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ABSTRACT

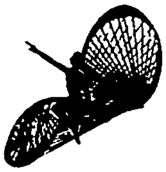
This report presents the findings of a study which examined the service delivery system for adolescents with chronic illness, through a survey of 248 directors of public agencies and programs of the 50 states and the District of Columbia, with a 73 percent response rate. The seven programs surveyed within each state were Maternal and Child Health Programs, Children with Special Health Care Needs Programs, Adolescent Health Coordinators, Departments of Special Education, Mental Retardation/Developmental Disabilities Programs, Developmental Disabilities Councils, and Vocational Rehabilitation Services. Study findings are analyzed in terms of which services are currently available to adolescents, which programs are emphasized, which agencies should provide services to adolescents with chronic illness or disability, identification of major issues, and preparation for the future. Key findings include: (1) adolescents are not considered a priority either for funding or programming; (2) specialty medical services appear to be universally available but primary health care and psychosocial and health promotion services are not; and (3) the three most important factors limiting successful transition to adulthood were insufficient transition planning, transportation/location of service, and vocational training. Seven policy recommendations are offered. (JDD)

Teenagers at Risk

Teenagers at Risk

A National Perspective of State Level Services for Adolescents With Chronic Illness or Disability

Acknowledgements



An effort of this magnitude requires the collaborative and cooperative efforts of many people, both within the National Center for Youth with Disabilities and across the United States. Sincere appreciation and gratitude is extended to Dr. Deborah Klein-Walker, Dr. Richard Nelson, Dr. Donna Petersen, and Ms. Holly Grason who expended much time and provided continued advice and assistance throughout the process of this undertaking.

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This report is dedicated to these state leaders and their staffs with the hope that the information they shared will increase awareness of the needs of youth with disabilities and lead to better responses to the needs of this underserved and often overlooked segment of America's youth.

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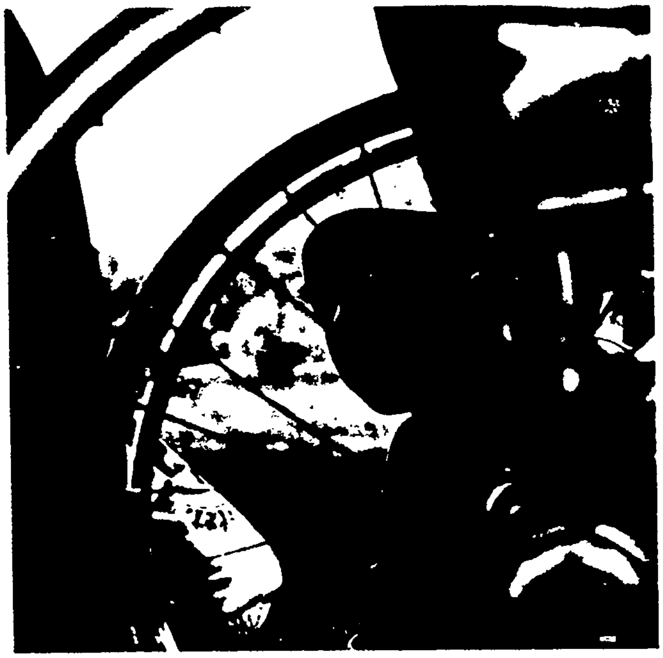
We began the decade of the 1990s knowing a few things about adolescents with chronic conditions. For example, we know that they are living longer. Indeed, at least 85 percent of all children born with disabilities will survive until their 20th birthday. Today, ninety percent or more of children with asthma, diabetes, sickle cell anemia, hemophilia and kidney disease survive well into adulthood, when less than a generation ago, the outlook was bleak.

We also know that, regardless of condition— health or illness— adolescence is a time of intense self-examination. By the time a child with a chronic illness or disability becomes an adolescent, that child is acutely aware of society's ideal physical image, and that image is not one that includes illness or disability.

We know that too often teenagers with disabilities move into adulthood with limited social skills. They have fewer opportunities to consolidate self-identity, to achieve independence from family and to find friends.

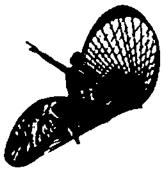
We also know that less than 20 percent of employment-aged individuals with disabilities are employed.



