmental scales, administered by personnel authorized in the manual accompanying the instrument used, which indicate impairment of general functioning similar to that of developmentally disabled persons;

- b. Cerebral Palsy - the results of a medical examination provided by a licensed physician;
- c. Epilepsy - the results of a neurological examination provided by a licensed neurologist and/or licensed physician;
- d. Autism - the results of a team evaluation by at least a licensed physician and a licensed psychological examiner."

The above criteria for eligibility for services operated, licensed and/or funded by Developmental Disabilities Services lists four conditions which had formerly been used in the federal definition of developmental disabilities: mental retardation, cerebral palsy, epilepsy and autism. These criteria also mandate that the individual "exhibit impairment to adaptive behavior", thereby requiring functional limitation. This eligibility requirement was adopted on May 10, 1982.

The Division of Developmental Disabilities Services operates, licenses and/or funds a wide variety of programs for the developmentally disabled throughout the State of Arkansas. The division, besides operating six Human Development Centers which are residential facilities for severely involved individuals, licenses and/or funds a variety of community programs usually provided by contract with a community based organization. The organizations which receive operational contracts are usually community based non-profit organizations which operate one or more programs and/or facilities in an identifiable geographical area.

The programs licensed and/or funded by the Division of Developmental Disabilities Services include the following, which are conducted by community organizations:

- Early Intervention/Family Maintenance
- Parent Training
- Preschool
- Adult Development Non-Work
- Work Activity Center
- Group Home
- Apartment Program
- Respite Care

The eligibility criteria for each of the programs is the responsibility of the local organization, but must conform to the legal definition of developmental disabilities contained in Arkansas Act 513. The organization which provides the service can devise the eligibility criteria for program participants which is unique to the organization's interests so long as it serves some or all of the individuals identified in the definition.

To be eligible for a program operated, licensed and/or funded by the Division of Developmental Disabilities Services a person must have a substantial handicap caused by mental retardation, cerebral palsy, epilepsy or autism or a condition requiring similar services, such condition being manifested prior to age 18 years and such condition expected to continue indefinitely.

Certainly part, if not all, the Developmental Disabilities Services population may be identified as developmentally disabled according to the definition of developmental disabilities in PL 95- 602. Since the definition of developmental disabilities in PL 95- 602 is a definition which focuses on the functional limitations of the individual rather than the cause of the individual's condition it is necessary to know the adaptive behavior of the individuals served by Developmental Disabilities Services and its projects in order to know the number of individuals who can appropriately be identified as developmentally disabled.

The fact that there are two acceptable definitions of developmental disabilities in the State of Arkansas may cause some confusion over the use of the term. One acceptable definition is that one mandated by State law in defining the population to be served by the Division of Developmental Disabilities, which is the definition which focuses on the cause of the disability, particularly naming mental retardation, cerebral palsy, epilepsy and autism. The other definition is that definition mandated in PL 95-602 and used by the Arkansas Governor's Developmental Disabilities Planning Council to identify the population for which it plans and evaluates services. The definition in PL 95-602 focuses on the functional limitations in major life activities regardless of the cause of the handicap.

There were 5,921 individuals provided services in programs operated, licensed and/or funded by the Division of Developmental Disabilities Services, according to a report released by the division dated November 13, 1981. This report listed the following distribution of the population:

Individuals in Community Client Services	1,268
Individuals in Community Based Programs	3,262
Individuals in Institutions	<u>1,391</u>
Total population known to agency	5,921

TITLE XX

Title XX of the Social Security Act is one of the major funding sources for providing social services to the residents of the State of Arkansas. In State fiscal year 1981, Title XX funds provided services for more individuals than any other single funding source in the State.

"Title XX of the Social Security Act enables states to claim limited federal funds on a matching basis to provide social services for low income individuals and families. The services assist an individual or family to become less dependent on others for financial support or personal care; to protect children and adults from neglect, abuse or exploitation and for family maintenance; to avoid unnecessary or premature institutionalization; or to gain an appropriate placement if institutionalization is necessary."48

The Title XX funds are provided to State agencies which contract with the Office of Title XX to provide specific services to eligible individuals through the agencies' facilities and programs. Title XX coordinates its activities with eight different divisions and agencies in the State of Arkansas, including the Office on Aging, Office of Alcohol and Drug Abuse Prevention, Mental Health Services, Developmental Disabilities Services, Rehabilitation Services, Division of Social Services, State Spinal Cord Commission, and Division of Youth Services.

The Title XX funded services must be provided free to the recipient. To be eligible for services funded by Title XX, an individual must be:

1. In need of one of the services which is in relation to the five national program goals,
2. A resident of the State of Arkansas, and
3. Financially eligible specific to the service for which the individual is applying.

In most cases the individual who is eligible for the service provided by the providing agency or office is eligible for Title XX funded services. For example, a person who has a valid Medicaid Card is eligible to receive Title XX services.

Each agency or office which applies for Title XX funds to provide services for individuals within its population must direct its Title XX funded services to one or more of the following national program goals:

- I. Achieving or maintaining economic self-support to prevent, reduce or eliminate dependency.
- II. Achieving or maintaining self-sufficiency, including reduction or prevention dependency.
- III. Preventing or remedying neglect, abuse or exploitation of children and adults unable to protect their own interests or preserving, rehabilitating or reuniting families.
- IV. Preventing or reducing inappropriate institutional care by providing for community based care, home-based care, or other forms of less intensive care.
- V. Securing a referral or admission for institutional care when other forms of care are not appropriate, or providing services to individuals in institutions.⁴⁹

The Title XX funds are primarily distributed through the eight State offices and agencies to provide services to the individuals. The particular services for which Title XX funds can be

used are listed in the Title XX State Plan under each of the agencies or offices in the section entitled Catalog of Services.⁵⁰ The services listed for each specific agency or office in the present Title XX State Plan are as follows:

