

A Study of the
Impact and Implications of
Expanding the Targeted Constituency
of the
Maryland Developmental Disabilities Council



The Maryland Developmental Disabilities Council
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A Project Undertaken for The Administration on Developmental Disabilities,
U.S. Department of Health & Human Services

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Results of a Project Undertaken for:
The Administration on Developmental Disabilities,
US. Department of Health & Human Services
as a
Developmental Disabilities Project of National Significance
by

The Maryland Developmental Disabilities Council

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A Study of the Impact and Implications of Expanding the Targeted Constituency of the Maryland Developmental Disabilities Council

Executive Summary

• Overview of the Study •

During the summer of 1994 the federal Administration on Developmental Disabilities, United States Department of Health and Human Services, requested proposals from state Developmental Disabilities Councils to study the impact and implications of expanding the current council constituency to include people with other severe disabilities. The examination of the implications of a potential expanded constituency would focus on issues of a council's effectiveness in broadening its mandated advocacy, capacity building, and systemic change activities. The Maryland Developmental Disabilities Council responded to the request for proposals and was selected to conduct such a study.

The report examines issues concerning potential expansion and collaboration in the context of the State of Maryland. The plan of the study led to extensive discussion within the disability community in Maryland; however, it did not require a final decision or action by the Maryland Developmental Disabilities Council regarding a change in its own constituency.

Central Questions of the Study

The Maryland Developmental Disabilities Council study focused on two central research questions. The study investigated the similarities and uniquenesses between people with developmental disabilities and others with severe disabilities. Second, it considered the impact and implications of expanding the Maryland Council constituency to a broader range of people while also maintaining the Council's existing commitment to children and adults with developmental disabilities and their families.

Methodology

The Council study utilized a variety of methods to identify the service and support needs of people in the current and potential expanded Council constituencies and to examine the impact and implications of expanding the Council. Individual interviews were conducted with over 30 representatives from "key stakeholder" advocacy and consumer organizations, service providers and state government organizations within the current and potential expanded constituencies. (See Appendix 3.) Further, individual interviews were conducted with over 200 people with

disabilities, representative of the potential expanded Council constituency. These individuals were located by contacting over 50 agencies that serve the potential expanded constituency, after providing them with information about the study. (See Appendix 4.)

The study also reflects comments from multiple focus and discussion groups, Council and advisory group discussions and participation, a poster session at a national conference for people with severe disabilities, and feedback from the circulation of draft reports. It utilized the findings of a panel of individuals experienced in analyzing and applying definitions of disability. Finally, it utilized newly developed and previously prepared analyses and reports. The study has been supported by an active Advisory Committee, including representatives of both the current and potential constituencies.

Supplemental Results of Study

The study generated considerable discussion within the disability community in Maryland. Much information was shared about the needs of people with different disabilities and the mechanisms for affecting systems change in various arenas. There was a great deal of discussion about the unique and similar political and economic incentives that can promote systems change within communities, as well as within the various government systems responsible for providing supports to people with different disabilities. The study helped to promote an increased understanding and awareness of areas of common needs and opportunities for potential collaboration. It also helped identify critical needs for support of people with developmental disabilities, that may not be the primary needs of people with other severe disabilities, that should not be abandoned or displaced.

• Findings of the Study •

Definitions

The study used the federal definition of developmental disability. This definition focuses on four criteria: the manifestation of disability before age 22 (during an individual's developmental period); the severe and chronic nature of the disability; the multiple ways in which the disability may result in substantial limitations; and the implications of the disability that require extended, individualized, and specialized services and supports. The study defined the potential expanded population to include individuals who met the above definition, without the requirement that the disability manifest itself before age 22.

General Findings

The study found that there were many considerations to be evaluated when attempting to merge the interests of all people with disabilities. There is no question that there is value in unity and that expansion of the Council would provide opportunity to advocate on behalf of a larger group of people in various arenas. However, there was a counterbalancing finding that there were, and continue to be, important reasons for emphasis originally placed upon advocacy for children and adults with developmental disabilities by the Developmental Disabilities Bill of Rights Act. Without additional resources, the study concluded that the Maryland Council could not maintain the commitment to addressing the unique needs of children and adults with developmental disabilities, while additionally expanding to thoroughly address the needs of an expanded constituency. However, the study identified ways in which extensive collaboration could maximize the impact of the Council's work on behalf of both people with developmental disabilities and other severe disabilities. It further identified mechanisms for joint action on behalf of all people with disabilities to promote unity and common advocacy.

Similarities and Differences in needs of the Current and Potential Expanded Constituencies

The study found that people with disabilities identify certain similarities in needs. They share difficulties in obtaining services and supports. They share modest hopes for typical living. They share needs in the general areas of housing, employment and transportation, and are generally impacted by the poverty that can accompany disability.

However, the study also found that there are differing specific needs based on disability. Families with young children with developmental disabilities face unique challenges in obtaining meaningful inclusion for their children. Obtaining this inclusion for children at a young age can help children to develop necessary social skills and community networks that may reduce the need for more extensive social supports later in life.

Further, the needs of adults with developmental disabilities, particularly mental retardation, are often unique. While broad domains such as housing, employment and transportation were identified as needs prevailing across disability groups, there were also significant variations in how different groups indicated they could utilize supports in these areas. Solutions and supports that may assist people with severe disabilities may be insufficient to support people with developmental disabilities.

The onset of disability during the developmental period plays a significant role in the future support needs of individuals, especially in major life activities of learning, socialization and communication. Without the opportunities to learn these skills as youngsters with other children without disabilities, many adults need significant assistance in these areas that are critical to successful inclusion as adults in all areas, including employment.

Self advocacy for people with developmental disabilities, particularly cognitive disabilities, raises other unique needs. While people with other severe disabilities are becoming increasingly accepted as self-advocates, people with developmental disabilities who may require assistance to present their opinions are still questioned regarding their "ability" to form and hold meaningful opinions. Self-advocates with mental retardation are often not consulted or included in policy making, with decisionmakers and legislators still selectively commenting that individuals with developmental disabilities are being "prompted" to promote a certain position, in a way that does not occur with individuals with other disabilities.

Finally, because the federal and state funding for provision of supports in Maryland is often separated for people with different disabilities, including developmental disabilities, the mechanisms for affecting change and barriers within each system are often different. Therefore, additional work and resources would be required in order to examine each system and to develop improved and cost effective services to all people with severe disabilities in Maryland.

Impact and Implications of Expansion

There was a general concern, both within the current and potential expanded constituencies, that expansion in Maryland would come at a cost. Given the finite and potentially diminishing resources of the Council, participants were concerned that the Council could not expand its membership to address the diverse systems and needs of an expanded constituency.

If the Maryland Council expanded, the stakeholders in the expanded constituency expected a shift in focus from people with developmental disabilities to include the individuals and the issues representative of the expanded population. The study examined a number of potential shifts that could occur. The study found that the Council could not continue its thorough examination of best practices in a full range of areas and provide demonstration projects to promote systems change for the full range of people in the expanded constituency, without additional resources.

However, there was genuine interest in expanding the impact of the work of the Maryland Council to promote systems change for all people with disabilities. Even if the Council expanded under the proposed definition, there was concern that it would still not include all people with disabilities and that additional work would still be required to obtain the benefits of unity. Towards this end, the study identified numerous opportunities for collaboration. By collaborating, the benefits of unity could be strengthened, the existing commitments and focus could be maintained, and by joining Council forces with the knowledge and resources of other groups, the impact of the Council's efforts could be expanded.

• Opportunities for Collaboration •

The study identified numerous areas of existing and potential expanded collaboration. Staff from other states that have expanded their constituencies in some form were also consulted. The study examined a number of areas in which Maryland's collaboration has been successful and benefited a broader group of individuals with disabilities.

With those areas in mind, the advisory committee identified a number of possible activities which are detailed in the report. A few of these areas include:

- Council-sponsored demonstration and systems change projects could disseminate results to all disability groups, not only within the developmental disabilities community.
- A specific Council committee could be established to regularly examine opportunities for broader collaboration and to foster such initiatives; a representative of the committee could work with specific Council projects to identify these opportunities and foster their implementation.
- Representatives of the broader disability community could be recruited to provide expertise in specific areas identified by the Council or ad hoc committees.
- Advisory groups established as part of specific projects could include individuals or representatives of people with other severe disabilities who would share interest in project accomplishments and outcomes and could apply the lessons learned to other constituencies support systems. Groups that have not traditionally applied to undertake Council grant projects could be encouraged to apply and be offered technical assistance.
- The Council could continue to expand its family support task force to bring together a wider array of family perspectives with respect to cultural differences, evolving care giving roles, and life span needs.
- The Council could work with board members of community nonprofit service providers to use their community contacts to increase support for people with developmental disabilities.
- The Council could increase its collaboration with other disability groups on issues of mutual interest in legislative activities at all levels and could expand its work with existing broad-based coalitions to advance mutual goals and issues.

- Future Action •

In the final analysis, the study emphasized commitment by the Maryland Council to its continued success in effectively expanding knowledge and promoting effective best practices to increase inclusion of people with developmental disabilities in communities. While there is a desire for Councils to benefit a broader group, the study pointed out that diverse systems and specific needs cannot be adequately addressed without additional resources, without sacrificing some of the needs of the original constituency of the Council. Since additional resources do not appear to be forthcoming at this time, a continuation and expansion of collaborative and creative projects with existing disability groups in Maryland can help promote effective systems change on behalf of all people with disabilities.

A Study of the Impact and Implications of Expanding the Targeted Constituency of the Maryland Developmental Disabilities Council

• Overview of the Study •

During the summer of 1994 the federal Administration on Developmental Disabilities, United States Department of Health and Human Services, requested proposals from state Developmental Disabilities Councils to study the impact and implications of expanding the current council constituency to include people with other severe disabilities. The examination of the implications of a potential expanded constituency would focus on issues of a council's effectiveness in broadening its mandated advocacy, capacity building, and systemic change activities. The Maryland Developmental Disabilities Council responded to the request for proposals and was selected to conduct such a study.

This final report of the Council's 15-month study is being provided to the Administration on Developmental Disabilities for its consideration and for Congressional review during the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act in 1996. The report examines issues concerning potential expansion in the context of the State of Maryland. It identifies issues that may be helpful to other states as they consider the issue, but does not undertake to make a recommendation for Maryland or other councils in this regard. The plan of the study led to extensive discussion within the disability community in Maryland; however, it did not involve or require a final decision or action by the Maryland Developmental Disabilities Council regarding a change in its own constituency.

Central Questions of the Study

The Maryland Developmental Disabilities Council study focused on two central research questions. The study investigated the similarities and uniquenesses between people with developmental disabilities and others with severe disabilities. Second, it considered the impact and implications of expanding the Maryland Council constituency to a broader range of people while also maintaining the Council's existing commitment to children and adults with developmental disabilities and their families. The Council study utilized a variety of methods to identify the service and support needs of people in the current and potential expanded Council constituencies in order to examine expectations for the

Council in existing and possible new roles. Currently, the Maryland Developmental Disabilities Council works to advance public policy, supportive practices, and opportunities that promote the following outcomes:

- Children with developmental disabilities will have the opportunity to be educated in the same schools as their siblings and neighbors with the supports they need to be effectively educated. They will grow up side-by-side with children their ages who do not have disabilities, preparing everyone to share the adult world.
- All children will be raised in families. The importance of families will be recognized through support that respects each family's decisions about its own needs.
- Adults with developmental disabilities will have homes, jobs, and social lives in the mainstream of their communities with the supports they need to participate fully and safely. Ties with family and friends will be encouraged and supported.
- People with developmental disabilities will have meaningful choices over important matters in their lives. When people rely on assistance and support from the service system, their privacy, security, and personal plans will be recognized as rights and honored.

The study examines issues related to Council effectiveness if its activities were extended to an expanded constituency, to additionally include adults with disabilities that are expected to continue indefinitely and result in substantial limitations in a number of major life activities, but whose disability is manifested after age 22. (See Appendix 1 for the Council's definition of the current constituency of people with developmental disabilities and Appendix 2 for the study's working definition of a potential expanded constituency.)

In keeping with questions identified by the Administration on Developmental Disabilities, these specific areas were addressed in the study:

- **The service and support needs of people with developmental disabilities (current Council constituency)** with attention to children and adults who are presently unserved or underserved
- **The service and support needs of people with severe disabilities manifested after the developmental period (the potential expanded Council constituency)**

- **Issues of similarity and uniqueness between the current and potential expanded Council constituency** with respect to service and support needs, cultural diversity, and the effects of poverty
- **Implications of expanding the Council's constituency**, with consideration of related challenges and critical issues involving the Council's focus and effectiveness and the impact on Council membership, operations, staffing and other resources
- **Systemic and organizational strategies, collaborative relationships, linkages and activities necessary to effect positive change** on behalf of people in the potential expanded constituency, the developmental disabilities network, and other stakeholders.

Methodology

Information for the study was obtained from a number of sources. Interviews were conducted with representatives from "key stakeholders" concerning the current and potential Council constituencies. These stakeholders represented advocacy and consumer organizations, service providers and state government agencies. Of these stakeholders, fourteen of the respondents worked in agencies or organizations representing individuals in the current constituency, twelve worked in agencies or organizations representing individuals in the potential expanded constituency, and five worked in agencies or organizations representing individuals in both constituencies. (See Appendix 3.)

Further, individual interviews were conducted with more than 200 people, representative of the potential expanded Council constituency. These individuals were located by contacting agencies that serve the potential expanded constituency, after providing them with information about the study. (See Appendix 4.)

The study also reflects comments from discussion groups, a session at a national conference for people with severe disabilities, and feedback from the circulation of draft reports. It relied on the findings of a panel of individuals experienced in analyzing definitions of disability. It utilized focus groups and discussions, extensive Council participation, as well as newly developed and previously prepared analyses and reports, particularly relating to the needs and unmet needs of the current constituency. The study has been supported by an active Advisory Committee including representatives of current and potential constituencies.

The report presents a qualitative, rather than a quantitative, analysis of the factors influencing a decision to expand. Many survey questions were open ended, designed to facilitate an examination of issues in conjunction with other responses, rather than measure only simple numerical rankings of a need or opinion. The study has prompted extensive discussion within the developmental disabilities network and broader disability community in Maryland. An important by-product of this effort has been increased communication and collaboration among people with all disabilities, their families, and the organizations involved with them in Maryland.

• **Current Maryland. Developmental Disabilities Council** •

mandate and Activities

The Maryland Developmental Disabilities Council was established by Maryland Executive Order in 1971 following the original enactment of the federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act), 42 U.S.C. §6000, et seq. All of the Council's mandated activities are outlined in the Act and fall within broad categories of advocacy, systems change, and building the capacity of communities to support people with developmental disabilities and their families. (See Appendix 5.)

Federal Criteria for Defining Developmental Disabilities

The DD Act contains a definition of developmental disability which the Council uses in targeting its activities and which has been used in this study. (See Appendix 1.) This definition focuses on:

- the manifestation of disability during an individual's developmental period (from birth through age 22)
- the severe and chronic nature of the disability
- the multiple ways in which the disability may result in substantial limitations to functioning, and
- the implications of the disability that required extended, individualized, and specialized services, supports, or other assistance.

The term "developmental disability" also applies to infants and children from birth through age five who have a substantial developmental delay or specific congenital or acquired conditions with a high probability of developmental disability if services are not provided, without requiring that they specifically meet the other definitional criteria. This is designed to encourage the provision of early intervention services to limit the impact of the potentially disabling condition.

Although certain types of disabilities have often been recognized as developmental disabilities, the DD Act no longer identifies specific disability types. It is evident that Congress envisioned applying the law to people not because of a certain diagnosis, but because of the resulting impact of a severe and chronic disability on their individual needs for services and supports.

It is important to note that not all disabilities that occur before age 22 result in the multiple functional limitations that meet the definition of a developmental disability. The definition of developmental disability contains a number of interrelated factors, all of which must be present in order to recognize an impairment as a developmental disability. As defined by the federal law, developmental disabilities are generally associated with the need for specialized lifelong services and supports.

Responsibilities

Council organizational responsibilities are specified in the DD Act. The Maryland Council is funded solely through an annual federal grant appropriated by Congress for councils in all of the states and territories. A grant is allotted to each state or territory based on a formula that accounts for factors such as population and poverty areas. To qualify for funds, the Council must establish its priorities with public input in a published State Plan. The Plan takes into account the services and supports available in the state, the unmet needs of individuals with developmental disabilities, and the key issues and priorities in the individuals' lives. Councils must also submit an annual performance report to the Administration on Developmental Disabilities, U.S. Department of Health and Human Services, and must maintain Council membership with the specific representation required by the DD Act. Federal regulations govern the Council's fiscal accounting responsibilities.

Membership Requirements

Under the DD Act, at least 50% of the Council's members must be people with a developmental disability or the immediate relatives or guardians of individuals with a developmental disability. Other required members include representatives of specified state government agencies, local community organizations, higher education, and other organizations in the state also created by the DD Act. The Act requires the governor to appoint the Council's members to carry out the Act's mandates. Currently there are 34 members of the Maryland Council, who typically serve a 5-year term. (See Appendix 6 for a list of current Council members.)

Operations

Although situated within state government, the Maryland Council is an independent, self-governing organization that determines and directs its own activities and staffing support using its federally allotted resources. The Council is required to establish an annual budget, with a minimum of 65% of its funds directed to activities involving systemic change, advocacy, and capacity building concerning people with developmental disabilities and their families in priority areas indicated in the State Plan. The Maryland Developmental Disabilities Council received approximately \$975,000 in fiscal year 1995.