Against this background we asked the question: "What services are available for these young people?" In late 1990 and early 1991, the National Center for Youth with Disabilities surveyed the directors of seven public agencies and programs of the 50 states and the District of Columbia. The seven public sector programs surveyed within each state were:

- Maternal and Child Heath Programs
- Children with Special Health Care Needs Programs
- Adolescent Health Coordinators
- Departments of Special Education
- Mental Retardation/ Developmental Disabilities Programs
- Developmental Disabilities Councils
- Vocational Rehabilitation Services

The survey asked about program priorities, what services are necessary and who should provide the services. The response rate was excellent— 73 percent— especially given the length and complexity of the questionnaires.



The information obtained provides valuable insight into our country's service delivery system for adolescents with chronic illness, but more importantly, helps indicate the direction for policy and program development on behalf of youth with disabilities.

Survey Findings

The single, overwhelming impression the data give is that adolescents are not considered a priority—either for funding or for programming. When asked which age group receives programming priority, more than 85 percent of program directors reported that infants and toddlers through the age of two-years, receive the greatest programming emphasis.

Yet, the increased survival rate of youth with chronic conditions, coupled with the relatively low priority given to services for teens, strengthens the challenge and need to provide social and psychological support for children and their families beyond childhood. This survey documents the gaps in service and challenges agencies to develop policy that guides adolescents into adulthood.

Specialty Medical Services

Specialty medical services, particularly those offered through Children with Special Health Care Needs programs, appear to be universally available to teens with chronic conditions: 98 percent of the states report making such services available. Case management services are offered by 89 percent of Children with Special Health Care Needs programs.

However, beyond these two services, youth-focused activities are far more sporadically available. For example, primary health care—critical to adolescents' overall good health—is provided by 47 percent of Maternal and Child Health programs, fewer than half of all the states. Primary health care is provided through fewer than a quarter of Children with Special Health Care Needs programs.

Psychosocial and health promotion services are offered with even less frequency. Overall, less than one in every five states appears to make such services available to youth with chronic conditions. A higher level of services in both Maternal and Child Health programs and Children with Special Health Care Needs programs exists in those states that have designated Adolescent Health Coordinators, especially in the areas of psychosocial and health promotion services, but only 33 states had such a position in 1990-1991.

Program Priorities for State Programs

The adolescent population tends to be underserved. Other age groups are consistently given higher priority for the provision of services. Some of that preference is historical, some is mandated by federal and state legislation, and some simply because other age groups appear to have more "aggressive" advocacy groups. In addition, some directors said that adolescents are "healthier" than other population groups.

Regardless, directors emphasize programming for either younger or older populations. Maternal and Child Health programs, Children with Special Health Care Needs programs, Departments of Special Education and Developmental Disabilities Councils place emphasis on birth through 5-years-of-age; Mental Retardation/Developmental Disabilities programs along with Vocational Rehabilitation Services place their emphasis on the young adult. Few saw adolescence —ages 12 to 18— as critical.

- Ninety-one percent of Maternal and Child Health directors and 86 percent of Children with Special Health Care Needs directors report that the birth to 2 age group received their most extensive program emphasis.

> ***"The single, overwhelming impression the data give is that adolescents are not considered a priority—either for funding or for programming."***

- Three age groups—birth to 2, 3 to 5 years and 6 to 11 years—account for three out of every four Special Education directors' choice as their most extensive program emphasis.
- Two of every three (67 percent) directors of Mental Retardation/Developmental Disabilities programs selected the 19 to 29 years and older than 29-years-of-age groups as the one currently receiving the most emphasis.
- Over 80 percent of Vocational Rehabilitation Services directors report that the 19 to 29 and 30 to 39 years age groups were their choice as receiving the most extensive program emphasis.

A "*wish list*" didn't change the outcome. When asked, "Who *should* receive the most extensive program emphasis were funding not to be a consideration?"— the results did not significantly change. Only the Vocational Rehabilitation Services directors selected adolescence as the age group which should receive the most extensive program emphasis. Clearly, money is not the sole reason for the preference for other age groups. Adolescence just doesn't sell.

A majority of directors said it was the school's responsibility to provide training and guidance in nearly every area, financial planning, vocational counseling, vocational skill development, sexuality, family life education, drug prevention, self-advocacy, health education, and health services. These data suggest that we may be seriously overloading our schools with responsibilities more appropriate for other programs and agencies.