- Office on Aging
 - Chore Services
 - Day Care for Adults
 - Home Delivered Meals
 - Socialization Services
 - Supervised Living Services
 - Transportation Services
- Office** of Alcohol and Drug Abuse Prevention
 - Special Services for the Disabled
 - Supervised Living Services
- Mental Health Services
 - Mental Health Services
 - Supervised Living Services
- Developmental **Disabilities** Services
 - Day Care for Adults
 - Day Services for Developmentally Disabled Children
 - Special Services for the Disabled
 - Supervised Living Services
- Rehabilitation** Services
 - Special Services for the Blind
 - Special Services for the Disabled
 - Supervised Living Services
 - Training and Education Services
- Social** Services
 - Adoption Services
 - Chore Services
 - Day and Residential Camping
 - Day Care for Children
 - Emergency Services
 - Employment Services
 - Family Maintenance Services
 - Family Planning Services
 - Health Related Services
 - Homemaker Services
 - Interstate Compact on Juveniles
 - Interstate Compact on the Placement of Children
 - Protective Services for Adults
 - Protective Services for Children
 - Services to Children In Their Own Home
 - Services to Unmarried Parents
 - Services to Youth in Need
 - Socialization Services
 - Substitute Care for Children
 - Transportation Services
- State **Spinal Cord Commission**
 - Chore Services
 - Day and Residential Camping
 - Special Services for the Disabled
 - Transportation
- Division** of Youth Services
 - Services to Youth In Need
 - Substitute Care for Children

Title XX also provides 100% funding for the Refuge Resettlement Program. This program provides social services designed to meet the resettlement needs of adult refugees 16 years of age or older.

Handicapped/disabled is defined for eligibility for Title XX programs as follows:

"Any individual who has a physical or mental condition which substantially limits one or more of such person's major life activities; has a record of such an impairment; or is regarded as having such impairment (includes alcohol and drug dependence). For the Adult Handicapped Center in Benton, those mentally retarded, recovering mentally ill, physically impaired, and alcoholic (with secondary disability of one or more of the above disabilities) individuals, ages 16 or above, who have never entered the competitive job market, or having entered were not able to compete because of a lack of basic skills necessary to survive in a vocational setting." 51

The above definition is of extreme importance to the Arkansas Governor's Developmental Disabilities planning Council since it is a functional definition of disability and requires the individual to have at least one or more functional limitations in a major life activity. The individual also must have a 'substantial' limitation in the life activity. Therefore, many individuals who are considered by service providers of Title XX programs to be handicapped/disabled according to the above definition may very well be individuals who can be appropriately identified as developmentally disabled individuals as defined in PL 95-602 for those individuals whose condition manifested itself prior to age 22. This definition of handicapped/disabled certainly presents a close proximity in identifying the individuals who are developmentally disabled, which is the responsibility of the Developmental Disabilities Planning Council.

A complete analysis of the Title XX population and that portion which can be appropriately identified as developmentally disabled is contained in the report entitled The World of Services to Adults Who Are Handicapped in the State of Arkansas, which is Report Number 4 in the Arkansas Series.

Title XX funded programs served a total of 321,897 individuals in the State fiscal year which ended June 31, 1981. Title XX purchased services for a total of 221,255 individuals from the agencies and offices listed above and provided direct funds for services to an additional 100,642 individuals.

CRIPPLED CHILDREN

The Crippled Children Program has almost come full circle since first appearing in federal law in August of 1935. The Crippled Children Program first appears in federal law in 1935 as Part 2 of Title V of the first Social Security Act. Title V in that act is entitled Grants to States for Maternal and Child Welfare. Part 1 of this title is Maternal and Child Health Services. Part 2 of this title is Services for Crippled Children.

The purpose of Part 2 is stated in Section 511 of Title V as:

"Sec. 511. For the purpose of enabling each State to extend and improve (especially in rural areas and in areas suffering from severe economic distress), as far as practicable under the conditions in such States, services for locating crippled children and for providing medical, surgical, corrective, and other services and care, and facilities for diagnosis, hospitalization, and aftercare, for children who are crippled or who are suffering from conditions which lead to crippling... ." 52

It was through the Crippled Children's part of the Social Security Act that many of the model programs for the individuals who were mentally retarded, research for individuals with cerebral palsy and epilepsy were carried out in the 1950's before the passage of the Mental Retardation Facilities and Construction Act of 1963. Crippled Children Programs have always sought out the children who are crippled or have conditions which cause children to be crippled, and provide the medical assistance necessary to blunt or eliminate the effects of the crippling condition on the child's developmental period of life.

Crippled Children Programs have been in the forefront of providing early intervention activities, even while the infant is still in the hospital, immediately after birth. The Crippled Children Program has been among the first to realize and stress the importance of early intervention in the success of blunting or eliminating the effects of a condition which cripples or disables a child.

The purpose and mission of the Crippled Children Program has changed little since its beginning in the fall of 1935. The program professionals in Arkansas continue to seek out those children who have conditions which cripple or could cripple, supplying medical, surgical, hospitalization and aftercare for such children.

As of last year, the Crippled Children Program was put back under the Maternal and Child Health Program in a block grant in the newest legislation for this important program. The Crippled Children Program is under the Division of Social Services in the Department of Human Services in the State of Arkansas at the present time.

As of April 1, 1982 there were 2,289 individual active cases in the Crippled Children Program.

HEAD START

The Head Start Program is a creation of the War on Poverty and first appeared in law in 1964. PL 88-452, the Economic Opportunity Act of 1964, carried the legal provision for the Head Start Program which was to give birth to a most important social program and a program which is still in existence today.

Ten years after the first Head Start Programs were operational, a second law was passed which eliminated some of the original programs contained in the War on Poverty. However, the Community Services Act of 1974, PL 93-644, was to highlight the importance of the Head Start Program and provide new enthusiasm for the program, its concept, and continuation.

In the last session of Congress, in the Omnibus Budget Reconciliation Act of 1981, PL 97-35, Head Start has a place all to itself in this act. Section 635 of the Omnibus Budget Reconciliation Act of 1981 contains the Head Start Act.

The statement of purpose for the Head Start Program has stayed intact through all the changes in law and all the rewrites. The fact that the statement of purpose has remained intact for 15 years indicates that the original concept must have been correct and that there is still a need to carry out programs based on that purpose in our society today. The Statement of Purpose for Head Start is:

"In recognition of the role which Project Head Start has played in the effective delivery of comprehensive health, educational, nutritional, social, and other services to economically disadvantaged children and their families, it is the purpose of this subchapter to extend the authority for the appropriation of funds for such programs." 53

Eligibility for the Head Start Program is "those children between three years of age and the age of compulsory school attendance." It is also noted in the statute that "at least 90 percent of the children who are enrolled in each Head Start Program shall be from low-income families." Also, since the passage of PL 93-644 there has been the requirement that "no less than 10 percent of the total number of enrollment opportunities in Head Start Programs in each state shall be available for handicapped children. The term handicapped children is defined to mean 'mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired, or other health impaired children or children with specific learning disabilities who by reason thereof require special education and related services.'"