Basis for Focus on Children and Adults with Developmental Disabilities

People who experience a severe and chronic physical and/or mental disability with onset in infancy, childhood, adolescence, or early adulthood ~ the "developmental period" ~ confront unique social, physical, and emotional consequences. These consequences are often the result of exclusion from typical childhood experiences due to social stigma and lack of physical access. By being isolated as children, many people with developmental disabilities may not acquire necessary language and communication abilities, everyday knowledge and skills, and other developmental experiences. Even with their best efforts, families are extremely challenged in raising a child with a developmental disability. A developmental disability is a lifelong severe disability that often blocks the *acquisition* of the complete childhood foundation needed for full access to opportunities later in life. Competent assistance and support can help reduce these consequences, and a lack of knowledge and inappropriate intervention can increase their severity.

Children with developmental disabilities are more isolated than other children, even with significant attempts at inclusion. These children generally do not have the opportunity to interact with other children on an equal basis and often spend more time with adults--

parents, teachers, caretakers, social workers, or therapists. Many adults with developmental disabilities were institutionalized as children and lacked virtually all meaningful interaction with children without disabilities.

Adults who experience a disability later in life or whose disabilities did not present significant functional limitations as children had at least 22 years during which they related to peers as friends, neighbors, and playmates. The same is true of adults whose disability occurred in childhood but did not result in multiple functional limitations that often lead to exclusion.

Congressional Findings Supporting the Focus on People with Developmental Disabilities

The DD Act was the first legislation to reflect specific Congressional policy values regarding children and adults with developmental disabilities and their families. These policy values recognize the unique capacities and contributions of people with developmental disabilities. They further serve as guides for changing from the historic proliferation of ineffective and inappropriate institutions and services that devalue children and adults with developmental disabilities. While certain broad principles of the DD Act apply to situations involving a wide range of people with severe and chronic disabilities, the Act makes findings and recognizes the unique consequences of the onset of such disabilities in childhood:

- "Individuals whose disabilities occur during their developmental period frequently have severe disabilities that are likely to continue indefinitely."
- "Individuals with developmental disabilities often require lifelong specialized services and assistance, provided in a coordinated and culturally competent manner by many agencies, professionals, advocates, community representatives and others."
- "A substantial portion of individuals with developmental disabilities and their families do not have access to appropriate support and services from generic and specialized service systems and remain unserved or underserved."
- The Act stresses the importance of a focus on early intervention services, child development services, education, transitional services, and preparation for participation in typical life activities.

- The Act places a priority value on supporting families to "strengthen the family's role as primary caregiver," "prevent inappropriate out-of-home placement and maintain family unity," and "reunite families with members who have been placed out of the home, whenever possible."
- The Act states the policy that "individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of achieving independence, productivity, and integration and inclusion into the community, and often require the provision of services, supports and other assistance to achieve independence, productivity, integration and inclusion."

Federal Emphasis on Lifelong Continuum of Supports

The Administration on Developmental Disabilities has federal responsibility for Developmental Disabilities Councils. The Administration is located within the Department of Health and Human Services Administration for Children and Families. This placement indicates that the federal view of advocacy and planning for people with developmental disabilities represents a continuum of services that begin in childhood and continues indefinitely. Responsibility for overseeing councils was placed with agencies responsible for preventing child abuse and neglect, addressing childhood poverty and economic disadvantage, and providing support to families raising children. Additionally, the federal government apparently recognized the necessity of early intervention with children with developmental disabilities by placing the responsibility for council oversight in the Administration for Children and Families.

The DD Act also mandates the responsibilities of two other "sister" agencies to the Developmental Disabilities Councils in each state. The University Affiliated Programs are interdisciplinary programs, operated or associated with colleges or universities, responsible for providing a leadership role in the promotion of independence, productivity, and integration and inclusion of individuals with developmental disabilities. The Protection and Advocacy systems are responsible for pursuing legal, administrative and other appropriate approaches to ensure the protection of, and advocacy for, the rights of people with developmental disabilities. It is interesting to note that the Protection and Advocacy Systems have been mandated to expand their services to protect and advocate for individuals with mental illness, as well as those with other disabilities. While their responsibilities and authorities expanded, so too have their funds, staff and resources. Without reducing or sacrificing their previous work on behalf of people with developmental disabilities, the Protection and Advocacy Systems can now address the needs of additional constituencies. It is equally important to recognize that the intent of

the DD Act was not altered in expanding this authority. Separate Acts govern these additional activities, and separate federal agencies have oversight responsibilities for the expanded responsibilities and constituencies. The focus of these other federal agencies differs from that of the Administration for Children and Families, often requiring a shorter duration of intervention or focusing less on lifelong and family supports.

• Current Council Constituency Characteristics • and Unmet Needs

As discussed in the "Methodology" section, information describing the characteristics and needs of the current constituency is based on interviews with stakeholders (advocacy, provider, and government organizations), focus groups, the Maryland Council's "1990 Report" (which utilized responses from extensive consumer interviews), information documented by the Council in the development of its state plans, and other research. This included state budget presentations, reports on services and unmet needs, and federal studies of the allocation of resources for people with developmental disabilities. Because of the extensive prior research and experience of the Council in studying the needs and characteristics of people with developmental disabilities, particularly its 1990 Report, this study did not conduct interviews with consumers as it did with the potential constituents. The Council also examines all aspects of the current constituency annually in preparing reports and strategic plans, and has significant consumer representation in its membership. A direct survey of the current constituency might have allowed for direct comparisons of the quantitative responses provided through interviews with the potential constituents. However the study was designed and is well supported by a qualitative, rather than quantitative, analysis.

Definition of need

Many dimensions are involved in assessing need, such as individuals' circumstances and preferences; existing support that may or may not be adequate; expertise necessary to provide appropriate support; availability and flexibility of funding; availability of experience, expertise, and resources; and immediacy of need. To understand service and support needs, these multiple factors must be examined as a whole.

Need is commonly assessed in terms of broad service domains. For example, the developmental disabilities service system in Maryland provides services based on needs in areas such as a person's living arrangement, employment, other daytime activity, and case management. Other service domains include education, transportation, housing

assistance, mental health services, medical care, and a host of other individual and family support categories. Actual assistance may be provided through the specialized developmental disabilities service system, through other service systems for people with disabilities, and through services for the general population.

Another way of examining need focuses more directly on the nature of supports needed, based on a person's abilities and individual characteristics. Reflecting this approach, the federal and state definitions of developmental disability refer to the duration and type of supports needed that result from the onset of disability during the developmental period (before age 22) and the chronic and severe nature of the disability.

These definitions are related. The federal DD Act definition of developmental disability refers to multiple limitations in significant life functions that "reflect the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated."

The Maryland statutory definition of developmental disability determines eligibility for services from Maryland's developmental disabilities services agency. It is similar to the federal definition in referring to a disability that "results in an inability to live independently without external support or continuing and regular assistance; and reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are individually planned and coordinated for the individual." However, it differs from the federal definition by excluding individuals with a sole diagnosis of mental illness, regardless of the age of onset. While the state definition and accompanying services and supports are of keen interest to the Council, the federal definition of developmental disability, rather than this state definition, applies to the Council's efforts and constituency since the Council is governed by federal law.

Service and Support Barriers: Crisis Mentality and the Resulting Haves and Have- Nots

A significant investment of public funds has been provided to meet the service and support needs of people with developmental disabilities and their families. However, even with this investment, thousands of people wait for services. The current allocation of resources within the state developmental disabilities system has been criticized by a number of individuals with disabilities and their families, by advocacy organizations, and by members of the state legislature. The service system creates dramatic situations of "haves" and "have-nots" in which extremely costly institutional services are provided to some individuals while many people with similar severe disabilities and intensive needs

receive little or no services. Long waiting lists reflect extensive unmet needs for supported employment services and vocational training as well as for supported community living arrangements and individual and family supports.

Providing comprehensive support to people with severe developmental disabilities through community living alternatives has become less costly than institutional services in Maryland. Yet a large institutional facility budget for people with mental retardation continues to be maintained, with per person costs continuing to increase as the institutional population declines. Meanwhile the service system devotes minute resources to supporting families in caring for a family member with a severe developmental disability at home. As a result, people receiving little or no support often experience crises that place high demand on a service system unprepared to respond effectively.

It is generally recognized that there will never be sufficient public funding to administer and maintain dual institutional and community services and also to develop services to respond to current and future unmet needs. Efforts have been made to address this problem by utilizing federal financing waiver opportunities that allow shifting of funds from institutional services (Intermediate Care Facilities for the Mentally Retarded) to community services in order to develop a more effective and equitable community long-term support system. This is an extremely wide-ranging "work in progress" that will require new provider reimbursement practices, regulatory reform, and the continuous collaboration of government, providers, advocacy groups, families, and consumers to maintain and enhance service quality.

Serving People with Complex and Multiple Disabilities

Inadequate supports for current constituents with complex and multiple disabilities was the most consistent theme identified by the study. Individuals within this diverse group are the group most often turned away by service providers. The service system does not offer consistent incentives and support for community providers who endeavor to serve people with the most challenging disabilities. Therefore, instead of attempting to meet intensive needs with potentially inadequate resources and expertise, many providers have applied risk management practices that make their services inaccessible to people with the most severe disabilities.

People who are underserved include those with cognitive disabilities who also have complicated behavioral and emotional involvements, or individuals who also have intensive medical and health care needs. Traditional mental health services have been unable to respond to the behavioral support needs of people with cognitive disabilities,

and the specialized behavioral services they need are often unavailable. The supports needed by people with cognitive disabilities are difficult to integrate with home-based health care and the corresponding requirements of the medical and nursing professions. Complications often arise in designing effective behavioral supports when an individual has difficulty communicating or does not communicate at all through speech and language.

Major shortages of community-based long-term support exist for particular groups of people with developmental disabilities in Maryland. These include people with head and traumatic brain injuries that occur during the developmental period, children with mental illness, elderly people with mental retardation residing in nursing facilities, and people with dual disabilities of mental retardation and mental illness. Litigation is ongoing on behalf of each of these groups to require the system to provide appropriate services. Clearly, strong advocacy is necessary to increase appropriate services and supports to these people with developmental disabilities.

It is important to recognize that it is much more difficult for individuals with dual or multiple disabilities including mental retardation to obtain appropriate services than it is for people with a single disability. Children and adults with a psychiatric diagnosis confined to state psychiatric hospitals but ready for discharge wait for community services and are the subject of litigation. However, discharge for people with a psychiatric diagnosis and mental retardation from these facilities takes much longer than for others with a sole diagnosis, often several years. The systems designed to support people with mental illness have not traditionally accepted people with cognitive limitations. Different advocacy is necessary to create the capacity for these supports and the developmentally appropriate approaches that will meet these needs. However, without strong advocacy by organizations focused on people with developmental disabilities, these issues are often overlooked in the attempt to resolve needs for the majority of the people with disabilities in the affected class.

Supports and Safeguards: Facilitation, Mentoring, and Guidance

For most people with developmental disabilities, which are lifelong, there is a need for positive interaction, involvement, and the presence of others to enable a person to take care of his or her needs and responsibilities. Support in the form of facilitation may be needed to compensate for limitations in a person's abilities that often result from a lack of experience due to isolation and exclusion from typical education and developmental experiences.

People with severe cognitive disabilities often have unique support needs as a result of how they receive, process, and express information. A facilitator is often needed to explain or review information or options, or otherwise assist a person in decision making. Because of their isolation as children, people with developmental disabilities that are not cognitive disabilities may also need mentoring and guidance to interact effectively in employment, advocacy, and other activities.

Supporting people with developmental disabilities to exercise choices and decisions necessary in managing practical life matters often requires a careful balance of leading and guiding, mentoring and counseling. Individuals with cognitive impairments often have limited ability to read, write, and comprehend complex materials; do arithmetic and manage money; and interpret and follow directions. Helping individuals attain control in their lives without exerting control over the person is a complex process requiring skill and insight.

People with cognitive disabilities at times need personal support in order to take part successfully in social, employment, and other interpersonal situations. Individuals may need ongoing guidance to develop acceptable social behavior and social awareness. Friends, co-workers, and other acquaintances may be identified as natural supports to mentor a person in need of support in interpersonal relationships, with the recognition that direct professional intervention in relationships is inherently unnatural.

Supporting people with developmental disabilities may raise complicated legal, ethical, and humanitarian issues because of the potential vulnerability of some of the people involved. Providing for the safety of children and adults with complex and multiple disabilities often involves extensive care and monitoring. At times, an individual's rights of privacy, autonomy, or freedom of expression and movement must be balanced against the rights of others and safety issues. Those responsible for designing and evaluating supports for a vulnerable person must carefully examine these issues on a continuous, individualized basis. Certain matters are governed by the state's guardianship and medical consent laws; others are influenced by state licensing and certification requirements. These assessments often are legally required to rest on judgements and expertise of the professionals and on the accepted standards and practices of each particular discipline.

Communication Needs

The service system for people with developmental disabilities faces extreme challenges in responding to people who use unconventional forms of communication. Communication is the means by which people affect the conditions of their existence. Many adults with developmental disabilities have not practiced communication skills as a result of isolation and frequent institutionalization as children. Even with assistive communication technology, adults may not have developed the language foundation as children to readily use this support. Communication technologies often are not provided to people with significant developmental disabilities because professionals believe they will have minimal value, based on the lack of trained people who supervise and monitor their use with this group. Failure to find alternative forms of communication for people without typical speech and language often results in a lack of understanding of their needs and choices and in misdirection of their services.

Communication development begins at birth, and yet specific intervention efforts aimed at enhancing communication and language development rarely begin until much later, when typical children already use sophisticated language. Children with developmental delays have historically been denied speech-language pathology services on the theory that they would not benefit because of lower cognitive levels. Full inclusion of children with limited language skills in preschool and school settings with their peers without disabilities is a way of recognizing that exposure to peer models with typical speech and language development is critical, regardless of whether specific speech-language services are provided.

Support Needs of Families and Children

Because developmental disabilities occur from birth through childhood and youth, the needs of families must be examined in defining the unmet needs of the current Council constituency. Families generally indicate strong desires and commitment to raise their children with disabilities at home. The majority of children with developmental disabilities are raised at home by their families with very limited or no outside support. This effort can place enormous economic, physical, and emotional stress upon parents and siblings. Those families who have sought residential placement often state that they had no alternative because of the absence of support at home. In most cases, it is easier to gain access to residential supports in a crisis than to family supports before a crisis.

Maryland's family support programs for families of people with developmental disabilities are comprehensive by definition but have very limited capacity, receiving less than 1% of the developmental disabilities state agency budget. Other initiatives for families include family-focused early intervention services under Part H of the Individuals with Disabilities Education Act (IDEA) and family support planning activities under the Family Preservation Act, although insufficient supports are available. Preschool programs for children with disabilities and Head Start programs have collaborated at various local levels, but availability of Head Start services to children with significant disabilities remains very limited. Respite care services are available in all counties, but demand far exceeds supply. In summary, public agencies are vocal about the needs of families, but they have not made family support a budget priority. The result is a crisis approach that, as previously discussed, leads to significant unmet needs and loss of opportunity for most families, as well as to referrals for out-of-home placements of children with severe disabilities.

This shortage of services to children with developmental disabilities is longstanding. Although state systems have been created to coordinate efforts among the state department of education, local departments of social services, and the state developmental disabilities agency, children are still sent out of state to restrictive residential treatment centers miles from home. Because this service meets the requirements of a free appropriate public education, it is funded by the state department of education. However, this does not provide the necessary in-home supports or other wrap-around services that could keep families together in their communities. These services could be provided by the state developmental disabilities agency, but because the services are not mandated as entitlement services, the state maintains that there are insufficient funds in their budget to provide these family services. This lack of financial commitment to family supports and to the increased development of children's specialized foster care by the developmental disabilities agency results in the movement of more children to costly out-of-state placements and increases the use of expensive pediatric nursing homes and institutions.

Need to Increase Community Inclusion

The vast majority of people with developmental disabilities and their families want the freedom to be part of community life just as most citizens do. Community inclusion goals involve increasing access and support for participation in community life, as well as advocacy for allocation of service and support resources to meet people's needs in their communities, not in segregated facilities or programs.

A number of supports necessary for inclusion have been discussed previously. Additionally, transportation needs are often difficult to meet, both in terms of availability and accessibility. Accessibility for people with cognitive disabilities involves support in learning how to utilize transportation, such as obtaining farecards, transferring, choosing correct routes, and understanding directions. Many obstacles that prevent individuals from maneuvering through their communities must be resolved through carefully designed individualized supports.

Supports for inclusion of people with developmental disabilities in Maryland have been encouraged and developed to the state of "best"—but not common—practice in many domains. The education inclusion movement reflects the strong interests of parents and educators in effectively preparing students with severe disabilities for participation in the community and adult world. Supported employment services have evolved with the recognition that training and preparation alone cannot always mitigate the effects of severe disability in competitive employment, and that many people with severe disabilities will need indefinite on-the-job support in order to be employed. The community supported living movement recognizes needs for increasing integrated support to end reliance on segregated living facilities. However, none of these inclusionary efforts are consistently found across the state.

Parents of preschool and school-aged children with developmental disabilities often face a year-to-year ongoing challenge in order to obtain or continue inclusive education and related services for their children. Local education agency commitment to inclusion varies greatly throughout the state; there is evidence of strong strategic planning, support to educators, and reallocation of resources in some districts and only token activities in others. As one commentator stated, "Inclusion is still the exception, rather than the rule."

Making sufficient supports available for people with developmental disabilities in inclusive settings is a constant challenge. Barriers include negative attitudes, including a lack of public understanding and acceptance of people with developmental disabilities. Other critical requirements to effective community inclusion include a commitment of state leadership and resources to provide technical assistance in best practices, to assist providers to maintain quality support-staff and programs, to increase the availability of transportation (agency and public), and to promote availability of specialized behavioral support services. Increasing inclusion opportunities for people with developmental disabilities requires resolving funding issues, particularly ceasing to fund and administer dual community and institutional systems. Further, agencies, professionals and support personnel must receive assistance and be given incentives to shift into inclusive settings.