Just What are the Issues in Transition?

All program directors acknowledge the importance of transition to adulthood for adolescents with chronic conditions, although there are a few differences in their perceptions of the most important factors:

- Overall, directors consider insufficient transition planning, transportation/location of service and vocational training as the three most important factors which limit successful transition.
- Maternal and Child Health and Children with Special Health Care Needs directors believe health care financing and insurance coverage to be the single most important factor. When all directors were included, insurance coverage was fifth on a list of nine factors.
- Generally, the public sector programs view access to health care as a far greater problem for adolescents with chronic conditions than the availability of health care.

> *"In this country, adolescents are not a priority and are vastly underserved."*

Seventy-seven percent of directors felt that adolescents with severe chronic illness, without overt manifestations of physical disability, would experience various employment-related problems. Survey data indicate that a significant percentage of directors did not know how successfully these problems were being addressed. A strong need for interagency collaboration was reflected in the findings.

What's Known?

Few programs actually conduct special studies or needs assessments of adolescents and young adults with chronic illness or disability. Overall, just one in five (20 percent) state agencies had ever conducted such a study.

This study shows that:

- State level legislation is viewed as a positive factor by 27 percent (it enables service); 15 percent say it interferes with service provision.
- One in every five directors agree that program expansion is necessary.
- One in every five directors emphasize the need for increased funding.

Those who work with adolescents have a clear obligation to make the situation known. This study shows more than a case of inequity. The differences in programs across the entire public sector are enormous. States need to improve delivery systems, making them more efficient, more collaborative and more coordinated. Given the increased survival of young people with disabling conditions, there is a compelling need that:

- Priorities across age groups must become more equitable.
- Adolescent Health Coordinators should be positioned in every state for coordination and resource allocation.
- States must translate the awareness and concern for transition health services into actual delivery systems that meet the needs of youth with chronic conditions.
- States need to develop specific policy initiatives to address the needs of adolescents with chronic conditions and to continue to aggressively advocate for programs and resources that, in fact, implement the goals of those policies.

Conclusion

This report elicits a complex set of reactions. There are both causes for concern and opportunities to be pursued. In many ways the lack of focus on youth is neither surprising nor historically inappropriate. Services for children throughout the twentieth century have focused on meeting the acute needs of preventing malnutrition through milk stations and, more recently, through preventing infectious diseases through sanitation and immunizations. The history of the "prevention movement" has had both early identification and early intervention as basic tenets.

Clearly, we have been the beneficiaries of those policies, for today over 85 percent of all children born with chronic and disabling conditions will reach their 20th birthday. Because of the success of many of our early interventions, it is more critical than ever that issues facing youth with disabilities be on national, state and agency agendas. What is being advocated here is not that we decrease our commitment to children with special health, education and social needs in the first few years of life; but rather that we expand our horizons, our mandates and resources to assure that all we have achieved in childhood is not lost in adolescence. It is time that we attend to the needs of youth with chronic and disabling conditions in ways we have yet to do in the United States.

Recommendation 1:

The issues facing adolescents and young adults with chronic and disabling conditions need to be better understood at the state level. States must understand and focus attention on the total needs of youth with disabilities: How does the health of a young person relate to career or educational choices or opportunities?

We call on state Children with Special Health Care Needs programs to undertake state-level needs assessments of young people 15 to 24 years-of-age to better understand their needs as they perceive them. Such a needs assessment must include physical, educational, vocational and social needs.

Recommendation 2:

The activities of state agencies which serve young people with chronic and disabling conditions need to be better defined.

We call upon state Developmental Disabilities Councils to undertake an in-depth analysis of state agencies that serve young people with chronic conditions so that those who provide services and run programs at the state and local level can have a better understanding of what each other is doing. There is a profound information gap at the state level of sister agency activities.

Recommendation 3:

Federal legislation should mandate increased priority be given and resources be directed to youth with chronic and disabling conditions.

We call upon lawmakers to address the needs of young people with disabling conditions. While many agency directors did not seem to believe that legislation will make much difference, it is also clear that many agency priorities are driven by legislative mandates and/or federal funding priorities. There is little reason to believe that without a bold federal initiative, many agencies will reorder or expand their priorities.

Recommendation 4:

A federal task force of interagency directors needs to be established.