The name of the program dramatically expresses the role of the program for the children involved. The program is to provide

a Head Start in all life areas wherein the preschool child might need help and assistance in order to be competitive in school, community and family. The Head Start Program seeks that magic combination of education, social and cultural experiences necessary for each individual to gain in order to understand and participate in the world around him or her. This is the ultimate program fabric from which a Head Start Program is cut.

The Head Start Program in the State of Arkansas is operated by 19 community organizations. Head Start Programs are operated throughout the State of Arkansas.

In FY '81 there were a total of 5,156 children enrolled in the Head Start Programs. On December 1, 1981 there were 751 preschool children who were diagnosed as handicapped according to the Child Count prepared by the Division of Special Education in the State of Arkansas.

REHABILITATION SERVICES

The Arkansas Rehabilitation Services are provided through a division within the Department of Human Services. The Division of Rehabilitation Services is divided into three operational agencies which are: Rehabilitation Services, which is the general agency that serves persons with disabilities other than blindness and deafness; Office for the Blind and Visually Impaired; and Office for the Deaf and Hearing Impaired.

The Division of Rehabilitation Services also operates in cooperation with the University of Arkansas, the Arkansas Rehabilitation Research and Training Center.

Rehabilitation Services provides services to any individuals who are disabled and who, after extensive evaluation, which may include medical, psychological and social components, by a rehabilitation counselor, are identified as eligible for Rehabilitation Services. Rehabilitation Services may have one or more goals in providing services to the disabled including employment, sheltered employment, unpaid employment, homemaker and/or independent living.

The majority of Rehabilitation Services are provided throughout the State in Field Offices. The major service provided in the Field Office is counseling. The counselor also identifies disabled people in the community and helps them by writing, in cooperation with the individual, an Individual Written Rehabilitation Plan (IWRP) through which the rehabilitation process and subsequent placement in employment is identified.

The rehabilitation counselor has the authority to purchase the treatment, education and/or training necessary for the individual which is identified on the individual IWRP. Most of the

services provided by Rehabilitation Services are purchased from existing service providers in or near the community wherein the individual resides.

Rehabilitation Services also operates the Hot Springs Rehabilitation Center, which is one of the few facilities in the country that has a comprehensive program of rehabilitation services. The Hot Springs Rehabilitation Center was opened in January, 1961. The Center is located on twenty-one acres of land which overlooks the downtown business district of the city of Hot Springs, Arkansas. The Center is composed of 42 buildings and is the property of the State of Arkansas. The first individuals were enrolled in the Center on January 2, 1961.

"Since then, more than 11,000 students have been enrolled for the various diagnostic, medical, and work preparation services. The current average daily census of the Center is above 350 which is primarily residential, although increasing numbers of students are enrolled as non-residents through special arrangement." 54

"The Center offers a complete combination of skilled services essential to achieve medical, social, psychological, and vocational rehabilitation. The service divisions are:

Medical - Complete physical medicine program, medical consultation and supervision for all clientele, physical therapy, occupational therapy, speech therapy, audiological consultation, and prosthetic and orthotic clinics.

Program Development - Complete counseling services, psychiatric and psychological services, vocational evaluation, organized recreational activities, dormitory supervision, student admission and chaplain services." 55

There is vocational preparation training which leads to minimum levels of competency in thirty major areas of vocational preparation offered at the Center. The training activity is very practical, which aids the handicapped individuals to acquire the skills necessary to accommodate a handicapping condition while learning the vocational skills necessary for employment.

The Division of Rehabilitation Services opened, in 1979, an Independent Living Center which is a non-residential, consumer oriented program with services available to all disability groups. The Independent Living Center is located in Little Rock.

Rehabilitation Services provides a complete range of services to both the blind and vision impaired, and the deaf and hearing impaired through separate sections of the division.

The Rehabilitation Services Agency of Arkansas has an agreement with the Social Security Administration to provide

rehabilitation services to selected persons who receive Supplemental Security Income. In order for a handicapped person who is an SSI recipient to be eligible for Rehabilitation Services the person must meet the following:

"(1) proof that the handicapped person does receive Social Security Disability Insurance, (2) must certify that the person does have a severe handicapping condition that will not improve unless VR services are provided and that the provision of services will enable that disabled person to return to work in the competitive labor market at minimum wage or above." 56

Rehabilitation Services also provides supervision and support services to the sheltered workshops in the State of Arkansas which are operated for the benefit of disabled individuals who cannot enter the competitive labor market because of their disability or whose work experience in the sheltered workshop will enable them to enter the competitive labor market. There are 23 sheltered workshops in the State of Arkansas.

The number of individuals who can be appropriately identified as developmentally disabled who are in the Rehabilitation Service population is difficult to determine. However, it is known that Rehabilitation Services purchases services from existing service providers and works in cooperative agreement with other State agencies which provide services to the disabled. For example, Rehabilitation Services provides services to individuals in Nursing Homes and individuals in the Mental Health Services program. Therefore, it is assumed that those individuals who are receiving Rehabilitation Services who may appropriately be identified as developmentally disabled will also be counted in other service systems such as Mental Health, Long Term Care and Developmental Disabilities Services.

There were a total of 22,156 individuals provided services by Rehabilitation Services in the federal fiscal year ending in September, 1981. An additional 431 individuals were provided services through the Arkansas Kidney Disease Commission during the same period of time.

LONG TERM CARE

Long Term Care services are descriptive by their title. The Long Term Care Programs are programs for individuals whose medical needs require long term care. Care for individuals found to be eligible for these programs is usually provided in nursing homes or health centers specializing in extended care activities.

In order to be eligible for a Long Term Care Program an individual must be so diagnosed by a physician. The physician must also recommend a care program for the individual.

In FY '81 there were 20,938 individuals participating in programs under the Long Term Care Program in the State of Arkansas. The population of participants is divided into the following groups: age 65 years and older, 15,944; blind, 164; disabled, 4,837.

OFFICE ON AGING

The Office on Aging is responsible for implementation of the Older Americans Act in the State of Arkansas. The program is coordinated through eight Area Agencies on Aging (AAA). These agencies are non-profit organizations which provide the coordination of services to the elderly in each of the eight regions in the State. (Regions referenced are the eight regions formerly used by the Division of Human Services in the State of Arkansas.)

Eligibility for programs depends upon the residency of the older residents in the State. The eligibility is not uniform throughout the State. In Regions I, II, III, IV and VIII, an individual must be sixty years old or older in order to be eligible for services. In Regions V and VI, those individuals 55 years of age or older are eligible for services. Handicapped or disabled individuals of any age are eligible for services in Region V. Handicapped or disabled individuals who are 55 years of age or older in Region VII are eligible for services.