• Potential Expanded Council Constituency • Characteristics and Unmet Needs

Information for this part of the study was obtained from interviews with stakeholder organizations (advocacy, provider, and government), significant material provided by these groups, a literature review, and in-depth personal interviews with individuals representing the potential expanded Council constituency. It also relied on the comments of focus groups, the advisory committee, and the expert panel reviewing the proposed definition of the expanded constituency. As indicated earlier, the study proposed using the same functional definition to define the potential expanded constituency as is used for people with developmental disabilities, except for the elimination of consideration of onset during the developmental period.

Because the Maryland Developmental Disabilities Council's goal is to support full community inclusion of all people with developmental disabilities, the study aimed to determine the service and support needs of people with other severe disabilities within the same framework. This approach assumed that the potential for collaboration among various groups of individuals with disabilities would be greater if they shared fundamental service and support goals.

The service and support needs of particular individuals with severe disabilities were examined, including individuals with disabilities related to aging, multiple sclerosis, head injury, AIDS, and chronic mental illness and individuals using wheelchairs and personal assistance services. These individuals were thought likely to be representative of a potential expanded Council constituency, and some groups had expressed interest in being involved with the Council.

Determining needs

As when examining needs among children and adults with developmental disabilities, the study encountered different perspectives of needs of the expanded constituency. Broad domains of service and support such as housing, employment, and transportation were frequently identified. Alternatively, specific support needs related to the functional abilities, needs, and characteristics of individuals were also identified. Interviews with individuals with severe disabilities or their families tended to provide depth from the latter perspective as compared with stakeholder interviews with organization representatives, who tended to speak more broadly about systemic domains in which supports and services are needed.

The vast majority of individuals interviewed for the study had no difficulty communicating their views and needs. The survey process did not attempt to compare the perspectives of individuals with disabilities and current care givers; however, when caregivers were interviewed in situations in which the individual did not participate, more emphasis was often given to the inability of the person and the need for more support.

Broad needs for Financial Assistance

As with the Council's current constituency, concern was pervasive about the lack of funding for needed services and supports for people in the potential constituency. Different types of providers were interviewed, some providing comprehensive long-term services and some providing informational and supportive services. Long-term service provider representatives indicated that funds were insufficient to extend existing services to many people seeking them. Other providers indicated that needed services had not been developed because eligibility criteria for public funds for their particular clients was very restricted.

Providers frequently spoke of being underfunded in providing personal assistance services and supported living assistance. It did not appear that the use of federal funding waivers was being significantly utilized to expand limited resources within the potential constituency. For example, a shifting of funding from nursing homes to home-based supports has not been achieved. Instead, for some groups, additional funding for community and home-based supports has been pursued with little new state revenue to support it.

The potential expanded constituency includes people with a wide range of medical needs associated with their disabilities. Numerous references were made to problems with health insurance coverage. This issue affected not only the overall financial circumstances of individuals but also their access to needed services and medical supplies, equipment, and technology.

A large proportion of highly ranked needs for assistance and supports by the potential expanded constituency resulted from economic need. Within the 210 individuals interviewed for the study, no single service or support was consistently identified as most critical by the majority of those surveyed. (See Appendix 7.) However, a significant number of people identified the need for housing assistance: the supply of safe, affordable, and accessible housing does not meet the needs of people with disabilities, and public programs to assure housing for poor people are continuously being curtailed. Many individuals described problems accessing state and federal government benefits,

and money management problems resulting from not having enough money to live independently. Many individuals described their desire to find employment. Within the group of individuals interviewed for the study, many were participating in nonvocational treatment and day programs. Thus, earnings were not available as a source of income.

Needs for Housing Assistance and Living Supports

Housing assistance was the greatest unmet need identified by stakeholders on behalf of the potential expanded constituency. "Housing assistance" is difficult to interpret and clarify. Many individuals with disabilities representing the potential constituency expressed a need for housing assistance along with a high preference for remaining in their present residence, where "outside" assistance was apparently not being provided. One explanation for this finding is that although people indicate satisfaction with present living arrangements, their choices are limited by their financial means. With the high incidence of poverty among people with disabilities, affordable, safe, and accessible housing is difficult to obtain. Architectural accessibility was a particularly common need among individuals with physical disabilities. For some individuals within the potential constituency, having money for housing and personal assistance could be the single form of help they need, as well as the alternative to homelessness or a nursing home placement.

A number of organizations representing individuals in the potential expanded constituency ranked the need for in-home supports and personal assistance highly. About half of the individuals interviewed indicated needs for this support. People repeatedly indicated that they want to live in their own home or apartment with their spouse, a future spouse, or a "significant other" or with children, relatives, or other informal supports. (See Appendix 8.) Several supports other than in-home assistance were rated as more helpful by the group as a whole, including affordable housing, support from friends and neighbors, religious or spiritual supports, and medical care.

It should be emphasized that the interviews were primarily conducted with individuals experiencing disability. Most of the individuals were not living in formal care settings. (See Appendix 9.) A small percentage of those interviewed were caregivers, primarily relatives. The stress of care giving was evident among relatives, and yet there was little indication of interest in receiving in-home supports. However, organizations speaking on behalf of individuals in the potential constituency indicated needs for support in the homes of caregivers.

A number of theories can be offered regarding why in-home living supports and personal assistance were not ranked higher by half of the individual study participants. The prospect of receiving in-home support or living in a family member's home may not seem desirable to people who have experienced typical private lives prior to the occurrence of their own or their family member's disability. People may not understand the alternative of in-home support, because the traditional experience of people who cannot care for themselves independently or with informal support is to move to a formal care setting. People also may have ruled out the possibility of in-home support because they could not afford it and know of no other payment source.

Individuals with physical disabilities and organizations representing this group indicated major needs for environmental modifications and assistive technologies to support independent living. People in this group do not describe their needs in terms of reliance on a service system but instead as seeking removal of barriers and opening access, generally physical and attitudinal, which would lead to the ability to live independently. While no group indicated a preference to have service providers occupy a central place in their lives, some groups appeared to recognize a necessity for continuous comprehensive services not indicated by this group as a whole.

Individuals interviewed indicated in many ways the importance they place on having control over their lives. Generally, they feel they make many of their own choices and decisions concerning friends, free time, personal spending, and time spent alone. (See Appendix 10.) People felt they had much less control when it came to determining and directing their medical care and service providers. While it is difficult to generalize about the sense of control and independence people feel in their lives, the majority of people surveyed indicated that they have some or quite a bit of control and independence.

Medical Needs

A majority of those interviewed identified access to adequate and appropriate medical treatment, medical supplies, medication management, and health insurance as areas of high need for assistance. For individuals with chronic mental illness, proper medication management is essential for sustaining a measure of independence and community living. Coordination of numerous medical and health disciplines is required in the recovery and rehabilitation of people with head and traumatic brain injuries. Continuous and consistent medical monitoring and intermittent treatments and adaptations are required for many people with multiple sclerosis. Individuals with disabilities related to aging may also experience a variety of medical and health related conditions and may require intervention for conditions that are exacerbated by age.

Few organizations representing groups of individuals whose disabilities require significant medical treatment identified this as a high-ranking area of need, with one notable exception. Medication management for people with chronic mental illness was highlighted by all organizational representatives surveyed. Medical needs may not have been stressed by many organizations because they perceive these needs to be more easily met, compared with the difficulty of obtaining nonmedical supports. People experiencing serious medical conditions may mention their needs for medical care and health insurance coverage more often because receiving effective medical treatment is a more immediate issue than other concerns in their lives. Further, without agency coordination, finding and accessing these services can be more difficult.

Employment Needs

Half of the organizations representing people in the potentially expanded constituency gave high rankings to the need for employment assistance. About 30% of individuals representing the potential expanded constituency selected employment assistance as a high-ranking need. Over half of the interview participants were involved in formal non-wage earning programs during the day including medical day treatment, rehabilitation training, and day care, and a number were hospitalized in psychiatric facilities. In all, only about 8% were earning full-time or part-time wages. (See Appendix 11.)

Interpreting the employment goals of study participants is difficult. Analysis of the survey group based upon the particular disabilities of the individuals participating may give some insight into interests in employment-related assistance. (See Appendix 12.) For example, individuals identified as having chronic mental illness, many of whom were hospitalized at the time of their interviews, indicated a high interest in employment assistance services. No individuals with multiple sclerosis interviewed for the survey chose employment assistance as a high priority. Some people with head injuries and spinal cord injuries indicated a need for employment assistance, whereas people with Alzheimer's disease and age related impairments indicated no interest in employment.

In describing unmet needs related to employment, the state agency responsible for vocational rehabilitation services has indicated that a shift in its philosophy to assist individuals with the most severe disabilities has resulted in the inability to serve many people due to lack of funding. This agency indicated that other barriers to employment result from negative community attitudes, lack of transportation, lack of medical insurance benefits, and a shortage of employers willing to provide supports.

Needs Concerning Community Inclusion

Stakeholder organizations responding on behalf of the potential constituency identified many barriers to providing integrated services and supports. Study participants associated numerous meanings with the terms *integration* and *inclusion*. Some people used the terms as the Council does, to refer to community living rather than institutional living and increased participation in community life by eliminating physical barriers and increasing access. Some study participants also used "integration" to refer to clustering of multiple services and "inclusion" to refer to loosening of eligibility criteria to make services available to more people. In spite of the variety of interpretations, continuous high ranking of needs for housing assistance, transportation assistance, access to religious and spiritual activities, and recreation facilities reflects the high value people with severe disabilities place on living in and taking part in their communities.

The study did not confirm a universal need for increasing inclusion opportunities among the potential expanded constituency. Although stakeholder advocacy organizations generally support inclusion, many individuals indicated that they were taking part in their communities and did not desire to be any more involved than they were when interviewed.

Only 72 out of the 210 surveyed indicated an interest in broader community involvement and inclusion. (See Appendix 13.) Many people with disabilities related to aging and other progressive disabilities said that they were not interested in greater general community involvement and choose to be with people their own age. Some stakeholder organizations indicated that certain groups of individuals with disabilities do not generally espouse philosophies of community inclusion, most notably the deaf community. The study did not segregate the responses of the large number of individuals interviewed who attended medical day care centers and rehabilitation facilities; it is not clear whether these consumers would have preferred more integrated service alternatives or more specialized rehabilitation facilities.

Overall, community inclusion was not as strong a theme within the potential expanded constituency as was maintaining or gaining independence, a related but not identical goal. More information is needed in order to understand the overlapping goals and the explanation for the differences.

• Comparison of Current and Expanded Constituencies •

General Similarities Among Populations

Difficulties in Obtaining Services and Supports. Study participants and other sources indicated that people are universally overwhelmed and frustrated in their efforts to obtain the services and supports needed. The problems people confront at a personal level often result from systemic problems that continue to cause individual suffering. The following issues are systemic concerns:

- Public funding is inadequate to provide services to all who need them, and significant new revenue is not foreseen.
- An institutional bias in many funding sources limits the development of integrated community services and perpetuates the inefficiencies of administering "dual systems."
- Many service providers are unable to meet the needs of people with the most severe and complex disabilities, often based on these resource limitations.
- Coordination among multiple sources of services is lacking.
- Services frequently are not individualized to support the unique abilities and choices of each person receiving them.
- Services are often sought to compensate for problems created by widespread poverty and by the lack of community understanding and support of people with disabilities.

Modest Hopes and Desire for Typical Living. The study also provided insight into certain qualities widely shared by people with disabilities and their families:

- Even though many people experience disability at some point in their lives, they are unprepared for the overwhelming effects of a severe and chronic disability in altering the course of their lives.
- People with disabilities and their families generally seek a basic and modest life and hope to use their own abilities and resources to maintain independence with support immediately available to them. They want the effects of disability in their

lives to be reduced through access to opportunities, understanding of their abilities, and elimination of barriers to typical living.

- People with disabilities and their families generally resist the intrusion of the service domain in their lives and turn to services out of genuine need, sometimes as a last resort. They want services and supports to respond to their specific circumstances and to be effective in reducing the impact of disability in their lives.

Cultural and Socioeconomic Factors. Maryland has experienced dramatic demographic shifts during the last decade. Cultural diversity has continued to increase and with it, there has been an increase in the state's population for whom English is not the primary language. In addition, there are major concentrations of the population living below the poverty level.

The study included a survey of provider agencies to identify the unique needs in supporting people with developmental disabilities and other severe disabilities that may result from cultural and socioeconomic factors. These included minority ethnic and racial backgrounds, non-English languages, and poverty status. The study assumed that these factors are at least as prevalent among members of the population with severe disabilities as they are among the population in general. Needs were specifically examined of people with developmental and other disabilities who are African American, Hispanic, and Asian, and/or who are living in urban, rural or age-related poverty.

Agencies serving people with disabilities commented that prejudice concerning disabilities is probably encountered more than ethnic or racial prejudice. Agencies have developed many ways of dealing with cultural differences. They hire bilingual staff or provide language training and interpreters to address language differences. Attempts are made by a number of agencies to make referrals to staff or providers of the same backgrounds, to utilize and develop culturally sensitive programs, to link people with similar ethnic backgrounds for mutual support, and to hire more diversified staff. The study did not determine how culturally competent service agencies are but it did show that agencies are aware of numerous needs in this area.

Agencies serving people living in urban poverty report that consumers are often unable to access help. Case management and other counseling services are provided to overcome this barrier. People seem to face a lack of support in general, from their community and at times, their families. Crime is a major concern, especially for

vulnerable people. As a result, agencies become involved in many ways in the lives of people they serve, from teaching street safety to providing family support and conflict resolution.

People in urban and rural poverty often lack basic necessities including transportation, food, clothing and housing. The lack of accessible, affordable housing has led to people living in unsafe or overcrowded dwellings. To meet the need for housing, some agencies have developed shelters and specialized housing arrangements. Agencies meet transportation needs by developing their own arrangements as well. In urban and rural areas, agencies are attempting to provide basic necessities for families as part of their effort to work with the person in the family with a disability. This even extends to providing school supplies for children.

Employment opportunities are limited in urban and poverty areas. They are even more limited in rural poverty areas. Agencies try to train and prepare people for the types of work which do exist in their areas. People who do not understand or cannot access work incentive programs are reluctant to enter employment because they believe that they will no longer be eligible for housing, Social Security, Supplemental Security Income and Medicaid benefits. Numerous reports reviewed indicate that loss of government benefits is a major concern among individuals and families and agencies report that they try to provide appropriate information.

Many agencies in rural poverty areas indicate there is a serious lack of health care providers that understand or will meet the needs of people with disabilities. It is especially difficult to access dental, vision, mental health or other medical specialties. Specialized medical services for children with multiple disabilities and medication monitoring for older adults with disabilities are specific services in short supply. Often, in order to access services, transportation must be arranged to other parts of the state.

Specialized programs for children in rural areas, including respite care, summer camp programs and day care are limited. Adults, particularly elders, in rural areas often lack appropriate day programs and often are socially isolated.

In summary, people with disabilities are culturally a very diverse population. Agencies that provide services related to disabilities must be competent in meeting the unique individual needs of people they serve. As indicated in other parts of the study, poverty is prominent among all people with disabilities, and access to appropriate and adequate

basic necessities is a common need. Often this requires agencies to extend their resources to support communities and families as well as the individual with a disability.

General Differences Among Populations

Differing Specific Needs Based on Disability. Although people with disabilities and those who support them generally do not believe diagnostic terms and labels are critical in determining service and support needs, the study continuously encountered particular needs that relate to specific disabilities. Individuals and stakeholder organizations repeatedly identified groups they considered underserved because service systems were currently unable to respond to their complex and challenging needs. Additional specialized expertise was considered necessary to support these unmet needs.

When broad domains such as housing and transportation were identified as needs prevailing across disability groups, there were also significant variations in how different groups indicated they could utilize supports in these areas. For example, eliminating physical barriers to accessing transportation may resolve issues for many people in the expanded constituency. However, many people in the current constituency additionally require ongoing training and assistance in learning how to use the system, buy fare cards, manage money, and utilize the system appropriately.

Additionally, the onset of disability during the developmental period plays a significant role in the future support needs of individuals, especially in major life activities of learning, socialization and communication. Without the opportunities to learn these skills as youngsters with other children without disabilities, many adults need significant assistance in these areas that are critical to successful inclusion.

In the potential expanded constituency, most interview participants indicated needs for assistance in activities of independent living and economic self-sufficiency; the fewest number needed assistance in learning and communication. Most interview participants were able to express themselves clearly and indicated no difficulty understanding others. Interviews with individuals in this group reflected feelings of moderate to high control in various aspects of their lives and a desire for more control directing services and supports.

Role of Families, Mentors and Self-Advocacy in Developmental Disabilities. Facilitation, mentoring, guidance, and supervision are prominent forms of support within the developmental disabilities service system. Appropriately or not, surrogates such as

family members have historically played a large role in advocating for and supporting the choices and decisions of individuals with cognitive developmental disabilities.

Because parents of minor children have legal responsibility and authority in decisions concerning their children, parents have a significant voice in evaluating services and supports for children with developmental disabilities and are active members of the current constituency. Families often continue to play important roles, including care giving, as people with developmental disabilities move into adulthood.

There are significant challenges for people with developmental disabilities and their families when legal responsibilities and rights generally shift from parents to their adult children at the age of majority. Supports are often necessary to assist the person with a developmental disability to exercise his or her rights to the maximum extent possible and to their family to understand their new role. Self-advocacy for people with cognitive disabilities experienced during the developmental period has not reached the level of effectiveness of other self-advocacy groups. These self advocates are often not included or consulted by general disability groups.

Increased Complexity of Issues in Other Disabilities. Several additional variables appear to influence support needs in the broader range of adults with severe and chronic disabilities, as compared with those with developmental disabilities. One important variable is the impact of disability on a person's life and the prospects of relying on or regaining former abilities. The study seemed to show a significant relationship between a person's support needs based on the phase of life in which the disability occurs. Plans for supports and services are affected by the uncertainties of progressive or cyclical diseases. The outcome of medical treatment is significant in the course of certain diseases and disabling conditions.

In addition, disabilities that affect a person's continuing capacity to make decisions raise difficult issues concerning surrogates. The role that children play in the lives of aging parents with disabilities is often quite different than the role that parents and family members play in the lives of their children with disabilities. While the abilities of the aging parent may be expected to decline over time, the parent of the child with a disability hopes that the child's abilities will increase with supports and experience. While the aging parent's needs are expected to be time limited, the child's needs are expected to outlive the supporting parent.

Differences in Ability to Advocate. Parents and families of people with developmental disabilities can have a unique influence on the long-range evolution of policies, opportunities, and support systems affecting people with developmental disabilities. This

impact occurs through the intervention and experiences parents try to obtain for their young children, through their hopes and expectations for their children, and through their actions to influence the long-range availability of future supports. Parents of children with developmental disabilities often adopt long range outlooks, recognizing that they need to prepare for a lifetime of changing support needs.

As a group, people with developmental disabilities have experienced major obstacles in influencing the quality of their own lives, particularly when communication problems are an issue. While people with developmental disabilities are becoming more vocal as support for self-advocacy has increased, most self-advocacy efforts continue to require support to help people recognize their power to speak for themselves and to provide the opportunities, information, and means they need to speak out. Many people with developmental disabilities will continue to need support from others in advocating for their interests.

Stronger consumer movements have developed within the potential expanded constituency. Many individuals with disabilities speak articulately for themselves. Some individuals have gained access to decision-making processes through significant representation on boards of directors, advisory bodies, and other formal vehicles for influence. A number of groups have effectively utilized community organizing strategies and other advocacy efforts to affect political processes.

Differences in Addressing Barriers to Meeting Needs and Advocacy Methods for Systemic Change. Presently, state and federal systems continue to separate the delivery of services to people with developmental disabilities, mental illness, disabilities relating to aging, and other areas. For example in Maryland, people with developmental disabilities are served primarily through the Developmental Disabilities Administration. Each agency, including the Mental Hygiene Administration, the Office on Aging, the Department of Human Resources and the Developmental Disabilities Administration, has different leadership and goals, receives a separate budget and operates under different regulations. Each agency can access different federal funding waivers and programs, with different requirements, on behalf of their constituencies.

Through this process, each constituency has unique factors that influence the operation of the agencies that provide supports to that constituency. Although similar broad needs may exist, different analyses and solutions may be appropriate. Although the study has not tended to highlight the simple quantitative responses of stakeholder representatives, their responses to barriers to providing service is most telling. The number one barrier identified by stakeholders to providing integrated services and supports in the potential expanded constituency is that housing is too expensive. (See Appendix 14.) This barrier was the least frequently given response of the stakeholders from the current constituency

to the same question. (See Appendix 15.) Alternatively, lack of state leadership was the most frequent response of the stakeholders from the current constituency. This response was mentioned by only one quarter of the stakeholders from the expanded constituencies.

This highlights the fact that while similarities may exist in certain needs of people with different disabilities, often different barriers exist to adequately address these needs. In these cases, very different approaches are necessary to evaluate the activities and projects necessary to serve as agents for systems change, to demonstrate best practices, and to develop supports that can meet these needs in a cost effective manner.

• Implications of Council Expansion for Constituencies •

Expectations of Potential Expanded Constituency

Most surveyed stakeholder organizations representing the potential expanded constituency indicated that they would support an expansion of the Council to include the individuals they represent. Many offered significant caveats to their support of expansion. Organizations with longstanding associations with the Council were familiar with its public policy positions, best practice goals, and systems change efforts and wanted to see the Council expand these benefits to others. They believed that a broader Council constituency could result in more political strength for people with disabilities. However, when the issues were discussed in focus groups, many of these representatives expressed less interest in formal Council expansion and more interest in broad collaboration, given the realities of current and anticipated future limited resources.

Knowledge of the Council's purpose and activities varied among representatives of the potential expanded constituency. Some participants did not know that the Council funds time-limited demonstration and systems change projects, focusing on the development of innovative and efficient ways to address the most complex and challenging needs of people with developmental disabilities. Some participants did not know that demonstration projects are generally expected to be replicated or that groups outside the current constituency may currently apply for grants if the projects meet the priorities of the Council and benefit people with developmental disabilities.

Study participants believed the expanded Council would address the particular service and support interests of new groups of constituents, in some cases through representatives of specific groups on the Council. They expected that the expanded Council would

determine common service and support interests among all constituents and set its priorities accordingly, possibly changing the focus from people with developmental disabilities to people with severe disabilities. The Council's potential expansion was also seen as providing a means for access to and influence on general funding and eligibility for services and supports through access to state agencies that provide services to all people with disabilities. Participants expected that Council grant funds would become available to fund projects to benefit the expanded constituency, and they believed that Council policy staff and resources would expand to meet the increased responsibilities and systems activity generated by a broader constituency.

A number of study participants from both state agencies and advocacy groups representing the expanded constituency believed that the Council has led the way in increasing inclusion and should not be slowed in this effort by attempting to advance the entire system related to severe disabilities. Rather, they believed the existing advocacy groups should work with the Council to apply the Council's results to benefit the potential expanded constituency.

Potential Changes in Council Focus

Many stakeholders in the current and potential expanded constituencies stated that the Council would most likely need to change its goals to address common issues within a broader constituency. This would require an examination of the priority needs of people with all disabilities to identify goals and outcomes for advocacy, systems change and capacity building.

This issue was discussed in numerous settings, and the following are a number of comments made regarding change in the Council's focus if its constituency were expanded:

- An expanded Council should include all philosophies and be very diverse; however, concern was expressed that the goals would become too general.
- Increased diversity would lead to decreased consensus and more time could be spent on the process than the outcomes.
- The focus could leave out certain people with developmental disabilities who are currently included under the Act. An "expansion" of the constituency, without additional resources, would result in a *shift* of focus, rather than a true expansion.

A broad-based council, with the Council's current resources, cannot address *all* people with disabilities' unmet needs as effectively and thoroughly as the current council does for people with developmental disabilities.

This shift in focus could be manifested in many different ways:

- Focus could narrow to people with most severe disabilities, leaving out people with milder developmental disabilities.
 - Focus might be on those with common needs related to cognitive disability.
 - Focus might be on persons with severe disabilities who don't need as much service and can be more independent of the system or whose needs are less costly, overlooking those with lifelong needs.
 - Focus could be limited to people who need support from the public sector rather than examining innovative supports for those with private resources or through private business that may benefit those in the public sector as well.
 - Focus might be on common issues important to a broad group, such as people with mobility impairments.
 - Focus could be on independent living for all, leaving out other important issues for people with developmental disabilities.
- Focus on people with developmental disabilities should be retained; all members of the expanded constituency would benefit from the Maryland Developmental Disabilities Council's work and could adapt activities in their own systems.
 - Collaboration, dissemination, and assistance with replication of Council initiatives and activities should be increased within and outside the developmental disabilities community, regardless of expansion.
 - Expansion could duplicate advocacy for those who already have strong advocacy groups while losing the focus for people with developmental disabilities, who have more difficulty advocating for themselves.

Possible Shift in Focus from Families and Children. The Council's current constituency includes children with severe and chronic disabilities and their families as a key focal point of its systems change strategies. The ability to maintain this focus with an

expanded constituency would be questionable, given that the study's examination of support and service needs of the potential expanded constituency encountered almost no reference to children. As previously discussed, family roles and needs for people whose disabilities arise after the developmental period were found to be different from those of families who are raising or have raised children with disabilities. Given the Maryland Council's strong advocacy role on behalf of children and families and the positive outcomes it has produced, a shift from this area would be quite detrimental.

Possible Weakening of Focus on People with Cognitive Disabilities. Many people from the current constituency believe that people with mental retardation and other cognitive disabilities would lose their effectiveness as self-advocates within an expanded Council constituency. The anticipated result would be a loss of recognition of their unique experiences and service and support needs in the Council's priorities. There was broad recognition that the Council needs to more effectively address the needs and issues of all members of its current constituency, including people with other types of severe and chronic cognitive or mental impairments such as head injuries and chronic mental illness occurring during the developmental period, and that addressing these needs is encompassed in the mission of Councils under the DD Act as currently drafted.

Possible Weakening of Focus on Inclusion. Full community inclusion is the main goal of the current Council constituency in systems change activities. This goal addresses the universal need to reverse the historical isolation of children and adults with developmental disabilities and their segregation in separate training facilities, special schools, and institutional residential facilities. The Council concentrates its resources on fostering the expansion of inclusive alternatives in integrated employment, inclusion in typical schools, and supported community living arrangements.

The Council's inclusion goal also recognizes the strong desires of people with developmental disabilities and their families to take part in community life and to be able to rely on their communities to offer support and security over a lifetime. Council efforts continuously have a direct or indirect objective in building community capacity to include people with developmental disabilities through greater understanding, increased competence, and positive expectations. In examining the priorities of the full range of people who might be included in an expanded constituency, questions arise as to whether the Council's single-minded approach concerning inclusion would be retained.

The responses of the expanded constituency were diverse. Many study participants expressed their desires to live in their own homes, have control in their lives, and have the means to be independent of service systems. Employment was not a priority goal for

many respondents or groups. Greater participation in community life was a relative matter, with many now participating and not strongly interested in having more involvement.

Some stakeholder groups representing older people with disabilities viewed their constituents as needing care, being dependent, and often choosing segregated facilities. Many individuals interviewed were attending medical day care centers, day treatment centers, and rehabilitation facilities. Their needs are frequently time-limited and their priorities somewhat different from those of people with other disabilities.

It is not known whether all advocacy groups would want to be coordinated into one group, particularly if it was formerly known as the Developmental Disabilities Council. The Council recently aired a public service announcement advocating community inclusion for people with disabilities ("Open Doors, Open Minds"). The radio spot mentioned access for people with mental retardation or cerebral palsy as well as for people who have blindness or deafness. The Council received a call from an advocate of people who are blind and another from an advocate of people who are deaf. Both were concerned that their constituencies not be further stigmatized by being grouped together with people who are mentally retarded or who have cerebral palsy. Regrettable as it may seem, this emphasized the existence of a "hierarchy" of disabilities, where people with developmental disabilities (particularly cognitive and communication disabilities), remain near the bottom. Because of this hierarchy, issues of people with developmental disabilities would be seriously jeopardized if the Council expanded to broad constituencies and broader focuses, without serious safeguards.

Difficulties in Defining A Potential Expanded Constituency

The study examined expansion of the Council constituency by applying a proposed working definition identical to the current definition of developmental disability with age of onset eliminated. As part of the study, a group of individuals who have experience applying various criteria in making eligibility determinations was asked to review and evaluate the strengths and limitations of various definitions currently being used in Maryland to distinguish people with disabilities who are eligible for publicly funded services and supports. The definitions reviewed are listed in Appendix 16.

The following are the panel's general findings regarding issues in applying various disability definitions:

- The terms "severe," "chronic," "manifested," and "continuing and regular assistance" are subjective even when tied to other factors such as functional limitations in major life areas.
- The assessment of functional limitations is more useful than diagnostic labels in providing a basis for projecting services and supports, but functional assessment is subjective.
- Medical information is constantly changing concerning which disabilities are "expected to continue indefinitely."
- Certain definitions may be unintentionally biased to include or exclude specific types of disability; e.g. cognitive, mental health, medical, physical.
- Age criteria such as age of onset and eligibility for senior programs are objective.
- The Americans with Disabilities Act definition gives broad access but does not address severity or provide a basis for projecting services and supports.

In summary, the panel found strengths and limitations in all definitions it reviewed, with the most frequent issue being the subjective nature of many criteria. The study suggests that any change in the current Council constituency would involve extended debate regarding how to retain a focus on people with severe and chronic disabilities and how to identify those to be included in the expanded constituency.

• Implications of Expanded Constituency on Council Effectiveness •

The Council's mission and priorities drive its activities. Many strategic considerations also enter into decisions about effective systems change, capacity building, and advocacy activities:

- Timing
- Stakeholders and Arenas of Influence
- Knowledge base
- Resources

These strategic issues must be considered when weighing the effects of potentially expanding the Council's constituency and the potential effectiveness of Council activities conducted on behalf of an expanded constituency.

Timing: Possible Drawbacks of Increased Numbers

As this report is being completed, virtually all federal policies and financial assistance affecting people with disabilities are the subject of major reform and reduction efforts. Future changes will dramatically affect people with disabilities who rely on public service and support. Unity within the disability community is more important than ever if legal commitments and protections for citizens with disabilities are to be recognized and maintained. Informed and competent strategies are needed now to achieve these outcomes.

However, information from the study does not definitively conclude that this is a good time to change Council constituencies. The consensus building necessary for change could be unifying or divisive. It is difficult to project where the Council's focus would eventually settle and the extent to which effectiveness in new areas would decrease effectiveness in current areas. For instance, concerns were expressed in the study that the Council's current impact on improving outcomes of support to children with severe and chronic disabilities and their families could be reduced in an expanded constituency; if so, a major strategy for reducing the later impacts of early disabilities would be forfeited.

Stakeholders and Arenas of Influence

Responses to Council positions on issues affecting their members by the various groups comprising the potential expanded constituency appear to be mixed. The study found clear indications that some groups in the potential constituency did not want the Council to speak for them. Less than one half of those interviewed in the expanded constituency (98 out of 210) were willing to lobby the issue of institutional closure, an issue of critical importance to the current Council and its constituency. Only about one third of the expanded constituents interviewed (72 out of 210) wanted to be more involved in their broader communities. Further, although a majority of the stakeholders indicated that their constituents would be willing to lobby with the expanded constituency, a number of stakeholders indicated that their constituents might not be willing to lobby with all groups.

Therefore, a major strategic issue is whether strength in numbers comes from unification into one Council with one voice, through many voices, or through a combination of both. Whether the Council expands or not, it is clear that the many organizations that now speak for the specific interests of certain groups of people with disabilities will continue to do so.

Likewise, advocacy groups such as the Maryland Disabilities Forum and state agencies like the Governor's Office for Individuals with Disabilities, which speak on behalf of all people with disabilities, will continue their efforts.

One representative of a large segment of the potential constituency suggested that it is most important for the Council to be successful in its present form because this translates to strength for others: "We don't want to be part of the Council because we will slow down your progress. We want you out ahead so we can ride your coat tails. We know how to influence our systems just like you know how to influence yours, and we use your experiences as evidence of things that work. If we slow you down we'll all end up behind in the long run." Rather, he advocated continuing and increased collaboration on issues of joint importance.

Issues of Collaboration and Duplication

The study also included an analysis of state organizations in Maryland that have been created to address the needs of individuals with disabilities or those at risk of disability. The Council has a long history of collaborating with others to accomplish mutual goals and recognizes that many organizations are striving to improve the quality of life for people with disabilities. To the extent that many of these groups are publicly mandated and therefore reflect state priorities, the study was interested in identifying common purposes and any potential for interagency collaboration or for eliminating duplication.

The analysis included an extensive list of organizations established through state statute or executive order, as opposed to private nonprofit organizations, many of which were involved as stakeholders in the study. (See Appendix 17.) The mission of each organization was compared to the Council's to determine similarities. This analysis identified opportunities for collaboration with many organizations responsible for developing, implementing, monitoring, and advocating for programs that ensure appropriate services and community education and support. A number of organizations serve a broad range of individuals, and many address smaller populations. Those addressing a specific disability appear to focus on prevention, disseminating information, and improving the quality of treatment and services.

Although the analysis identified similarities in the broad mission statements of organizations, further examination reveals unique purposes and responsibilities. Substantial duplication of effort is not apparent among the organizations included in the analysis, despite the existence of many parallel and complementary activities. Most organizations have a distinct focus, usually concerning a specific disability, age group, service domain, or socioeconomic issue. Organizations appear to harness a variety of expertise, generally with significant consumer and citizen involvement. Most have communication and reporting responsibilities to government agencies, elected bodies, and the general public.

In considering the potential effects of expanding the Council's constituency, a number of the organizations would probably develop new associations with the Council if expansion occurred. Those addressing specific disabilities could provide expertise and support to the Council in accomplishing its mission or could seek support from the Council in furthering their goals. The Council has had positive experiences in collaborating with state-mandated organizations and would expect the same with new associations.

There is no precedent for having the Council replace other existing state organizations or assume formal coordination of their activities. The Council's federal mandate has allowed it to be an independent resource to many organizations; because of the independent role and origins of the Council, it could not replace other state organizations with specific mandated state responsibilities. If the Council expanded its constituency, state-mandated organizations involved with the new constituency would likely provide increased input to the Council while continuing to function as they had previously. The primary effect of expansion with respect to state organizations would generally be increased communication and information exchange and potential for collaboration. A later section of this report addresses the potential for increased collaboration, with or without formal Council expansion.

Need for Increased Knowledge Base

Stakeholders in the potential expanded constituency repeatedly indicated that the Council would need to acquire new knowledge in order to understand and address needs if its constituency were expanded. Failure of the Council to thoroughly educate itself concerning its full constituency would be viewed as unacceptable.

The Maryland Council is now considered effective in large part because of its state-of-the-art knowledge of policy, practice, and the support needs of its current constituency. Many recognize the Council as a think tank that can be consulted and relied upon for

expertise. A substantial amount of information is accumulated through Council staff research, targeted demonstration efforts and studies, and collaboration with related organizations, constituents, and national networks. If the Council expanded its constituency, it would need to acquire an extensive new knowledge base to retain its credibility. Some of the specialized issues requiring increased knowledge would include forced medication for people with chronic mental illness, cessation of life support for people who are elderly, stand-by guardians for people with AIDS, and hospice services for people with terminal illnesses.