The services are provided by service providers funded through contracts with the Area Offices on the Aging. The service providers are local organizations, usually non-profit organizations located in local communities.

The services are divided into two classifications. One classification is Social Services and the other is the Congregate Nutrition Services. Social Services can be divided into four categories, which are: access, in-home services, community services, and services in care providing facilities. The Congregate Nutrition Services are divided into two categories, which are: congregate meal services, and home delivered meals.

Under the category of access, the services of transportation, outreach and information and referral are provided by local service providers to the elderly.

In-home services consist of homemaker, home health aide, visiting/telephone reassurance, and chore maintenance services which are provided on an as needed basis to the elderly in the local communities.

Community services consist of legal assistance, escort service, residential repair and renovation as needed, and health services where needed to individuals who are elderly.

Services in care providing facilities can be for protective housing, group home placement, but in most cases mean referral and placement in a nursing home for those individuals who cannot care for themselves and need the programs provided in the residential setting.

The congregate meals are meals served in locations accessible to the elderly population both in the rural areas and the urban areas. A variety of different facilities are used to provide these congregate meals, including but not limited to, churches, schools, public and low income housing sites, and restaurants.

Home delivered meals are for those individuals who cannot fix their own meals and who cannot travel to the location where the congregate meals are served. The purpose of the home delivered meals is to insure that the elderly receive at least one hot, nutritional meal each day.

The Office on Aging served a total of 88,437 in fiscal year 1981. The following is a breakdown of the number of individuals receiving social services and the number of individuals receiving meals during that period of time. There were 49,623 individuals who received social services and 38,814 who received meals in programs coordinated by the Office on Aging.

ELIGIBILITY REQUIREMENTS

Table 7 contains a summary of the requirements for eligibility for participants in programs which provide the majority of services to the disabled in the State of Arkansas. Table 7 also contains the number of individuals served in each of these programs according to the most recent data available. It is admitted that in the form in which the data is presented there is a great deal of duplication of count. However, the information contained in Table 7 shows that many of the programs provide services to individuals who can be appropriately identified as developmentally disabled using the definition of developmental disabilities contained in PL 95-602.

The number and percent of all individuals appropriately identified as developmentally disabled are contained in Report Number 1 of the Arkansas Series, which is entitled The Developmentally Disabled Population Registry for Arkansas.

The number and percent of individuals in Special Education programs in the State of Arkansas who can appropriately be identified as developmentally disabled are contained in Report Number 3 of the Arkansas Series, which is entitled Decoding

TABLE 7. ELIGIBILITY REQUIREMENTS INCLUDING SERVICE POPULATION. OTHER PROGRAMS SERVING SAME POPULATION AND NARRATIVE CONCERNING THE SERVICE POPULATION RELATIVE TO THE DEVELOPMENTALLY DISABLED FOR SSI, MEDICAID, MEDICARE, AFDC, SPECIAL EDUCATION, MATERNAL AND CHILD HEALTH, MENTAL HEALTH, DDS, TITLE XX, CRIPPLED CHILDREN, HEAD START, REHABILITATION SERVICES, LONG TERM CARE, AND OFFICE ON AGING IN THE STATE OF ARKANSAS

Program	Service population	Eligibility requirements	Other programs wherein individuals will be found	Portion of population identified as developmentally disabled
Supplemental Security Income (SSI)	75,473 of which 33,700 disabled (Sept. 1981)	A person of any age, must have a severe impairment which causes functional limitations in work, school or other life activities continuous for at least a twelve month period	Medicaid; Special Education; Mental Health; DDS; Title XX; Crippled Children; Rehabilitation Long Term Care	All children and youth under 22 years and all adults over 22 years whose disability was manifested prior to age 22
Medicaid	45,425 Medicaid eligible for 1980-81 because of blindness or disability	Any individual who is a recipient of SSI benefits or AFDC benefits is automatically eligible and individuals who are determined eligible as medically needy are eligible	SSI; AFDC; Special Education; Mental Health; DOS; Title XX; Crippled Children; Rehabilitation Long Term Care	All children and youth under 22 years and all adults over 22 years whose disability was manifested prior to age 22 who are SSI recipients, probably few, if any, AFDC or medically needy recipients
Medicare	Unknown	Individual must be 65 years of age or over and entitled to retirement benefits under the Social Security Act. In some cases, disabled individuals are eligible for benefits	Office on Aging	None of Medicaid population if Medicare is only program for which individual is eligible
Aid to Families of Dependent Children (AFDC)	128,731 for 1980-81	Individuals under 21 years, deprived of parental support and who are income eligible	Service programs appropriate to age	None of AFDC population if AFDC is only program for which individual is eligible
Special Education	49,747 (Dec. 1, 1981)	A child (3-21), must be diagnosed as having a specific impairment or impairments and who, because of those impairments, is adversely affected in his or her learning experience	Service programs appropriate to age including Crippled Children, DDS, Mental Health, etc.	Individuals who are diagnosed as mentally retarded, orthopedically impaired, seriously emotionally disturbed, other health impaired, deaf-blind, multi-handicapped and placed in other than the regular classroom for their education program

TABLE 7 (Continued)

Program	Service population	Eligibility requirements	Other programs wherein individuals will be found	Portion of population identified as developmentally disabled
Maternal and Child Health	Various programs, numbers specific to each program	Programs are mostly designed to serve pregnant women and critically ill infants and children, usually focusing on AFDC, Medicaid recipients, and low income families and children	Service programs such as Crippled Children; Developmental Disabilities; Special Education and others such as Medicaid and SSI	Primarily the programs are designed to prevent infants from being born with developmental disabilities. All clients served who could be appropriately identified as DD probably are in other service agency populations and more easily counted on those rolls
Mental Health	46,956 Unduplicated fiscal year ending 6/30/80	Serves all ages of individuals from birth through elderly populations who are in need of mental health services and provides a wide range of education and information programs and diagnostic services for other service programs	SSI; Medicaid; Title XX; Special Education; Medicare; Head Start; Developmental Disabilities	That portion of the chronically mentally ill population in which illness manifested itself prior to age 22. Children and youth with severe mental, emotional and/or substance abuse problems
Developmental Disabilities Services	5,921 (Report dated 11/13/81)	Individuals with substantial handicaps caused by mental retardation, cerebral palsy, epilepsy, autism or other similar conditions, manifested prior to 18 years of age and expected to continue indefinitely	SSI; Medicaid; Special Education; Medicare; Rehabilitation; Head Start	That portion of the population which has substantial handicaps which limit the individuals in three or more of the seven major life activities listed in the definition of developmental disabilities contained in PL 95-602
Title XX	321,897 Unduplicated State fiscal year ending 6/30/81	Individuals: 1. who need a service which meets one of the priority areas; 2. who are residents of Arkansas; 3. who are financially eligible for specific service for which they are applying	Aging; Alcohol and Drug Abuse; Mental Health; Developmental Disabilities Services; Rehabilitation; Social Services; Spinal Cord; Youth Services	That portion of the population which has substantial handicaps in three or more areas of seven major life activities and which were manifested prior to age 22 years