Impact on Fiscal Resources

As part of the study, a fiscal analysis was undertaken to obtain a general estimate of fiscal resources involved in meeting the service and support needs of the expanded constituency. The high degree of need among the current constituency requires a broad understanding of needed allocation of fiscal resources to people with disabilities in Maryland. Addressing this question remains the Council's role.

The fiscal analysis highlighted major complications involved in planning for public services and supports to people with disabilities. The technology and practice of needs assessment are not definitive. Prevalence data is available to estimate the number of people with disabilities in Maryland, but only limited efforts are made to estimate service needs as part of an ongoing planning process within state agencies. This is further complicated by significant differences in the nature and duration of services needed and provided.

The findings of stakeholder interviews were used as a starting point in estimating needs. These findings point to the state's need to allocate additional funds to satisfy needs, but they do not provide information about the amount of increase that is necessary. Moreover, these findings do not address the question of changing existing services or shifting resources to more flexible alternative supports to increase their effectiveness in satisfying needs. Given these limitations in data available, a very cautious range of needed resources was calculated.

Stated in broad terms, Maryland's resources for services and supports to people with disabilities are contained in numerous state budgets with a total FY 1996 appropriation of \$725,439,789. Federal financial participation through the Medicaid program was \$549,592,597 for FY 1994, the most current year for which actual payment data is

available. The analysis estimates that an increase of approximately \$275 million would be necessary to satisfy the unmet needs of the current and expanded constituencies, without reducing expenditures in any current area.

In spite of numerous limitations in the fiscal analysis performed for the study, its findings support concerns about seriously inadequate resources, the necessity of shifting current resources into the most cost effective appropriate services to meet individual needs, the vast responsibility of ensuring equitable, effective distribution of existing resources, and the enormous scope of maintaining the resource base for services and supports to people with disabilities. If the Council constituency is expanded, the Council would have to be much more broadly involved in analyzing these issues for an expanded constituency. This would require greater knowledge of numerous additional support systems and funding mechanisms, often applicable to individual groups in the expanded constituency, and methods for shifting resources to more effective sources. This would require additional staff knowledge and resources.

Strain on Council Resources

Concern was virtually unanimous across current and potential constituency stakeholders that the Council would need additional financial and staff resources if its constituency expanded. While other factors also would be critical to retaining the Council's present level of effectiveness with a larger, more diverse constituency, additional resources would be necessary to support increased responsibilities and to meet the expectations of an expanded constituency.

The expanded scope of Council activities and the need for an increased knowledge base would require additional Council activity and therefore necessitate additional resources for staff coordination, research, and support to Council members. Further, to provide the detailed analysis of issues and activities in order to promote systems reform on behalf of an expanded constituency, without sacrificing the work on behalf of people with developmental disabilities, would require additional knowledge, staff and resources.

A common expectation of stakeholders in the potential constituency was direct representation on the Council. Some growth in Council membership should be anticipated in order to achieve a representative organization if the constituency expands. To date, the Council has assumed the costs associated with the support and expenses of consumer and community members as a way of ensuring their full participation. These costs have corresponded directly with the size of the Council and the specific support

needs of consumer members; presumably these would increase with an expanded constituency. Further, Council members have questioned whether a larger Council could function as effectively or directly.

In light of current Congressional efforts to reduce federal involvement in state activities, a detailed analysis of the costs of a potential Council expansion seems peripheral. It is clear that an increase in current activity would be necessary. In the current climate, it may be more productive to discuss ways in which the Council can serve an expanded constituency without incurring the costs of a formal organizational expansion.

• Opportunities for Collaboration •

It is not surprising that the study identified numerous areas of common interest throughout the broad population of people with severe disabilities in Maryland, many of which the Council had discovered through its 25 years of seeking partners in addressing the needs of people with developmental disabilities. Similarly, the Council has often been asked to join forces with others concerned with the interests of Maryland citizens with disabilities.

The study highlighted opportunities and imperatives for renewing these efforts in collaboration. The Council's federally authorized role in public policy development and reform is unique within the broader disability community in Maryland. The desire for stakeholder groups in Maryland to gain visibility and legitimacy through participation in partnership with the Council must be taken seriously. In addition, current efforts to significantly reduce federal spending could affect people with disabilities and their families in staggering proportions, necessitating broad collaboration on many fronts.

History of Collaboration

The nature of the Council's activities requires it to collaborate in practically all of its activities. Though people with developmental disabilities have been the targeted constituency, many Council strategies have purposely and/or indirectly involved a broad range of people with disabilities and other groups to effect positive change for those targeted. Following are a sampling of major Council efforts to achieve broad results, which have extended beyond individuals with developmental disabilities:

- Co-authored proposal to obtain the first federal statewide supported employment systems change grant
- Established and continue to support the Maryland Coalition for Inclusive Education
- Established and supported the Parents' Place of Maryland, the state's parent information and training center
- Sponsored the state's first business sponsored supported employment initiative within the Marriott Corporation
- Designed and funded the state's only Benefits Resource Network to advise individuals of the work incentive provisions of the Supplemental Security Income and Social Security disability programs
- Sponsored Partners in Policymaking leadership development program for parents and for individuals with disabilities
- Sponsored preschool inclusion pilot initiatives in partnership with local school districts and Head Start
- Provided leadership for development and expansion of family support services
- Initiated Home-of-Your-Own projects influencing state and local housing opportunities for individuals with disabilities.

Examples of Collaboration by Other Councils

To consider the full potential for collaborating effectively within the broad disability community in Maryland, the Maryland Council contacted the Indiana, Virginia, New Mexico and Utah Developmental Disabilities Councils to obtain their views on collaboration. Each of these councils has a specific state mandate to expand its efforts to some extent beyond people with developmental disabilities and therefore has experience with broader collaboration.

This broader collaboration is accomplished within the mandates and principles of the current DD Act. Each of the four state Councils indicated that although they engaged in a variety of activities involving a broad spectrum of people with disabilities, the federal DD Act continues to maintain their focus on people with developmental disabilities, particularly with their expenditures for demonstration grants. Each of the states saw merits to their increased broad collaboration, but felt a strong need to retain a focus on people with developmental disabilities.

The state mandates requiring broad collaboration vary considerably. At one end of the spectrum is a state mandate to expand activities to "all" people with disabilities; at the other is a limited requirement to support a task force representing one additional disability group, persons with head injuries. The following are brief profiles of the various ways in which these states are collaborating to benefit a broad range of people with disabilities:

- One broadly based council collaborates by setting council priorities to address common interests across a broad range of disability groups, e.g., housing, employment and personal assistance. Within priority areas it is sometimes necessary to develop parallel strategies to address the needs of people with the most intensive support needs. They indicated that there is a tendency to simplify needs when they are addressed broadly and it takes continuous effort to keep a focus on the needs of people with severe disabilities. This Council relies on members who represent the "original" developmental disabilities constituency to serve as a "conscience" within the Council to speak for people who are unable to speak for themselves.

- Another council supports collaboration by funding a broad based state disability coalition, with the council participating in the coalition on behalf of people with developmental disabilities. This coalition addresses legislative and public policy concerns. Because the Council funds the coalition, the council assures that the coalition's positions appropriately represent the needs of people with developmental disabilities. The coalition is the single form of broad collaboration that this Council consistently promotes. Its benefits are significant, bringing many limited and diverse interests together to present "the big picture" to policymakers.

- Another council has provided coordination for ten years among state agencies with various responsibilities for people with disabilities. This "niche" for the council may be diminishing now that its state government has become much more centralized. A new role emerging for the Council is advocating for the needs of people with the most severe disabilities, particularly those with developmental disabilities who cannot speak for

themselves. With imminent Medicaid changes, this council indicates that it may need to return to its "traditional core"—people with developmental disabilities and people with intensive long-term support needs.

- One council with a state mandate to support a limited expanded constituency coordinates policy positions with other groups who share common interests. However, it determined that it could expand its activities to specifically apply to an expanded group only if it receives increased resources. It is currently collaborating broadly in promoting "home-of-your-own" options for people with disabilities.

These councils identified many advantages to their broad collaborations. They say there is a "ripple" effect of council collaboration, especially in the area of public policy. They could jointly support a broader variety of issues and share information between groups. At the same time, they stressed that circumstances and timing were critical for successfully expanding collaboration and should be considered carefully by others.

Three councils indicated that the DD Act currently should and does promote broad collaboration and that their efforts could be adopted under the current language. They stressed that the Act's focus on people with developmental disabilities should not be changed. Alternatively, the one remaining council indicated that expanding the constituency of councils would not change operations significantly in the short run. The Council representatives frequently pointed out that their broad collaboration activities or "expansion" under the current DD Act should not serve as predictors of success if the DD Act was changed. All of the states indicated it requires particular efforts to keep attention directed to the needs of people with developmental disabilities.

Maximizing and Expanding Benefits of Current Council Activities

The study frequently encountered the viewpoint that the Council is effective because it is focused and thorough. Individuals believed that this focused and thorough examination must be maintained, regardless of expansion. The challenge raised, therefore, is maximizing these efforts to benefit a larger group of people without incurring additional costs, since additional Council resources are not presently forthcoming.

Highly ranked common needs identified by some representatives of the potential constituency fit well within the Council's existing priorities and community inclusion goals. Examples include housing assistance, employment, and personal assistance. While the actual supports within these areas are unique to various groups, overall policy implications are often shared and call for unified systemic strategies. The Council could

further open its initiatives to people with other severe disabilities, as well as groups that advocate and represent their interests, to encourage progress on behalf of both the current constituency and others.

The DD Act requires that the results of the Council benefit people with developmental disabilities. This requirement has generally assured that a focus is kept on people with severe and chronic disabilities. Within this parameter, the Council could examine activities that share potential benefits with a broader range of people with severe disabilities. The advisory committee for the study identified the following possible activities:

- All Council-sponsored demonstration and systems change projects could be required to disseminate results to all disability groups, not only within the developmental disabilities community.
- A specific Council committee could be established to regularly examine opportunities for broader collaboration and to foster such initiatives; a representative of the collaboration committee would be responsible for working with specific Council projects to identify these opportunities and foster their implementation.
- Representatives of the broader disability community could be recruited to provide expertise in specific areas identified by the Council or ad hoc committees. This activity would exceed current requirements for input into development of the Council State Plan.
- Advisory groups established as part of specific projects could include individuals or representatives of people with other severe disabilities who would share interest in project accomplishments and outcomes and could apply the lessons learned to other constituencies' support systems.
- Groups that have not traditionally applied to undertake Council grant projects could be encouraged to apply and be offered technical assistance.
- The Council could continue to expand its family support task force to bring together a wider array of family perspectives with respect to cultural differences, evolving care giving roles, and life span needs.

- Representatives of community groups, such as churches and businesses, could be involved more purposefully in Council activities in an effort to integrate and exchange knowledge and experience to increase support for all people with disabilities.
- The Council could work with board members of community nonprofit service providers to use their community contacts to increase support for people with developmental disabilities.
- The Council could increase its collaboration with other disability groups on issues of mutual interest in legislative activities at all levels.
- The Council could expand its work with existing broad-based coalitions such as the Maryland Disabilities Forum to advance mutual goals and issues.

• **Summary and Conclusions** •

The study found that people with disabilities share many concerns in general domains such as housing, employment and transportation. However, further examination revealed that the characteristics and needs of people with developmental disabilities in the Maryland Council's current constituency and those of the potential expanded constituency are frequently unique and different in significant ways. Common general needs often translate into different specific requirements, particularly when developing strategies to meet those needs.

Meeting the goal of full inclusion of people with developmental disabilities in school, work and community life continues to be a high priority and a great challenge. The Council's effectiveness in pursuing this goal relies heavily on the extensive knowledge of its members, staff and of the findings of its past and current research of the needs of people with developmental disabilities, as well as the systems and supports that respond to those needs. Acquiring similar extensive knowledge of the expanded constituency, including specific needs and issues, as well as the unique systems and supports that meet those needs, would require significant additional resources for both expanded analysis and staff support. This could be accomplished if the additional resources followed the expanded constituencies, in a similar fashion to the expansion of the protection and advocacy systems.

The study identified major unmet needs among children and adults with developmental disabilities. It recognized that the effects of disability and isolation experienced during childhood and formative years often leads to the need for certain additional supports for people with developmental disabilities. It identified the need for the Council to increase its activities and inclusion of all people with developmental disabilities, including those with head injury or chronic mental illness experienced during the developmental years, to address those unmet needs. In addition, the study reaffirmed the need to continue the Council's efforts to assist people with severe and multiple developmental disabilities and their families to advocate effectively for themselves and for the necessary supports to meet their individual and collective needs.

These issues highlighted the current need for the Council to continue to maintain the ability to choose issues and strategies that increase supports for inclusion of people with developmental disabilities in community life, and to maintain, both publicly and internally, this primary focus of the Council. Stakeholders representative of the potential expanded constituency were clear that if the Council expanded its formal constituency, they expected that their interests, issues, and needs would be considered and addressed by the Council. They indicated that the Council would also be expected to identify and act on issues of common interest to a wide range of people with disabilities. This led to the conclusion that, without additional resources, an expanded Council constituency would cause a shift in its focus away from people with developmental disabilities and the mission of full inclusion. Alternatively, if the focus of the DD Act was retained on people with developmental disabilities but the constituency was expanded, the additional members in Maryland could become quite frustrated with the Council's inability to address their unique and specific needs and issues.

The study found that the Council is widely seen as effective because it is focused and thorough. Many stakeholders representing the potential expanded constituency shared the concern that an expansion would dilute this focused, thorough approach and analysis. This information, as well as other results of the study, led to consensus within the Maryland Council's focus group discussions that it currently should not alter its constituency, while it should concentrate on expanding the opportunities and means by which other groups could benefit from the Council's work. Other groups, with resources and more expertise in the mechanisms for system change within the expanded constituency, could then apply the Council's findings and demonstration projects to the needs of their constituencies and the systems that deliver supports. In the final analysis, the study emphasized interest in the Council's continued success in effectively expanding knowledge and promoting effective best practices to increase inclusion of people with developmental disabilities in communities. There was a strong desire to continue the

Council's work promoting effective strategies to meet the needs of children and adults with developmental disabilities and their families. If additional resources could be identified to expand the Council's efforts, rather than merely shift its focus or expand the group for which it is responsible, there is interest in revisiting the issue of expansion. Until that time, the Council's approach of collaboration, particularly with the implementation of the increased activities identified by the study, produces significant benefits to others with severe disabilities and related needs.

The study itself generated a great deal of discussion among representatives of the disability community and identified additional avenues for collaboration and dissemination of information. With knowledge of the results of the study, and implementation of the suggestions that arose from the discussions generated, the Council can continue to advocate for people with developmental disabilities, while collaborating more effectively within the broader disability community to benefit all people with disabilities.

DEVELOPMENTAL DISABILITY

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

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

B) is manifested before the individual attains age 22;

C) is likely to continue indefinitely;

D) results in substantial functional limitations in three or more of the following areas of major life activity--

- 1) self care
- 2) receptive and expressive language
- 3) learning
- 4) mobility
- 5) self-direction
- 6) capacity for independent living and
- 7) economic self-sufficiency, and

E) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated

except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

POTENTIAL DEFINITION
OF EXPANDED DD COUNCIL CONSTITUENCY

A severe and long term disability of an individual five years or older that ~

- (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (B) is likely to continue indefinitely;
- (C) 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 self-sufficiency; and
- (D) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated,

except that such term, when applied to infants and young children means individuals from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in disabilities.

KEY STAKEHOLDER INTERVIEW PARTICIPANTS

Current Constituency: Advocacy Representatives

Michael Brill
Will Fields
Marcelle Meisel
Connie Reinwald
Maryland Developmental Disabilities Council Members
300 W. Lexington Street
Baltimore, Maryland 21201
Phone: 333-3688

Mark Mlawer, Executive Director
MD Coalition for Inclusive Education
7257 Parkway Drive, Suite 209
Hanover, Maryland 21076
Phone: 712-4837

Nan Gootenberg, President
People on the Go
6810 Deerpath Road #310
Baltimore, Maryland 21227

Cristine Marchand, Executive Director
The ARC Maryland
6810 Deerpath Road Suite #310
Baltimore, Maryland 21227
Phone: 379-0400

Current Constituency: State Agency Representatives

Fred Meyer, Regional Director
Developmental Disabilities Administration
Southern Maryland Region
3100 Gracefield Road
Silver Spring, Maryland
Phone:(301)595-5000

Richard Steinke, Assistant Superintendent
Division of Special Education
Maryland State Department of Education
200 W. Baltimore Street
Baltimore, Maryland 21201-2595
Phone: 767-0238

Linda Thompson, Ph.D.
Special Secretary
Office of Children, Youth, and Families
301 W. Preston Street, Room 1502
Baltimore, Maryland 21201
Phone: 225-4160

Current Constituency: Provider Representatives

Lee Ann Kingham, Executive Director
Epilepsy Association of Maryland
300 E. Joppa Road #1103
Towson, Maryland 21286
Phone: 828-7700

Michael Chapman
Assistant Vice President, Community Resources
Kennedy Krieger Institute
University Affiliated Program
2911 East Biddle Street
Baltimore, Maryland 21213
Phone: 550-9700

Rick Roland
United Cerebral Palsy, Central Maryland
31 Walker Ave., Suite #110
Baltimore, Maryland 21208

Alan Lovell, President, MACS
CHI Center
10501 New Hampshire Ave.
Silver Spring, Maryland 20903

Expanded Constituency: Advocacy Representatives

Dori DiVenti, Executive Director *
Joyce Leher, Assistant Director
Multiple Sclerosis Society
1055 Taylor Ave., Suite 201
Towson, Maryland 21204
Phone: 821-8626

Frank Smith, Executive Director *
Alliance for the Mentally Ill
711 West 40th Street, Suite 451
Baltimore, Maryland 21211

Bea Rodgers, Immediate Past President, Board Member *
Mental Health Association of Maryland Inc.
711 West 40th Street Suite 428
Baltimore, Maryland 21211
Phone: 235-1178

Peg Sullivan, Executive Director *
On Our Own
5422 Belair Road
Baltimore, Maryland 21206
Phone: 488-4480

Cass Naugle, Executive Director
Alzheimer's and Related Diseases Association
1850 York Road Suite D
Timonium, Maryland 21093
Phone: 561-9099

* Though some members of these organizations may have developmental disabilities, as defined by the study with age of onset occurring before age 22, these organizations were considered to represent the expanded constituencies because the majority of their members were thought to have primarily nondevelopmental disabilities. As the study progressed, the needs of people with developmental disabilities represented by these organizations were discussed in more detail.

Elmer Sewell, National Service Officer
E. Paul Stecklein, National Service Officer
Disabled American Veterans
National Service Office Supervisor
31 Hopkins Plaza, Rm. 114D
Baltimore, Maryland 21201
Phone: 962-3045

Expanded Constituency: State Agency Representatives

Lissa Abrams, Chief *
Division of Program Development & Special Projects
Mental Hygiene Administration
Department of Health and Mental Hygiene
201 W. Preston Street
Baltimore, Maryland 21201
Phone: 225-5332

Sue Ward, Director
John Coe, Planner
Violet Sloat, Chief of Planning & Intergovernmental Affairs
Office of Aging
301 W. Preston Street Room, 1004
Baltimore, Maryland 21201-2374
Phone: 225-1100

Karen R. Wulff, Planner *
Ellen Caldeia, Epidemiologist
Evelyn Duan, Service Coordinator
AIDS Administration
500 North Calvert Street, 5th Floor, DHMH
Baltimore, Maryland 21201
Phone: 767-5043

Expanded Constituency: Provider Representatives

Francis Bateson, Executive Director *
Maryland Head Injury Foundation
916 South Rolling Road
Baltimore, Maryland 21228
Phone: 747-7758

Frank Pinter, Executive Director *
Maryland Center for Independent Living
6305-A Sherwood Road
Baltimore, Maryland 21239

Steve Johnson, People Encouraging People, Director *
Emily Gedden, New Phases, Director
Herb Cromwell, Executive Director
MAPSS
109 Melrose Ave., Suite C
Catonsville, Maryland 21228
Phone: 788-1865

Both Constituencies: Advocacy Representatives

Elizabeth Jones, Director
Maryland Disability Law Center
1800 N. Charles Street, Suite 204
Baltimore, Maryland 21201
Phone: 234-2791

Both Constituencies: State Agency Representatives

William Barber, Ph.D.
Manager, In-Home Aide Program
Department of Human Resources
311 W. Saratoga Street
Baltimore, Maryland 21201
Phone: 767-7097

Robert Burns, Assistant State Superintendent
Diane Pawlowicz, Director of Communication and Community Relations
Division of Rehabilitation Services
2301 Argonne Drive
Baltimore, Maryland 21218
Phone: 554-3276

Kathryn King
Michael Franch, Ph.D.
Division of Program Services
Medical Care Policy Administration
201 W. Preston Street
Baltimore, Maryland 21201
Phone: 225-5220

Diane Ebberts, Director
Governor's Office on Individuals with Disabilities
300 W. Lexington Street
Baltimore, Maryland 21201
Phone: 333-3098

AGENCIES CONTACTED FOR THE INTERVIEW SAMPLE*

Mental Health Agencies

Johns Hopkins Hospital

Dr. Nestadt

600 North Wolfe Street

Baltimore, Maryland 21205

955-2883

Springfield Hospital Center*

Dr. Sherrill Cheeks, Clinical Director

Sykesville, Maryland 21784

795-2100

Liberty Medical Center

Dr. Orlando Davis, Clinical Director

2600 Liberty Heights Ave.

Baltimore, Maryland 21215

383-4900

Walter P. Carter Center*

Ilene Hastings, Clinic Coordinator

630 West Fayette Street

Baltimore, Maryland 21201

328-2144

Francis Scott Key Medical Center*

Sheila Seltzer, Adult Outpatient Coordinator

4940 Eastern Avenue

Baltimore, Maryland 21224

550-0100

University Hospital

Institute of Psychiatry and Human Behavior

Dr. Giannandrea

645 West Redwood Street

Baltimore, Maryland 21201

328-6822

* Agencies that provided referrals for the interviews.

Changing Directions*

Thomas Arthur, Chief Executive Officer
1400 East Federal Street
Baltimore, Maryland 21213
727-2611

STEP, Inc.*

Patricia Dieter, Executive Director
11 East Chase Street
Baltimore, Maryland 21202
625-1877

People Encouraging People*

Kelli Kinsey, Assistant Residential Director
4201 Primrose Ave.
Baltimore, Maryland 21215
764-8560

Mar-Lynn Inc.

Barton Azwalinsky
20 Court House Square, Suite 217
Rockville, Maryland 20850
486-8074 (Janet Horowitz) (301)762-2922

Project PLASE*

Bonnie Rohr, Director
2029 St. Paul Street
Baltimore, Maryland 21218
837-1400

Key Point Inc.*

Bill Kordonski, Program Director
7A Shipping Place
Dundalk, Maryland 21222
282-3831

Harbor City Unlimited

Digna Cloud, Director of Residential
Rehabilitation Services
University of Maryland Medical Systems
1 North Carey Street
Baltimore, Maryland 21223
328-8560

North Baltimore Center
Mobile Treatment Team and Team for the Homeless
Karen Harvest
2225 North Charles Street
Baltimore, Maryland 21218
243-7882

On Our Own
Peg Sullivan, Executive Director
5422 Belair Road
Baltimore, Maryland 21206
488-4480

Alliance for the Mentally Ill*
Frank Smith, Executive Director
2114 North Charles Street
Baltimore, Maryland 21218
889-4878

Almost Family*
Carol Miller, Executive Director
16671 Knecht Ave.
Arbutus, Maryland 21227
242-8900

Dorchester County Health Department
Debbie Gootee, Clinic Director
751 Woods Road
Cambridge, Maryland 21613
(410)228-6800

Go Getters*
Dick Bearman
108 West Lehigh Ave
Salisbury, Maryland 21801
(410)546-0381

Channel Marker, Inc.*
Romey Robinson, Director
433 Race Street
Cambridge, Maryland 21613
(410)228-8330

Eastern Shore Hospital Center*
Mary Kay Noren, Acting Superintendent
P.O. Box 800
Cambridge, Maryland 21613
(410)221-2300

Somerset County Health Department*
Caroline Aloisi, Program Director
7920 Crisfield Road
Westover, Maryland 21871
(410)651-5660

Peninsula General Hospital
Bill Elliott, Program Director
100 East Carroll Street
Salisbury, Maryland 21801
(410)546-6400

Sacred Heart Hospital
Steve Richard, Program Director Mental Health
900 Seton Drive
Cumberland, Maryland 21502
(301)759-4200

Thomas B. Finan Center*
Dr. Michael Ehlers, Clinical Director
P.O. Box 1722
Country Club Road
Cumberland, Maryland 21502
(301)777-2200

Community Mental Health Center*
Ann Abrahamson, Mental Health Clinic Director
Willowbrook Road
Cumberland, Maryland 21502
(301)777-5606

Archway Station*
Lou Van Hollen
408 North Centre Street
Cumberland, Maryland 21502
(301)777-1700

Lighthouse*
Debbie Joe Adams-Noroski
P.O.Box 116
Oakland, Maryland 21550
(301)334-9126

Garrett County Memorial Hospital*
Dr. Stuart Callis
251 North Fourth Street
Oakland, Maryland 21550
(301)334-2155

Garrett County Health Department
Rex Archer, Health Officer
253 North Fourth Street
Oakland, Maryland 21550
(301)334-8111

**Agencies Serving: Persons Who Use Wheelchairs and Have Personal Care Attendants;
 Persons with Severe and Chronic Conditions Related to Aging; and
 Persons with HIV/AIDS**

Department of Human Resources
In Home Aide Services Program
Dr. Willie Barber, Executive Director
201 West Preston Street
Baltimore, Maryland 21201
767-7097

Lakeview Medical Day Care*
Ms. Rosemary Terry, Director
727 Druid Park Lake Drive
Baltimore, Maryland 21217
669-7171

Lillian S. Jones Day Care
Ms. Francis Walford, Director
730 George Street
Baltimore, Maryland 21201
539-7566

Keswick Day Care*
Mr. Garret Falcone, Executive Director
700 West 40th Street
Baltimore, Maryland 21217
235-8860

Levindale Day Care
Michelle Hassen
2434 West Belvedere Avenue
Baltimore, Maryland 21215
466-9700

Almost Family*
Ms. Christine Pistoia, Executive Director
9980 Liberty Road
Randallstown, Maryland 21133
922-9600

Waxter Center*
Ms. Neetu Dhawan-Gray, Executive Director
861 Park Avenue
Baltimore, Maryland 21201
396-1333

In Home Aide Services*
Mr. Phil Parker
1800 North Charles Street
Baltimore, Maryland 21201
361-2792

Centers For Independent Living*
Mr. Frank Pinter
6305A Sherwood Road
Baltimore, Maryland 21239
377-5900

Shore Up, Chrisfield Adult Day Care
Mr. Freddie Mitchell
520 Snowhill Road
Salisbury, Maryland 21803
(410)749-1142

Dorchester Developmental Unit*
Santo Grande, Director
P.O. Box 637
Cambridge, Maryland 21613
(410)221-1900

In Home Aide Program*
Wendy Wilson
P.O. Box 217
Cambridge, Maryland 21613
(410)228-5100

Westernport Adult Day Care*
Betty Turner
25701 Shady Lane Southwest
Westernport, Maryland 21562
(301)359-3058

Frostburg Village
Adult Day Care
Paula James, Program Director
1 Kaylor Circle
Frostburg, Maryland 21532
(301)463-5559

In Home Aide Services
Rick DeWhitt
P.O. Box 556
Oakland, Maryland 21550
(301)334-9461

HRDC/Adult Day Care Director
Terry Froelich
19 Frederick Street
Cumberland, Maryland 21502

Cumberland Center Adult Medical Day Care*
Sharon Metz, Center Manager
720 Furnace Street
Cumberland, Maryland 21502
(301)777-8422

Agencies Serving Persons with Other Conditions

Chesapeake Head Injury Center
Dale Zinn, Program Director
26726 St. Michaels' Road
Easton, Maryland 21601
(410)822-3949

Deer's Head Center
Ms. Bradshaw, Director
P.O. Box 2018
Salisbury, Maryland 21801
(410)543-4000

Developmental Services Group*
Deborah Yates Youngquist, Program Director
938 D Gerwig Lane
Columbia, Maryland 21046
381-7171

Return! Sinai Hospital*
Ms. Judith Coho, Manager of Clinical Supports
Greenspring and Belvedere Avenues
Baltimore, Maryland 21215
578-6185

L.I.F.E.
Thomas Noto, Executive Director
6630 Baltimore National Pike
Suite 207-B
Baltimore, Maryland 21218
788-4570

Montebello Rehabilitation Hospital-Brain Injury Unit
Dr. Daniel Drubach
2201 Argonne Drive
Baltimore, Maryland 21218
544-5200

Western Maryland Center
Dr. Carl Fischer, Hospital Director
1500 Pennsylvania Avenue
Hagerstown, Maryland 21740
(301)791-4430

M.S. Society Central Maryland*

Kate Jacobson

1055 Taylor Avenue, Suite 201

Towson, Maryland 21286

821-8626

M.S. Society Eastern Shore Branch*

Sandy Smith

923 B Eastern Shore Drive

Salisbury, Maryland 21801

(410)543-0571

M.S. Society Western Maryland Branch*

Clara Clow

Robin Turner

5 Public Square, Room 313

Hagerstown, Maryland 21740

(301)791-5754

Alzheimer's Disease and Related Disorders

Cass Naugle, Executive Director

1850 York Road, Suite D

Timonium, Maryland 21093

561-9099

Contact Letter

This letter was sent to agencies to request referrals of persons to participate in the consumer interviews.

Dear:

I am writing to request your participation in a study the Maryland Developmental Disabilities Council is conducting called "Expanding the Targeted Constituency of the Maryland Developmental Disabilities Council: A Feasibility Study." The study is a "project of national significance" funded through a grant to the Maryland Council from the federal Administration on Developmental Disabilities (ADD).

Briefly, the study aims to determine the impact of expanding the Council's activities beyond the developmental disabilities community to respond to a broader constituency which would include people with other severe, chronic conditions. The Council currently uses the federal functional definition of developmental disability which limits eligibility to people whose disabilities begin before age 22. Initially, our study will examine the implications of using the same definition without the age of onset limitation.

The two most significant questions addressed in the study are:

- 1) How will the potentially expanded constituency be identified and defined?
- 2) Will a broader constituency support and benefit from the Council's mission of increasing the community inclusion and self-determination of people with severe disabilities?

The study also will examine whether the Council could maintain its mission of community inclusion if it broadened the scope of people it represents ~ would different groups representing people with severe disabilities be more effective separately or collectively through the Council or a similar entity?

The results and recommendations of the Council's study will be reported to the Administration on Developmental Disabilities and considered in the next Congressional reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act in 1996.

Structured personal interviews and focus groups will be conducted with members of the potential expanded constituency and their representatives. The information generated from these interviews and focus groups will be used to identify service and support needs of people with severe, chronic disabilities other than developmental disabilities.

We are requesting your organization's participation as part of this feasibility study. We may ask for your assistance in identifying individuals within the potential new constituency to be interviewed and to take part in focus groups.

The Council is working with Alice Wells, Ph.D., and Linell Cahn-Gold from the University of Maryland to complete this study. They will be contacting your organization to identify participants for the interviews.

Additional information about the Council, a more detailed summary of the project, and a draft of the study definition of disability are enclosed. The project proposal is available from the Council office. If you have questions about the project, please call Cathy Lyle at the Council (410-333-3688) or Alice Wells at the University of Maryland (410-328-2140). Thank you in advance for your interest and cooperation in this effort.

Sincerely,

Joanna Pierson
Chairperson

Enclosures

COUNCIL RESPONSIBILITIES

Developmental Disabilities Assistance and Bill of Rights Act

A Council, through Council members, staff, consultants, contractors, or sub grantees, shall have the responsibilities described in paragraphs (1) through (11).

(1) **SYSTEMIC CHANGE, CAPACITY BUILDING, AND ADVOCACY ACTIVITIES**

The Council shall serve as an advocate for individuals with developmental disabilities and conduct programs, projects, and activities that carry out the purpose under section 121.

(2) **EXAMINATION OF PRIORITY AREAS**

Not less than once every 3 years, the Council shall examine the provision of and need for the four Federal priority areas and an optional State priority area to address, on a statewide and comprehensive basis, urgent needs for services, supports, and other assistance for individuals with developmental disabilities and their families, pursuant to section 122.

(3) **STATE PLAN DEVELOPMENT**

The Council shall develop and submit to the Secretary the State plan required under section 122 after consultation with the designated State agency under the State plan. Such consultation shall be solely for the purposes of obtaining State assurances and ensuring consistency of the plan with State law.

(4) **STATE PLAN IMPLEMENTATION**

The Council shall implement the State plan by conducting and supporting the Federal priority area of employment, not less than one of the remaining three Federal priority areas, and an optional State priority area as defined in section 102, through systemic change, capacity building, and advocacy activities such as those described in subparagraphs (A) through (K).

(A) **DEMONSTRATION OF NEW APPROACHES**

The Council may conduct, on a time-limited basis, the demonstration of new approaches to enhance the independence, productivity, and integration and inclusion into the community of individuals with developmental disabilities. This may include making successful demonstrations generally available through sources of funding other than funding under this part, and may also include assisting those conducting such successful demonstrations activities to develop strategies for securing funding from other sources.

(B) OUTREACH

The Council may conduct activities to reach out to assist and enable individuals with developmental disabilities and their families who otherwise might not come to the attention of the Council to obtain services, supports, and other assistance, including access to special adaptation of generic services or specialized services.

(C) TRAINING

The Council may conduct training for individuals with developmental disabilities, their families, and personnel (including professionals, para professionals, students, volunteers, and other community members) to enable such individuals to obtain access to, or to provide, services, supports and other assistance, including special adaptation of generic services or specialized services for individuals with developmental disabilities and their families. To the extent that training activities are provided, such activities shall be designed to promote the empowerment of individuals with developmental disabilities and their families.

(D) SUPPORTING COMMUNITIES

The Council may assist neighborhoods and communities to respond positively to individuals with developmental disabilities and their families by encouraging local networks to provide informal and formal supports and enabling communities to offer such individuals and their families access, resources, and opportunities.

(E) INTERAGENCY COLLABORATION AND COORDINATION

The Council may promote interagency collaboration and coordination to better serve, support, assist, or advocate for individuals with developmental disabilities and their families.

(F) COORDINATION WITH RELATED COUNCILS, COMMITTEES AND PROGRAMS

The Council may conduct activities to enhance coordination with:

(i) other councils or committees, authorized by Federal or State law, concerning individuals with disabilities (such as the State Interagency Coordinating Council under part H of the Individuals with Disabilities Education Act, the State Rehabilitation Advisory Council and the Statewide Independent Living Council under the Rehabilitation Act of 1073, the State Mental Health Planning Council under part B of title XIX of the Public Health Service Act and other similar councils or committees);

(ii) parent training and information centers under part D of the Individuals with Disabilities Education Act and other federally funded projects that assist parents of children with disabilities; and

(iii) other groups interested in systemic change, capacity building, and advocacy for individuals with disabilities.

(G) **BARRIER ELIMINATION, SYSTEMS DESIGN, AND CITIZEN PARTICIPATION**

The Council may conduct activities to eliminate barriers, enhance systems design and redesign, and enhance citizen participation to address issues identified in the State plan.

(H) **PUBLIC EDUCATION AND COALITION DEVELOPMENT**

The Council may conduct activities to educate the public about developmental disabilities and their families and to develop and support coalitions that support the policy agenda of the Council, including training in self-advocacy, educating policymakers, and citizen leadership skills.