TABLE 7 (Continued)

Program	Service population	Eligibility requirements	Other programs wherein individuals will be found	Portion of population identified as developmentally disabled
Crippled Children	2,289 active cases on 4/1/82	Disabled children to age 21 years, depending on severity of disability and cost of treatment	DDS; Pre-School; Head Start; Special Education	All children whose disability results in functional limitations in three of five major life activities
Head Start	5,156 Unduplicated count for FY '81 751 Unduplicated handicapped being served 12/1/81	Children 3 to 6 years of age. Ninety percent of children must be from families which meet financial test, 10% must be children with handicaps	Special Education	Probably very few of these children, since Head Start does not generally involve severely involved children with handicaps
Rehabilitation Services	22,156 FY '81 Unduplicated count, 431 Arkansas Kidney Commission	Eligibility requirements for Rehabilitation Services are: 1. a disabling condition must exist; 2. It must be demonstrated that this condition imposes a substantial handicap to employment; and 3. there must be a reasonable expectation that an individual can benefit in terms of employability after the provision of Rehabilitation Services	SSI; Medicaid; DDS; Mental Health; Youth Services; Spinal Cord; Special Education	Some individuals who are receiving Rehabilitation Services may very well be appropriately identified as developmentally disabled
Long Term Care	5,004 Unduplicated count far FY '81 because of blindness or disability	Eligibility is determined by physician's diagnosis and determination that services are required	SSI; Office on Aging; Medicaid; Medicare; Rehabilitation; DDS; Mental Health	Those individuals whose conditions are severe and whose condition was manifested prior to age 22
Office on Aging	49,623 Unduplicated count FY '81 for Social Services 38,814 Unduplicated count FY '81 for meals	All individuals 60 years of age or older are eligible for services. In regions V and VI, individuals 55 years of age and older are eligible for services. disabled/handicapped individuals of any age in Region V	SSI; Medicaid; Mental Health; Medicare; Rehabilitation; Long Term Care	Most individuals diagnosed as disabled/handicapped whose condition was manifested prior to age 22

Special Education Statistics: Counting the Developmentally Disabled Population. The method used for extracting the developmentally disabled population from the Special Education population is described in detail in this report.

The number and percent of individuals who are in programs designed to serve the adult population which is handicapped and/or disabled throughout the State of Arkansas is the subject of Report Number 4 of the Arkansas Series. Report Number 4 is entitled- he World of Services to Adults Who Are Handicapped in the State of Arkansas. This report contains a detailed description of the method used to identify the developmentally disabled population within each of the programs which provide services to individuals who are handicapped. The report also contains the number and percent of adults who can appropriately be identified as developmentally disabled using the definition of developmental disabilities contained in PL 95-602.

INDIVIDUALIZED PLANS

Service programs for individuals who are handicapped and disabled have alternated between institutionalization and integration into the community throughout the last century and one-half. There were times before the turn of the century that program implementors wanted to 'mainstream' the disabled into society, followed by periods when it was felt that mainstreaming was an overly idealistic and unrealistic goal. Therefore, at the turn of the century, institutionalization was the practice rather than the exception.

The White House Conference on Children and Youth in 1930 was the culmination of a quarter century of great professional productivity and enthusiasm in the field of mental retardation. The momentum generated by the 1930 conference was blunted by the ensuing depression, which was followed by the Second World War. However, during these troubled times the amendments to the Social Security Act of 1935 contained federal grants in aid to states for Maternal and Child Health and Welfare and services to Crippled Children.

The National Mental Health Act of 1946 brought about some support for the mentally retarded. This act was followed by the establishment of the National Institute of Neurological Disease and Blindness in 1950. The Institute supported research in epilepsy and cerebral palsy.

Higher education became involved in training professionals for work with the mentally retarded in the 1950's. One of the most famous of the early efforts was in Nashville, Tennessee at the George Peabody College for Teachers. Here, a doctoral curriculum in psychology was established which emphasized mental retardation.

Projects for the mentally retarded and other handicapped persons were funded out of the Children's Bureau during the last half of the 1950's. In 1955, this bureau funded seven such projects with a total of \$121,064. By 1960, the bureau had increased the number of projects to 49 and the amount of money to \$1.1 million.

The great leap forward for services to the mentally retarded and ultimately the developmentally disabled came in 1961 when President Kennedy appointed the 27 member "President's Panel on Mental Retardation."

Public Law 88-164 was the first law which established a categorical program for individuals with mental retardation. The law, Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, mandated the building of research centers, established University Affiliated Facilities, and encouraged states to build community facilities for the mentally retarded.

Today, there are many programs which provide services to the handicapped and the disabled. There are a variety of Public and State Laws which identify certain individuals as disabled and who are **therefore** eligible for specific services. The following definitions are provided as illustrations of the variety of definitions of disability which exist at the present time. The definition of disability used by the Arkansas Governor's Developmental Disabilities Planning Council is:

- "A developmental disability is a severe, chronic disability of a person which
- (A) is attributable to a mental or physical **impairment, or** combination of mental and physical impairments;
 - (B) is manifested before the person attains age twenty-two;
 - (C) is likely to continue indefinitely;
 - (D) results in substantial functional limitations in three or more of the following areas of major life activity:
 - (i) self-care,
 - (ii) receptive and expressive language,
 - (iii) learning,
 - (iv) mobility,
 - (v) self-direction,
 - (vi) capacity for independent living, and
 - (vii) economic self-sufficiency; and
 - (E) reflects the person's need for a combination and sequence of special, **interdisciplinary**, or generic care, treatment, or other services which are individually planned and coordinated."⁵⁷

The eligibility for services used by Developmental Disabilities Services in the State of Arkansas is:

"Criteria. Eligibility for services is restricted to persons who have been diagnosed as being developmentally disabled under the legal definition of Act 513, exhibit impairment in adaptive behavior to such an extent that the ability to function with peers is substantially limited, and who require services available from Developmental Disabilities Services or its licensed affiliates. A developmental disability is established by the following evidence during the developmental years **and/or** prior to the chronological age of 18 years:

a. Mental Retardation - scores of intelligence which fall two or more standard deviations below the mean of a standardized test of intelligence administered by a licensed psychological examiner; **Infants/Preschool** - developmental scales, administered by personnel authorized in the manual accompanying the instrument used, which indicate impairment of general functioning similar to that of developmentally disabled persons;

b. Cerebral Palsy - the results of a medical examination provided by a licensed physician;

c. Epilepsy - the results of a neurological examination provided by a licensed neurologist and/or licensed physician;

d. Autism - the results of a team evaluation by at least a licensed physician and a licensed psychological examiner."⁵⁸

The definition of disability used to determine individuals eligible for Supplemental Security Income (SSI) is as follows:

"The law defines disability as the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. To meet this definition, you (the recipient of the benefits) must have a severe impairment which makes you unable to do your previous work or any other substantial gainful activity which exists in the national economy. To determine whether you are able to do any other work, we (the federal government) consider your residual functional capacity and your age, education and work experience. We will use this definition of disability if you are applying for a period of disability, or disability insurance benefits as a disabled worker, or child insurance benefits on disability before age 22."⁵⁹

The definition of the chronically mentally ill used by Mental Health in the State of Arkansas is:

An individual with a long term mental illness refers to a person, 18 and over who:

(a) Is severely impaired in at least two of the three following areas of behavioral functioning:

- (1) Social Role: The ability to function independently in the role of worker, student, or homemaker;
- (2) Daily living skills: The ability to engage independently in personal care (grooming, personal hygiene, etc.), and community living activities (handling personal finances, using community services, performing household chores, etc.) at an age-appropriate level;
- (3) Social acceptability; the ability to exhibit appropriate social behavior, the absence of which would result in the demand for intervention by the mental health and judicial system;

(b) Has experienced this impaired behavioral functioning for one year or longer, or, if less than one year, carries a diagnosis of a mental illness that is likely to result in seriously impaired behavioral Functioning for one year or longer.

The definition of disability used to determine if a person is eligible for Special Education services in the State of Arkansas is:

"A child is determined eligible when the child has been evaluated in accordance with state and federal regulations and has been determined to be mentally retarded, hearing impaired, speech/language handicapped, visually handicapped, seriously emotionally disturbed, orthopedically handicapped, other health impaired, deaf-blind, severely/profoundly handicapped, or to have specific learning disabilities, and who, because of those impairments and the adverse effect on his/her educational performance is determined eligible for special education and related services."⁶⁰

The definition of disabled/handicapped used for programs which receive funds from Title XX in the State of Arkansas is as follows:

"Any individual who has a physical or mental condition which substantially limits one or more of such person's major life activities, has a record of such an impairment, or is regarded as having such impairment (includes alcohol and drug dependence). For the Adult Handicapped Center at Benton, those mentally retarded, recovering mentally ill, physically impaired, and alcoholic (with secondary disability of one or more of the above disabilities) individuals, ages 16 or above, who have never entered the competitive job market, or having entered, were not able to compete because of a lack of basic skills necessary to survive in a vocational setting." 61

The definition of disability used by Rehabilitation Services for individuals referred for rehabilitation from the Supplemental Security Income Program is as follows:

"In order for a handicapped citizen to receive VR services under this program the following requirements must be met: (1) Proof that the handicapped person does receive Social Security Insurance, (2) Must certify that the person does have a severe handicapping condition that will not improve unless VR services are provided and that the provision of services will enable that disabled person to return to work in the competitive labor market at minimum wage or above." 62

It is easy to see from the examples presented that the definitions for disability vary from program to program throughout the State of Arkansas. It is again appropriate to note that each local community developmental program and sheltered workshop establishes its own eligible criteria for individuals whom it will serve, therefore further proliferating the definitions of disability within the State.

Regardless of the definition of disability which is used by a program, it has been demonstrated that there is some relationship between the various populations of disabled served in the various programs. It has been established that these individuals with a disability can, in fact, be identified either by the cause of the disability or the limitations in functional ability in major life activities. Identification and relationship between populations are discussed in sections 2 and 3 of this report.

Since the individuals who are eligible for services in the various programs have been identified, the question now becomes, what is going to happen to the individual? How are effective and productive services going to be provided to the individual?

It was late in the last decade, in 1968, that a new approach to providing services to the disabled was being formulated. The federal government, in an effort to insure quality services and facilitate coordination among programs providing services to the disabled, included in pertinent legislation requirements for Individualized Plans, defined as:

"...a written tool to organize and coordinate the goal-oriented care of each individual with a handicapping condition. It is based on the interdisciplinary or multidisciplinary evaluation of the individual's specific medical, education, developmental, social and rehabilitative needs."⁶³

Since this beginning in 1968, Individual Plans have become a requirement of most of the programs which provide services to individuals who are disabled. Most of the programs which provide services to individuals who are disabled in the State of Arkansas require an Individualized Plan to be prepared for each participant.

Most of the legislation which provided programs for individuals who are disabled which was passed in the 1970's included requirements for or encouraged the use of Individualized Plans for the benefit of individuals receiving services through the various programs. Examples of legislation which require Individual Plans are the Developmental Disabilities Act (PL 95-602), Rehabilitation Act (PL 93-516), Education For All Handicapped Children Act (PL 94-142), Social Services - Title XX of the Social Security Act (PL 93-647), and Medicaid - Title XIX of the Social Security Act (PL 89-97).

It was in 1974, with the passage of PL 94-103, that the developmental disabilities community became intimately involved with habilitation plans. Section 112 was added to the law in this year. This section of the law contains a mandate that:

"...each program which receives funds from the state's allotment under such part [Part C], (1) has in effect for each developmentally disabled person who receives services from or under the program a habilitation plan meeting the requirements of subsection (b); and (2) provides for an annual review, in accordance with subsection (c), of each such plan."⁶⁴

The Individualized Plans presently used in the State of Arkansas contain most of the components required in the Habilitation Plan as described in Section 112 of PL 95-602, the Developmental Disabilities Act. A copy of Section 112 of PL 95-602 is contained in Appendix 1 of this report. The Individual Program Plan (IPP) required of service providers under contract to the Division of Developmental Disabilities Services in the State of Arkansas contains all of the components required in the IHP described in PL 95-602. A copy of the requirements of the components to be included in the Individual Program Plan (IPP) required by Developmental Disabilities Services (DDS) is contained in Appendix 2 of this report.