(I) **INFORMING POLICYMAKERS**

The Council may provide information to Federal, State, and local policymakers, including the Congress, the Federal executive branch, the Governor, State legislature, and State agencies, in order to increase the ability of such policymakers to offer opportunities and to enhance or adapt generic services or provide specialized services to individuals with developmental disabilities and their families by conducting studies and analyses, gathering information, and developing and disseminating model policies and procedures, information, approaches, strategies, findings, conclusions, and recommendations.

(J) **PREVENTION**

The Council may conduct prevention activities as defined in section 102.

(K) **OTHER ACTIVITIES**

The Council may conduct other systemic change, capacity building, and advocacy activities to promote the development of a consumer and family-centered comprehensive system and a coordinated array of culturally competent services, supports and other assistance designed to achieve independence, productivity, and integration and inclusion into the community of individuals with developmental disabilities throughout the State on a comprehensive basis.

MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL

Membership List - December 1995

1.	Naznin Adams	Secondary Consumer
2.	Michael Brill	Primary Consumer
3.	Jim Burns	Secondary Consumer
4.	Michael Chapman Kennedy Krieger Institute	University Affiliated Program Representative
5.	Ruth B. Coates	Secondary Consumer
6.	John Coe	State Agency Rep. Office on Aging
7.	M. Doreen Croser	Secondary Consumer
8.	Diane Ebberts	State Agency Rep. Developmental Disabilities Administration
9.	Laurence Eisenstein, Esq.	Secondary Consumer
10.	William Fields	Primary Consumer
11.	Sarah Glenner	Primary Consumer
12.	Carole Glowacki	Secondary Consumer
13.	Santo Grande	Service Provider
14.	Elizabeth Jones	Dorchester Developmental Unit Protection and Advocacy Maryland Disability Law Center
15.	P. Sue Kullen	Service Provider The Arc of Southern Maryland
16.	Alan C. Lovell	Service Provider CHI Centers
17.	Cristine Marchand	Secondary Consumer
18.	Leslie Seid Margolis	Primary Consumer
19.	Mary Jo McGovern	Secondary Consumer

20.	Marcelle Meisel	Primary Consumer
21.	Joseph Millstone	State Agency Rep. Medical Care Policy Administration
22.	M. Sherril Moon, Ed.D.	Higher Education Rep. University of Maryland Department of Special Education
23.	Mary Murphy	Primary Consumer
24.	Diane Pawlowicz	State Agency Rep. Division of Rehabilitation Services
25.	Joanna Pierson	Service Provider The ARC of Frederick County, Inc.
26.	Constance Reinwald	Primary Consumer
27.	Bea Rodgers	State Agency Rep. Governors Office for Individuals with Disabilities
28.	James Rosner	Secondary Consumer
29.	Richard Rowland	Service Provider UCP of Central Maryland
30.	Patti Saylor	Secondary Consumer
31.	Allen Schepps	Secondary Consumer
32.	Jacqueline Shields	Secondary Consumer
33.	Richard J. Steinke	State Agency Rep. MD State Department of Education
34.	Tim Wiens	Service Provider Jubilee Association of Maryland

HELPFUL SERVICES AND SUPPORTS**n = 210**

Service and Support Area	Frequency	Percent
Assistance locating and securing employment	67	31.9
Assisted/supported living services	62	29.5
Assistance securing medical care and supplies	49	23.3
Assistance locating and securing housing	45	21.4
Religious or spiritual programs	44	21.0
Personal assistance services	38	18.1
Interpreter services	36	17.1
Assistance securing state/federal benefits	30	14.3
Assistance managing finances	25	11.9
Addiction services	22	10.5
Homemaker services	20	9.5
Transportation services	19	9.0
Medication management	19	9.0
Family/significant other support group	19	9.0
Respite care services in and out of home	18	8.6
Educational programs	13	6.2
Environmental modification at home/work	11	5.2
Occupational and physical therapies	11	5.2
Mental health services	9	4.3
Assistance with legal issues	8	3.8
In-home nursing care	6	2.9
Child care/after school care	3	1.4
Parent training/parent support groups	3	1.4
Prosthetics	1	0.5
Other	6	2.9

PREFERRED LIVING ARRANGEMENTS
n = 210

Preferred Living Arrangement	Frequency	Percent
My current residence	114	54.3
My own house/apartment	35	16.7
With parents	9	4.3
With relatives other than parents	7	3.3
Supported living	6	2.9
Shared house or apartment with support	6	2.9
With spouse or significant other	5	2.4
Shared house or apartment without support	2	1.0
Group home	2	1.0
Halfway house	1	0.5
With different house/roommates	1	0.5
Boarding home	1	0.5
Nursing home	1	0.5
Other	20	9.5

CURRENT LIVING ARRANGEMENTS
n = 210

Current Living Arrangement	Frequency	Percent
Own home without support	45	21.4
Parents'/relatives' home	43	20.5
Mental health hospital	38	18.1
Own home with support	35	16.7
Alternative living unit	8	3.8
Shared house or apartment without support	7	3.3
Boarding home	6	2.9
Nursing home	5	2.4
Shared house or apartment with support	4	1.9
Group home	4	1.9
Temporary shelter	3	1.4
Other	12	5.7

DECISION MAKING
n = 210*

Percent Making These Decisions:

Decision Making Area	Always	Sometimes	Rarely/Never
Medical care	44.8	25.6	29.6
Friends and acquaintances	67.7	21.4	10.9
Free time activities	59.5	29.0	11.5
Personal spending	56.5	21.5	22.0
Alone time	58.2	19.4	22.4
Service providers	36.1	24.2	39.7
Needed services	33.0	27.3	39.7

*The number of individuals responding to each of the decision making questions ranged from a low of 194 to a high of 203.

PRIMARY AND SECONDARY DAYTIME ACTIVITIES
n = 210

Primary Activity	Frequency	Percent
Medical day program	46	21.9
Day treatment program	39	18.6
Hospitalized	26	12.4
Rehabilitation training program	18	8.6
Retired	12	5.7
Day care	11	5.2
Volunteer job	7	3.3
Take care of relatives	6	2.9
Take care of children	5	2.4
Part time paid work	5	2.4
School	2	1.0
Full time paid work	2	1.0
Unpaid supported employment	1	0.5
Continuing education	1	0.5
Paid supported employment	1	0.5
Other	14	6.7
No organized primary activity	14	6.7

Secondary Activity

Medical day program	7	12.5
Rehabilitation training program	6	10.7
Retired	5	8.9
Take care of children	3	5.4
Part time paid work	3	5.4
Sheltered workshop	3	5.4
Day treatment program	2	3.6
Continuing education	2	3.6
Volunteer job	2	3.6
Hospitalized	2	3.6
Paid supported employment	1	1.8
Unpaid supported employment	1	1.8
Day care	1	1.8
Other	18	32.1
No organized secondary activity	154	73.3

PRIMARY AND SECONDARY DISABILITIES
n = 210

Primary Disability	Frequency	Percent
Chronic mental illness	79	37.6
Multiple sclerosis	34	16.2
Impairments related to aging	27	12.9
Alzheimer's Disease	19	9.0
Head injury	18	8.6
Spinal cord injury	12	5.7
Neurological impairments	11	5.2
Mobility impairment	6	2.9
Other	4	1.9
Secondary Disability		
None	115	54.8
Other health condition	49	23.3
Neurological impairments	11	5.2
Chronic mental illness	8	3.8
Impairments related to aging	8	3.8
Mobility impairments	6	2.9
Blindness/severe visual impairment	3	1.4
Alzheimer's Disease	2	1.0
Other	8	3.8

IMPORTANT FACTORS FOR COMMUNITY INCLUSION
n = 72*

Factors	Frequency**	Percent
Financially afford to live where you want	63	87.5
Friends nearby	61	84.7
Neighbors who respect you	61	84.7
Available/accessible transportation	61	84.7
Family nearby	58	80.6
Affordable housing alternatives	56	77.8
Community recreational activities	56	77.8
Medical care available when needed	55	76.4
Employment nearby	53	73.6
Religious/spiritual programs nearby	52	72.2
Adequate job supports	51	70.8
Someone to help you find a job	51	70.8
Opportunity to try out different jobs	49	68.1
Available in-home supports	49	68.1
Personal assistance providers nearby	47	65.3
Flexible work schedule	46	63.9
Community college/adult education	44	61.1
Accessible work areas	34	47.2
Home accessible to wheelchairs/walkers	34	47.2
Political participation	30	41.7
Assistive technology services/devices	29	40.3
Other	4	5.6

*In all, 72 interviewees wanted to be more involved in their broader communities.

**BARRIERS TO PROVIDING INTEGRATED SERVICES AND SUPPORTS:
CURRENT CONSTITUENCY**

n = 14

Barrier	Frequency	Percent
Lack of state leadership	7	50.0
Community attitudes	7	50.0
Lack of agency leadership	6	42.9
Lack of transportation	6	42.9
Lack of resources to adequately train staff	4	28.6
Inaccessible mental health services	4	28.6
Lack of skilled support personnel	4	28.6
State regulations *	3	21.4
Lack of adequate job supports	3	21.4
Lack of resources to recruit qualified staff	3	21.4
Lack of employers willing to provide integrated employment opportunities	3	21.4
Inaccessible housing	3	21.4
High turn over rates among direct care staff	2	14.3
Lack of emergency services	2	14.3
Lack of medical care	2	14.3
Lack of assistive technology	1	7.1
Housing is too expensive	1	7.1
Other**	7	50.0

* State Regulations: Licensing and certification for adult community services should be modified. Regulations are too prescriptive, rigid and process oriented. Independent state agencies need more than coordination.

** Other:

- Categorical funding (age specific and disability/disease specific)
(1 respondent)
- Inadequate funding (2 respondents)
- Fear of job loss by professional staff (1 respondent)
- Professional turf (1 respondent)
- Lack of knowledge about providing supports for people with head injuries (1 respondent)
- Lack of assistance to obtain appropriate jobs (1 respondent)

**BARRIERS TO PROVIDING INTEGRATED SERVICES AND SUPPORTS:
POTENTIAL EXPANSION CONSTITUENCY**

n = 12

Barrier	Frequency	Percent
Housing is too expensive	6	50.0
Lack of transportation	6	50.0
Lack of skilled support personnel	4	33.3
Lack of employers willing to provide integrated employment opportunities	4	33.3
Lack of emergency services	4	33.3
Lack of medical care	4	33.3
Lack of community interest and support	3	25.0
Lack of state leadership	3	25.0
Housing is not accessible	3	25.0
Lack of resources to adequately train staff	3	25.0
Community attitudes	2	16.7
Inaccessible mental health services	2	16.7
State regulations*	2	16.7
Lack of adequate job supports	2	16.7
Lack of resources to recruit qualified staff	2	16.7
Unsafe neighborhoods	2	16.7
Inaccessible addiction services	1	8.3
High turn over rates among direct care staff	1	8.3
Other**	9	75.0

*State regulations: CSLA eligibility criteria limiting age of onset prevent some people from receiving services (1 respondent).

Too many different state agencies (3) provide assisted housing and personal care services with different eligibility criteria and regulations (1 respondent).

** Other:

Lack of integrated services and cross integration of services (1 respondent);

Lack of education within the veteran community about available benefits (1 respondent);

Cost and inadequate funding of long term care services (1 respondent);

For people with chronic mental illness:

lack of financial support for advocacy groups to provide crisis services (1 respondent);

complications of substance abuse and mental illness (1 respondent);

inadequate funding (1 respondent);

lack of client income including disincentives for work (1 respondent);

financing strategies which rely heavily on Medical Assistance and are not consistent with community integration philosophy (1 respondent); and

additional risks faced by those in the correctional system (1 respondent).

POTENTIAL DEFINITION
OF EXPANDED DD COUNCIL CONSTITUENCY

A severe and long term disability of an individual five years or older that ~

- (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (B) is likely to continue indefinitely;
- (C) 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 self-sufficiency; and
- (D) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated,

except that such term, when applied to infants and young children means individuals from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in disabilities.

MARYLAND DEVELOPMENTAL DISABILITY DEFINITION

DEVELOPMENTAL DISABILITY

"Developmental disability" means a severe chronic disability of an individual that:

- (1) Is attributable to a physical or mental impairment, other than the sole diagnosis of mental illness, or to a combination of mental and physical impairments;
- (2) Is manifested before the individual attains the age of 22;
- (3) Is likely to continue indefinitely;
- (4) Results in an inability to live independently without external support or continuing and regular assistance; and
- (5) Reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are individually planned and coordinated for the individual.

FEDERAL DEVELOPMENTAL DISABILITY DEFINITION

DEVELOPMENTAL DISABILITY

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

- (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (B) is manifested before the individual attains age 22;
- (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 individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated,

except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

EXAMPLE OF MENTAL HEALTH SERVICE PROVIDER ELIGIBILITY DETERMINATION DEFINITION

Source: Steve Johnson, People Encouraging People (764-8560)
Services to people with mental illness

Provide residential, day and vocational services - varying array of services in each category.

Provide services based on what the individual wants and is determined to be his/her need (do an assessment)

Functional needs determined based on information from the individuals, family, therapist, referral source

Don't categorize people based on needing a specific level of support; make a general statement of need

Eligibility

Diagnosis of a major mental illness ("major" defined as chronic or serious and persistent -- typically an Axis I diagnosis using the DSM)

Can have other disabilities in addition to mental illness (e.g., mild/moderate developmental disability, substance abuse, multiple mental illness)

Most of the time it is clear to PEP if the individual can be well served in the mental health system or should be referred to DDA;

Difficult getting appropriate services if person is dd/mh

Even though people with mental illness and people with developmental disabilities have basically the same needs, the way in which those needs are met are often different

EXHIBIT 5-1
DEFINITION OF PRIORITY POPULATION
ADULTS AGED 18-64

MHA identifies the adult priority population as those individuals 18-64 years of age, who are seriously mentally ill, who lack sufficient financial resources to obtain required treatment, and who meet the criteria in the following categories:

1. Primary Diagnosis - Major mental illness as defined by:
 - a. Schizophrenic disorder (DSM-III-R 295.00-295.99); or
 - b. Major affective disorder (DSM-III-R 296.00-296.99); or
 - c. Organic mental disorder (DSM-III-R 290.00-290.99, 293.00-294.99 and 310.00-310.99); or
 - d. Other psychotic disorder (DSM-III-R 290.00-297.99, 298.9) or 1
 - e. Borderline and schizotypal personality disorders (DSM-III-R 301.83, 301.20-301.22) with the exclusion of an abnormality that is manifested only by repeated criminal or otherwise antisocial conduct,

AND

2. Impaired Role Functioning Resulting from Mental Illness:

In addition to meeting the above categories, clients must meet at least three of the following five criteria on a continuing or intermittent basis for at least two years.

- a. Is unemployed, employed in a sheltered setting, or has markedly limited skills and a poor work history.
- b. Exhibits inappropriate social behavior which results in a demand for intervention by the mental health system.
- c. Is unable, due to cognitive disorganization, to procure financial assistance to enable him/her to remain outside of the hospital.
- d. Shows severe inability to establish or maintain a personal social support system.
- e. Requires help in basic living skills.

Note: Adults who would have met impaired role functioning criteria during the referenced years without the benefit of treatment or other support services are considered to be members of this priority population for adults aged 18-64.

3. Priority for Services

When resources are limited, consumers who meet criteria 1 and 2 and have the following psychiatric history will have priority for services:

- a. Single psychiatric hospitalization of six months or more in duration during the past ten years; or who have been
- B. Psychiatrically hospitalized more than once during the past two years.

EXAMPLE OF SENIOR PROVIDER

ELIGIBILITY DETERMINATION DEFINITION

Source: Cathy Abbott, DDU (410/221 -1695)
DD programs and Senior programs

Age eligibility is 60 for senior services according to state and 62 for Senior Assisted Living

Senior programs (mostly seniors who do not have developmental disabilities; although some do):

Assess dependency in ADLs - eating, transferring, dressing, bathing, toileting, grooming, ambulating

Assess dependency in Instrumental ADLs - preparing light meal, maintaining home, grocery shopping, traveling more than 50 feet, taking meds, managing money, using the phone, planning and making decisions

Rate each of these numerically and then arrive at a total score. Keep in mind that some people never could do certain things independently (e.g., manage finances). This helps to determine which program to place them in: Senior Center, senior Center Plus or Adult Day Care

Involve other professionals to determine where best to serve. Individualized. For example, a person with Parkinson whose scores indicate they need Adult Day Care but they have high cognitive skills might be placed in Senior Plus instead (less restrictive).

Using this criteria works well -- just look at functional skills, doesn't matter if they are impaired from a disability before the age of 22 or due to aging. Works for appropriately placing both seniors and people with developmental disabilities.

AMERICANS WITH DISABILITIES ACT DEFINITION

DISABILITY

The term "disability" means, with respect to an individual -

- (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
- (B) a record of such an impairment; or
- (C) being regarded as having such an impairment

Organizations in Maryland Created to Address the Needs of Individuals with Disabilities or Those At Risk

There are several organizations created by state law and executive order that address the needs of children and adults with developmental disabilities, disabilities that occur after age 22, psychiatric disabilities, and age-related disabilities.

The following organizations are described based upon their composition and their missions. The descriptions may not entail every duty performed by the organization; those duties significant to the scope of this study have been listed.

ORGANIZATIONS ADDRESSING THE NEEDS OF CHILDREN OR CHILDREN AT RISK

Advisory Council for the Program for Hearing Impaired Infants

The Council is created by Title 13 of the Annotated Code of Maryland (§13-603). The Council consists of representatives from the medical and education professions, the State Departments of Education and Health and Mental Hygiene, and members who are experts in the field of deafness including educators, mental health professionals, parents, and an audiologist. The duties of the Council include advising the Department of Health and Mental Hygiene on the implementation of an early identification program for hearing-impaired infants and those at risk, consulting the Department of Health and Mental Hygiene in the development of the program, reviewing the program, developing educational programs, providing quality assurance, and reviewing materials distributed to the public.

Maryland's Infants and Toddlers Program/ The Interagency Coordinating Council

The Program is created by Executive Order .01.01.1988.15. The Program is monitored by the Subcabinet for Youth and Children and the State Department of Education is the lead agency. The Interagency Coordinating Council is established to advise and assist the State Department of Education in the development of the State Plan for early intervention services and in the performance of their lead agency responsibilities. The Council consists of parents of infants and toddlers with disabilities, public and private providers of early intervention services, representatives from the General Assembly, representatives of personnel preparation programs and the Departments of Health and Mental Hygiene, Human Resources, and Education. The mission of the Program is to develop and implement a comprehensive, coordinated, multi-disciplinary, interagency program of early intervention services for all eligible infants and toddlers, birth through age two, and their families.

Education Coordinating Council for State Hospital Centers

The Council is created by Title 22 of the Annotated Code of Maryland (§22-201). The Council consists of members who are citizens of Maryland and not employees of any State or county government agency, the State Superintendent of Schools, the Secretaries or their designees of Health and Mental Hygiene and Public Health Services, the Director of the Developmental

Disabilities Administration, the Superintendent of Public Instruction of Baltimore City, and two county superintendents of schools from counties where a State hospital center is located. The Council shall develop and monitor education programs for each State hospital center.

Governor's Council on Child Abuse and Neglect

The Council is created by Executive Order 01.01.1995.01. The Council consists of members of the Senate and House of Delegates, representatives from the Departments of Human Resources, Health and Mental Hygiene, Juvenile Services, and Education, the Judicial Branch, State's Attorney's Association, Maryland Nurses Association, a law enforcement agency, private social service agencies, educators, physicians, and members of the general public with a special interest in child abuse and neglect. The mission of the Council is to improve intervention strategies, raise community awareness in the area of victimization, and ensure that programs and policies aimed at improved prevention, detection, prosecution, and treatment are effectively implemented and assessed.

State Coordinating Council within the Office for Children, Youth, and Families

The Council is created by Article 49D of the Annotated Code of Maryland (§14). The Council consists of the Secretaries or their designees of the Departments of Health and Mental Hygiene, Juvenile Services, and Human Resources, the Superintendent of Schools or designee, Director of the Governor's Office for Individuals with Disabilities, and the Special Secretary of the Office of Children, Youth, and Families or designee. Some of the Council's duties include establishing a local coordinating council for residential placement of children with disabilities in each county and Baltimore City, reviewing recommendations of placements by local coordinating councils, assuring the local coordinating councils consider all alternatives for provision of services to children with disabilities and their families in the community, planning and coordinating with local coordinating councils concerning the adequate provision of multiple agency services to children with disabilities requiring residential placements, monitoring services being provided in residential placements, and establishing and maintaining a multiple agency information system to assure agency accountability.

Governor's Subcabinet for Children, Youth, and Families

The Subcabinet is created by Executive Order 01.01.1989.12. The Subcabinet consists of the Special Secretary for Children, Youth, and Families, the Secretaries of the Departments of Health and Mental Hygiene, Human Resources, Juvenile Services, and Budget and Fiscal Planning, the State Superintendent of Schools, and the Director of the Office for Individuals with Disabilities. The Subcabinet recognizes that the most effective and responsible solution to the problems facing children, youth, and families requires a comprehensive, coordinated interagency approach that emphasizes prevention, early intervention and community-based, in-home services whenever possible. The Subcabinet's mission is to provide a thorough examination of the effectiveness of Maryland's current structure for delivery of services.

Lead Poisoning Prevention Commission

The Commission is created by Title 6 of the Annotated Code of Maryland (§6-807). The Commission consists of members of the Senate and House of Delegates, several Secretaries or their designees from State agencies such as the Department of Health and Mental Hygiene, representatives involved in housing such as insurers, landlords, tenants, and financial institutions, and parents, health care providers, and advocates who address the needs of children poisoned by lead paint. The purpose of the Commission is to reduce the incidence of childhood lead poisoning, while maintaining the stock of affordable rental housing.

ORGANIZATIONS ADDRESSING SPECIFIC DISABILITY ISSUES

Governor's Council on HIV Prevention and Treatment

The Council is created by Executive Order 01.01.1991.21. The Council consists of members of the Senate and House of Delegates, representatives from health care provider agencies, education, community, civic, or service organizations, the private business sector, State or local government, and the general public. The mission of the Council is to spread information about the facts of the disease, its transmission, and its prevention and ensure the availability of prevention, treatment, and health care services.

The Governor's Council on Substance Abuse, Tuberculosis and AIDS

The Council is created by Executive Order 01.01.1993.31. The Council consists of members of the Senate and House of Delegates, health care providers with experience in HIV/AIDS and tuberculosis, educators, infected individuals, representatives from a local health department and the Department of Health and Mental Hygiene, and members from the public. The mission of the Council is to develop a comprehensive and coordinated strategy to reduce illegal drug use and alcohol abuse through prevention, education, treatment, and law enforcement, and to recognize the interrelationship and overlap of cost-effective approaches to drug and alcohol abuse, tuberculosis, and HIV/AIDS.

Advisory Committee for the Program for Hearing Impaired Individuals

The Committee is created by Title 10 of the Annotated Code of Maryland (§10-910). The Committee consists of members of the Maryland Associations for the Deaf and for Hearing Impaired Children, mental health practitioners who are and those who are not hearing impaired, educators in the field of deafness, members of the community at large, and the parent of a hearing impaired individual. The Committee shall be consulted about the administration of the Program for Hearing Impaired Individuals and link the program to the community of hearing impaired individuals.

Council on Cancer Control

The Council is created by Executive Order 01.01.1991.22. The Council consists of Secretaries or their designees of the Environment and Health and Mental Hygiene, the President of University of Maryland at Baltimore or designee, members of the Senate or House of Delegates, members from the general public, and leading representatives of health and scientific disciplines relevant

to cancer. The mission of the Council is to educate and provide information to all Marylanders on the importance of nutrition, early screening and treatment, and prevention. The Council also seeks to coordinate among various agencies in order to enhance the effectiveness of Maryland's cancer prevention and treatment services.

Advisory Council on Arthritis and Related Diseases

The Council is created by Title 13 of the Annotated Code of Maryland (§13-502). The Council consists of physicians or arthritis health professionals from the State's two medical schools, representatives from the Department of Health and Mental Hygiene, the Division of Vocational Rehabilitation, the Office on Aging, the Governor's Committee on Employment of People with Disabilities, voluntary agencies, the health care industry, hospitals or health professionals outside of the major metropolitan areas, and arthritic patients or their family members. The duties of the Council include making recommendations for an integrated State program of education and research in gerontology and geriatrics, developing and coordinating plans for patient education, addressing gaps in the delivery system, and coordinating activities of public and private agencies, medical schools, and other related professional groups.

ORGANIZATIONS ADDRESSING THE GENERAL NEEDS OF INDIVIDUALS WITH DISABILITIES

Maryland Advisory Council for Individuals with Disabilities

The Council is created by Title 9 of the Annotated Code of Maryland (§9-1106). The Council consists of members of the Senate and House of Delegates, Secretaries or their designees from the Departments of Budget and Fiscal Planning, Human Resources, Transportation, and Business and Economic Development, and representatives from the State Departments of Education, Health and Mental Hygiene, and Justice, the Human Relations Commission, local government, and the general public, including individuals with disabilities. The Council shall review statewide activities for individuals with disabilities, foster coordination of and support for programs, study ways to maximize use of facilities and services, hold open meetings to enhance communication, and assist any local governing body to establish a local advisory council for individuals with disabilities for purposes of implementing provisions of the Americans with Disabilities Act of 1990.

Maryland Advisory Council on Mental Hygiene

The Council is created by Title 10 of the Annotated Code of Maryland (§10-301). The Council consists of representatives from the Courts, police, probation offices, clergy, labor, management, the legal and medical professions, mental health advocates, State and local government, private employee groups, local citizen groups, and major socio-economic and ethnic groups. The Council shall advise the Department of Health and Mental Hygiene generally on carrying out Title 10 of the Annotated Code of Maryland and be a strong advocate of a comprehensive, broad-based approach to the social, economic, and medical problems of mental hygiene.

County Mental Health Advisory Committees

The Committees are created by Title 10 of the Annotated Code of Maryland (§10-308). The Committee consists of the health officer for the county, a representative of a state inpatient facility that serves that county, the directors of county and regional mental health and the core service agency, and in jurisdictions with designated State inpatient beds located in local general hospitals, a representative from that facility. The purpose of the committees shall be to serve as advocate for a comprehensive mental health system for persons of all ages.

ORGANIZATIONS ADDRESSING THE HOUSING/LIVING NEEDS OF INDIVIDUALS WITH DISABILITIES

Maryland Statewide Independent Living Council

The Council is created by Executive Order .01.01.1993.24. The Council serves under the Division of Rehabilitation Services. The mission of the Council is to promote independent living among individuals with disabilities to maximize their independence and productivity.

Community Services Advisory Commission

The Commission is created by Title 7 of the Annotated Code of Maryland (§7-204). The Commission consists of members of the Senate and House of Delegates, the Secretary and Director of the Developmental Disabilities Administration, the Secretary of the Department of Budget and Fiscal Planning or designee, representatives from the State Department of Education, organizations that provide community program services, the financial community, advocacy-related organizations, and a member from the general public. There is a wait list of individuals with disabilities for appropriate community services and programs. The Commission shall identify funding alternatives, provide incentives to facilitate the establishment of new service providers, and assure appropriate levels of program accountability for the purpose of locating and developing programs for individuals on the wait lists.

Maryland Housing Policy Commission

The Commission is created by Title 8 of the Annotated Code of Maryland (§8-101). The Commission consists of citizens actively engaged in the residential building and banking industries, a citizen who is a resident of government assisted housing, a citizen who is a member of a neighborhood organization, local public officials involved in housing and community development, and members of the public at large. Among other duties, the Commission examines, develops, and recommends to the Secretary of Housing and Community Development innovative programs relating to the building, financing, insuring, and managing of housing for those families, elderly citizens, and other special populations that cannot be adequately served by the private market.

ORGANIZATIONS ADDRESSING THE VOCATIONAL NEEDS OF INDIVIDUALS WITH DISABILITIES

Maryland State Rehabilitation Council

The Council is created by Executive Order .01.01.1993.25. The Council consists of representatives from the Statewide Independent Living Council, a parent training and information center, the client assistance program, business, industry, labor, disability advocacy groups, the Director of Division of Rehabilitation Services, a community rehabilitation program service provider, current or former applicants for, or recipients of, vocational rehabilitation services, and at least one vocational rehabilitation counselor. The mission of the Council is to provide an opportunity for individuals with disabilities and their advocates to be full partners in the rehabilitation program and be involved in a meaningful manner in the development and implementation of policy and programs affecting them.

Governor's Committee on Employment of People with Disabilities

The Committee is created by Executive Order .01.01.1989.14. The Committee consists of representatives from the State Division of Vocational Rehabilitation, the State Departments of Human Resources, Personnel, Education, Transportation, Economic and Employment Development, the Office for Individuals with Disabilities, the Human Relations Commission, business, industry, labor, consumers, private agencies with disabled client populations, members of the Senate and House of Delegates, and at least fourteen individuals with disabilities. The mission of the Committee is to promote meaningful employment opportunities for citizens with disabilities as well as public awareness of issues faced by people with disabilities when seeking employment.

County Advisory Councils on Vocational-Technical Education

The Councils are created by Title 21 of the Annotated Code of Maryland (§21-101). The Councils consist of members of the general public, especially representatives of business, industry, organized labor, each sex, racial and ethnic minorities, and the geographic regions of the county. The Councils shall distribute vocational-technical education funds, accountability reports, and advise the county boards of education as to county job needs and the adequacy of vocational-technical programs being offered.

Apprenticeship and Training Council

The Council is created by Title 11 of the Annotated Code of Maryland (§11-403). The Council consists of representatives of employee organizations, and African-American, female, and disabled persons. Among other duties, the Council shall encourage the establishment of local apprenticeship committees, develop apprenticeship standards and monitor apprenticeship programs.

ORGANIZATION ADDRESSING THE HEALTH CARE DECISIONS NEEDS OF INDIVIDUALS WITH DISABILITIES

Health Care Decisions Act Advisory Council

The Council is created by Executive Order .01.01.1994.11. The Council consists of nineteen members who are representative of diverse and pertinent ethical, provider- and public-interest viewpoints. The Council's mission is to ensure that the Health Care Decisions Act of 1993 is correctly and ethically implemented and adequately understood by citizens, health care providers and agents, families and guardians. The Act recognizes society's ethical value that every citizen's life has worth in and of itself, and the individual's right to control her or his own health care as well as the State's right to safeguard those individuals deemed to be incompetent.

ORGANIZATIONS ADDRESSING THE NEEDS OF THE AGING

Commission on Aging

The Commission is created by Article 70B of the Annotated Code of Maryland (§3). The Commission consists of members of the Senate and House of Delegates, and those members selected to reflect geographic representation and because of their interest in the problems of the aging. The commission shall review and make recommendations with respect to ongoing statewide programs and activities and prior to implementation of new programs serving the elderly.

Interagency Committee on Aging Services

The Committee is created by Article 70B of the Annotated Code of Maryland (§4 A). The Committee consists of the Directors of the Office on Aging and the Governor's Office for Individuals with Disabilities, the Secretaries of Health and Mental Hygiene, Human Resources, Transportation, Housing and Community Development, and Business and Economic Development, a member of the general public, and a representative from a local area agency on aging. The Committee shall develop and update a plan for providing coordinated health services, social services, transportation, housing, and employment services to elderly persons in Maryland and assist county agencies to establish local interagency committees to coordinate and expedite the delivery of services to the elderly at the local level.

A REVIEW OF DUPLICATION AND POTENTIAL FOR COLLABORATION WITH THE MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL

The Maryland Developmental Disabilities Council ("Council") believes that all people, regardless of how complex or severe their disability, belong in their communities with the quality of support they need to be secure. There are several organizations listed above that specifically promote this notion, including the State Coordinating Council within the Office for Children, Youth, and Families; the Governor's Subcabinet for Children, Youth, and Families; the Maryland Statewide Independent Living Council; the Community Services Advisory Commission; and the Maryland Housing Policy Commission.

The Council strives to ensure that children with disabilities have the opportunity to be educated in the same schools as their siblings and their neighbors, with the support they need. It is the mission of organizations like the Advisory Council for Hearing Impaired Infants, the Maryland Infants and Toddlers Program, and the Governor's Subcabinet for Children, Youth, and Families to provide services or develop policies that address the needs of children in their communities and in their schools.

The Council recognizes that people with disabilities have meaningful choices over important matters in their lives. People with disabilities have the opportunities for homes and jobs in the mainstream of their communities. Several of the organizations described are dedicated to bolstering individuals with disabilities as they make meaningful choices, including the Maryland Advisory Council for Individuals with Disabilities, the Maryland Advisory Council on Mental Hygiene, the County Mental Health Advisory Committees, the Maryland Statewide Independent Living Council, the Community Services Advisory Commission, the Maryland Housing Policy Commission, the Maryland State Rehabilitation Council, the Governor's Committee on Employment of People with Disabilities, the County Advisory Councils on Vocational-Technical Education, the Apprenticeship and Training Council, the Health Care Decisions Act Advisory Council, and the Interagency Committee on Aging Services.

In order to promote the inclusion of all people with developmental disabilities in community life, the Council advocates for public policy and supportive practices and opportunities. Many of the above described organizations are responsible for developing, implementing, monitoring, and advocating for programs that ensure inclusion, appropriate services, and community education and support. These organizations include the Advisory Council for the Program for Hearing Impaired Infants, the Maryland Infants and Toddlers Program, the Governor's Council on Child Abuse and Neglect, the Governor's Council on Substance Abuse, Tuberculosis and AIDS, the Advisory Committee for the Program for Hearing Impaired Individuals, the Advisory Council on Arthritis and Related Diseases, the Maryland Advisory Council for Individuals with Disabilities, the Maryland Advisory Council on Mental Hygiene, the County Mental Health Advisory Committees, the Maryland Statewide Independent Living Council, the Community Services Advisory Commission, the Maryland Housing Policy Commission, the Maryland State

Rehabilitation Council, the Governor's Committee on Employment of People with Disabilities, the Apprenticeship and Training Council, the Health Care Decisions Act Advisory Council, and the Interagency Committee on Aging Services.

The purpose of listing organizations that support the mission of the Council is to highlight the fact that there are many organizations striving to improve the quality of life and programs designed for individuals with disabilities. There are similar philosophies behind these organizations. Therefore, plenty of opportunities for collaboration appear to exist. There are organizations that address the needs of smaller populations and therefore could contribute a certain expertise to the Council in their specific areas. There are also organizations that serve a broad range of individuals with disabilities that could benefit from the Council's expertise on developmental disabilities.

Organizations designed for the purpose of addressing a specific disability appear to focus on prevention, the spread of information, and improving the quality of treatment. The purpose of listing these organizations is to alert the Council of additional resources that focus specifically on a particular disability. These organizations may provide support to the Council in accomplishing its mission and expanding its constituency or may require support from the Council in furthering its goals.

In sum, there are numerous organizations that address developmental disability issues, many of them focus on the provision of services to individuals with disabilities. The Council's expertise in advocacy and public policy could provide tremendous support to these organizations as they direct their attention to providing opportunities for individuals with developmental disabilities. Organizations that focus on individuals with non-developmental disabilities could collaborate with the Council and use it as an invaluable resource to teach about public policy, advocacy skills, and innovative projects to show responsive, positive ways of supporting people with disabilities.