Table 8 contains a comparison of the components in five of the Individualized Plans required of service providers or agencies or organizations which fund and/or license programs for individuals who are disabled in the State of Arkansas. The five programs for which the components in Individualized Plans are compared in Table 8 are: The Arkansas Governor's Developmental Disabilities Planning Council (DDPC), Developmental Disabilities Services (DDS), Rehabilitation Services, Special Education, and Supplementary Security Income (SSI).

There are a variety of Individualized Plans required. Most of the plans require the same or similar information. The plans are referred to by different names and are displayed in different formats. The following is a list of the names of the different Individualized Plans required for selected programs which provide services to individuals who are disabled in the State of Arkansas.

<u>Program</u>	<u>Name of Individualized Plan</u>
DDPC	Individual Habilitation Plan (IHP)
DDS	Individual Program Plan (IPP)
Special Education	Individual Education Plan (IEP)
Rehabilitation	Individual Written Rehabilitation Plan (IWRP)
SSI	Individual Plan (IP)

There is certainly a need which can be demonstrated for the State of Arkansas to seriously consider establishing a uniform Individualized Plan and planning process for individuals who are disabled. If it is agreed that Individualized Plans are the cornerstone to a quality case management system and if it is agreed that Individualized Plans assist program providers to provide quality services meeting the needs of each individual, then there must be a need to insure that services are uniformly provided by all service providers both during the same time period and across time.

A uniform Individualized Plan and planning process would assist each service provider to build on the programs and attainments of the former service providers and current service

TABLE 8. COMPARISON OF COMPONENTS REQUIRED IN INDIVIDUALIZED PLANS FUNDED BY AND/OR PROVIDED BY THE ARKANSAS GOVERNOR'S DEVELOPMENTAL DISABILITIES PLANNING COUNCIL (DDPC), DEVELOPMENTAL DISABILITIES SERVICES (DDS), REHABILITATION SERVICES, SPECIAL EDUCATION, AND SUPPLEMENTARY SECURITY INCOME (SSI) IN THE STATE OF ARKANSAS AS REQUIRED BY FEDERAL AND/OR STATE LAW OR REGULATIONS

Individualized Plan Components ¹	Service Providers				
	DDPC ²	DDS ³	Rehab ⁴	Special Ed	SSI ⁴
Goals	+	+	+	+	+
Objectives	+	+	+	+	+
Steps and Methods	+	+	+	+	+
Criteria for Evaluation	+	+		+	+
Persons Responsible	+	+		+	+
Qualifications of Program Implementors	+	+			
Frequency of Program	+	+		+	+
Data on Progress	+	+			
Start Date	+	+	+	+	+
Target Date	+	+		+	+
Completion Date	+	+	+	+	+
Review Date	+	+	+	+	+
Exit Plan				+	
Cost					+
Integration of Other Plans					+
Approval of Individual	+	+	+	+	
Approval of Parent (where appropriate)	+	+	+	+	
Least Restrictive Environment		+		+	
Assurance of Rights			+	+	

+ means Plan has (required) component

¹ A listing and explanation of each Plan component is contained in Appendix 3 of this report.

² Required under Section 112 of PL 95-602.

³ Developmental Disabilities Services requires an Individual Program Plan (IPP) for each participant in all programs which it operates and/or supervises.

⁴ Information collected by the Individualized Plan Coalition of the Utah Council for Handicapped and Developmentally Disabled Persons.

providers for each individual. A uniform Individualized Plan would greatly assist in guaranteeing the smooth transition between service providers. For example, a uniform Individualized Plan would assist in the transition between early intervention programs to preschool programs; from preschool programs to school programs: and from school programs to day and work p-ograms.

The developmentally disabled, by definition, are individuals who are substantially handicapped and are in "need of 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," according to the definition of developmental disabilities contained in PL 95-602.

There are many laws, as has been reviewed in this report, through which services are provided to the individuals who are developmentally disabled. Each of these services requires or encourages the development of an Individual Plan for the services provided under the specific law. However, none of the laws requires the integration of plans with other Individual Plans which affect the same developmentally disabled person. Therefore, individuals may have several different Individual Plans and there is no guarantee that the plans will not require contradictory procedures or will not require a person to be involved in developmental activity more than 100% of his or her time.

As has been already pointed out in this report, there are five laws which require an Individual Plan for each individual receiving services from programs funded by the law. The five programs are:

- Education For All Handicapped Children
- Rehabilitation
- Title XX
- Developmental Disabilities
- SSI

There are also other laws which encourage the development of Individual Plans, such as the Maternal and Child Health Law.

It would facilitate the developmental process for the individuals who are developmentally disabled in Arkansas if all agencies which are required to write Individualized Plans would use the same or a similar format for the development of the Individualized Plan. It would also aid the developmental process of the individual if each agency or program would use an Individualized Plan which contains the same or similar components since two or more plans may be written for the same person and comparison of developmental services is difficult if not impossible if the Individual Plans contain different components.

The uniform Individualized Plan would also assist the individuals who are developmentally disabled and the individual's

parents and guardians in participating in developing a service plan across time. The present situation requires that the individual and his or her parents or guardian are required to become familiar with and understand a new and different Individualized Plan each time the individual changes service providers. A uniform Individualized Plan would allow the individual and his or her parents or guardian to be familiar with the planning process and the Individualized Plan format from early intervention through adult day care and work training programs. The uniformity would greatly enhance the effectiveness of the participation of the individual and his or her parents or guardians in developing and responding to the service program.

Services to individuals who are developmentally disabled are usually age specific. If the Individualized Plan used in the developmental program for the preschool child differs from the Individualized Plan used in the school system there is a chance that the developmental plan used in the school system will not capitalize on the developmental program previously provided to the individual. Uniformity of the Individualized Plan would provide for coordination of programming between service providers across time.

There is a need, in the opinion of this author, to develop, field test, and attempt to implement a uniform Individual Plan format containing the same components and to be completed by individuals who are similarly trained throughout the service community which provides services to individuals who are developmentally disabled in the State of Arkansas.

FOOTNOTES

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APPENDIX

PUBLIC LAW 95-602

HABILITATION PLANS

SEC. 112.(a) The Secretary shall require as a condition to a State's receiving an allotment under part C that the State provide the Secretary satisfactory assurances that each program (including programs of any agency, facility, or project) which receives funds from the State's allotment under such part (1) has in effect for each developmentally disabled person who receives services from or under the program a habilitation plan meeting the requirements of subsection (b), and (2) provides for an annual review, in accordance with subsection (c), of each such plan.

(b) A habilitation plan for a person with developmental disabilities shall meet the following requirements:

(1) The plan shall be in writing.

(2) The plan shall be developed jointly by (A) a representative or representatives of the program primarily responsible for delivering or coordinating the delivery of services to the person for whom the plan is established, (B) such person, and (C) where appropriate, such person's parents or guardian or other representative.

(3) The plan shall contain a statement of the long-term habilitation goals for the person and the intermediate habilitation objectives relating to the attainments of such goals. Such objectives shall be stated specifically and in sequence and shall be expressed in behavioral or other terms that provide measurable indices of progress. The plan shall (A) describe how the objectives will be achieved and the barriers that might interfere with the achievement of them, (B) state objective criteria and an evaluation procedure and schedule for determining whether such objectives and goals are being achieved, and (C) provide for a program coordinator who will be responsible for the implementation of the plan.

(4) The plan shall contain a statement (in readily understandable form) of specific habilitation services to be provided, shall identify each agency which will deliver such services, shall describe the personnel (and their qualifications) necessary for the provision of such services, and shall specify the date of the initiation of each service to be provided and the anticipated duration of each such service.

(5) The plan shall specify the role and objectives of all parties to the implementation of the plan.

(c) Each habilitation plan shall be reviewed at least annually by the agency primarily responsible for the delivery of services to the person for whom the plan was established or responsible for the coordination of the delivery of services to such person. In the course of the review, such person and the person's parents or guardian or other representative shall be given an opportunity to review such plan and to participate in its revision.

APPENDIX 2

DEVELOPMENTAL DISABILITIES SERVICES
MINIMUM STANDARDS
FOR
INDIVIDUAL PROGRAM PLAN

Surveyor _____

Hating of 0 = No Compliance
 Rating of 1 = Partial Compliance
 Rating of 2 = Program is in Substantial
 Compliance with Standards
 N/A = Not Applicable
 * = Indicates Mandatory Item, 100%
 Compliance Required Within 30 Days

[illegible]

Programming - General (Cont'd)

6.
 - *e. With criteria for success;
 - *f. **Methods/Materials** for implementation;
 - *g. Which specifies each person responsible.
 - *7. Contains a summary of input from client, parent, and/or guardian **in development** of the plan;
 - *B. Describes the conditions that interfere with the achievement of the needed **goals/objectives**;
 - *9. Evidence indicates that coordination of the program plan exists when clients participate in an adult activity center, work activity center, sheltered workshop, day service center, infant stimulation program, and/or group living facility.
- Each client service record contains a descriptive report of client progress:
- *1. Progress reports written at least quarterly. (every 3 months), with formal update by entire team annually.
 - *2. Progress reports are written, dated and signed by staff responsible for implementation.
 - *3. Progress reports relate to goals/objectives on the IPP.
 4. Other pertinent **information**, if applicable.
- Progress notes document referral to program team for modification of **IPP**, as applicable.

[illegible]

APPENDIX 3

COMPONENTS OF AN IDEAL INDIVIDUAL SERVICE (HABILITATION) PLAN

1. Goals
2. Objectives
3. Steps and Methods
4. Criteria for Evaluation
5. Persons Responsible for Implementation
6. Qualifications of Program Implementors
7. Frequency of Program
8. Data on Progress
9. Starting Date
10. Target Date
11. Review Dates
12. Completion Date
13. Exit Plan
14. Integration of Other Plans
15. cost
16. Approval of the Individual
17. Approval of Parent or Guardian
18. Rights
19. Least Restrictive Environment

These nineteen components for an Individualized Plan are the result of a report compiled by The Individualized Plan Coalition of the Utah Council for Handicapped and Developmentally Disabled Persons and contained in the report entitled Recommendations to Upgrade the Potential for Utilization of Individualized Plans, Utah Council for Handicapped and Developmentally Disabled Persons, March, 1981.

DEFINITION **OF** THE IDEAL COMPONENTS
OF AN INDIVIDUAL SERVICE (HABILITATION) PLAN

1. Goals

The most basic component of an individualized plan is the goal statement. This provides clear direction of service outcomes for both the consumer of the service and the provider of the service.

2. Objectives

The objective statement sets forth in broad terms the means necessary to achieve stated goals. The objective statement breaks down the goal into specific areas for achievement.

3. Steps and Methods

The steps and methods of the plan describe how the objectives will be achieved. The steps and methods may be presented by a time frame for task completion, speed of work, date of acquisition of specific skills, etc.

4. Criteria **for** Evaluation

Criteria for evaluation are to be written for both the objectives of the plan and the methods which are to be used in obtaining the objectives.

5. Persons Responsible for Implementation

Persons responsible for implementation of the steps and methods necessary for objective and goal achievement.

6. Qualifications of Program Implementors

Qualifications of the persons responsible for implementation of the plan should be listed by professional training, position and experience.

7. Frequency of Program

The frequency of programming is provided to ensure that the components of the program are offered which permit achievements of the program objectives and habilitaton goals.

8. Data on Progress

The type of data and frequency of reports on the developmental progress of the individual relates directly to the criteria for evaluation in obtaining objectives.

9. Starting Date

The date on which services will begin are part of the habilitation plan.

10. Target Date

The date which specifies when services will be completed, at which time the objectives will be obtained.

11. Review Dates

Review dates at which time the progress in training will be assessed to determine the appropriateness of programming methods and the reality of goals and objectives.

12. Completion Dates

Date at which the individual will be terminated from the program.

13. Exit Plan

The exit plan which describes the transition plan to the next appropriate services for the individual.

14. Integration of Other Plans

A listing of all activities in which the individual is involved from other programs to ensure coordination and compatibility of programming for the individual.

15. Cost

The cost of the service identified by component parts.

16. Approval of the Individual

The plan must be signed by the individual for whom the plan is written.

17. Approval of Parent or Guardian

In cases where the individual is either too young or too disabled to consent, the parent or guardian must sign the plan.

18. Rights

The rights of the individual to protest the provision of unwanted services or program methods must be described in the plan.

19. Least Restrictive Environment

A description of a systematic evaluation of the appropriateness of the placement of the individual in each agency and/or program ensuring the activity is provided in the least restrictive environment.