We call upon federal agencies which serve young people with chronic and disabling conditions to implement the rhetoric of interagency collaboration which has been long espoused. Federal leaders need to role-model such collaboration. An ongoing working group of directors of agencies that serve children and youth with disabilities would accomplish a number of objectives:

- increased awareness and recognition of the needs of youth at the national level.
- shared information of agency priorities and activities;
- potential reduction in duplication and/or competitiveness;
- development of multiagency initiatives;
- role-modeling interagency collaboration.

Recommendation 5:

Broad-based interagency collaboration at the state level should be federally mandated.

We call upon federal agencies to mandate their state counterparts require documentation of state-level interagency collaboration. This can be done in much the same way as other agency requirements are established and documented. Furthermore, if federal agencies collaborated at the national level, new programs and projects could be established to encourage new collaborative initiatives at the state and local levels.

Recommendation 6:

Interagency programs and projects need to be carefully evaluated.

Does interagency coordination and collaboration really improve the services to adolescents? We need to carefully assess program outcomes as we expand programs. We need to study models of collaboration to learn what works and for whom.

Recommendation 7:

States need a focal point for coordinating interagency activities related to youth with disabilities.

We call upon Adolescent Health Coordinators to have the responsibility for coordinating youth-related interagency activities as part of their defined roles. For this to occur, every state needs to establish such a coordinator position. Survey data clearly indicate that the Adolescent Health Coordinators serve a valuable role by maintaining the visibility and in addressing youth issues. These individuals are ideally situated to chair interagency task forces and to facilitate interagency programs at the local level.

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Executive Director

This report presents the results of a survey conducted by the National Center for Youth with Disabilities on issues related to adolescents with chronic illness and disability. The survey was completed in 1991. Seven agencies within each state were surveyed:

- Maternal and Child Health Programs
- Children with Special Health Care Needs Programs
- Adolescent Health Coordinators
- Special Education Departments
- Developmental Disabilities Councils
- Mental Retardation/ Developmental Disabilities Programs
- Vocational Rehabilitation Services

The intent of the study was to obtain a comprehensive picture of the nation's public sector service delivery system for youth with disabilities.

In late 1990, questionnaires were sent to the directors of the seven state agencies listed above. Three weeks later, a second mailing was sent to non-respondents. Subsequently, a reminder telephone call was made to non-respondents as the final means of obtaining a response. Ultimately, responses were received from 248 program directors, which represented an overall response rate for the survey of 73 percent. (See Appendix A.)

The survey process is complicated by the fact that state agencies across the country do not offer consistent programs. In some states, the seven program/agency areas into which the survey was structured were indeed separate; in others, they were combined. And, in other states, some do not exist at all. For example, at the time of the survey, only 33 states had someone designated as an Adolescent Health Coordinator. Collecting even descriptive information across states is complicated. They use different terms, titles, services, organizations, jurisdictions, jargon, and acronyms. Even populations served and eligibility criteria are not always the same. Some states administer services on a state-wide basis; others do so through smaller units, such as counties or school districts. Many agencies simply do not collect data that focuses on those who are age 10 to 21; thus, agency responses frequently represented "best guesses."

Finally, interagency comparisons were limited. At times, it was possible to aggregate and compare responses across agencies; at other times, the questions asked were agency-specific, allowing only for presenting information on a program-specific basis.

> ***"I don't think, at this time, that the state is looking beyond the special needs of younger children. This is a forgotten population primarily because we have little data on the extent of the problem and the needs."***

Title V Programs • Maternal and Child Health • Children with Special Health Care Needs • Adolescent Health Coordinators

The purpose of Title V is to improve the health of all mothers and children. Title V funding provides and assures access to quality maternal and child health services. Traditionally, state Maternal and Child Health programs and Children with Special Health Care Needs programs are leaders in developing and supporting coordinated systems of care.

> *"The multiple and long term needs of such adolescents cannot be met by a single agency. Interagency collaboration is the only hope an individual has for long term support services."*

Each state has the authority to determine, within certain parameters, its program priorities. They allocate funds to develop and support coordinated systems of care. State Title V programs engage in a range of activities: program planning and development; services delivery; coordination and financing; standard setting and monitoring; technical assistance; information and education; and interagency coordination and reporting. In recent years state Title V programs have increased their adolescent focus.

Table 1

Services Offered by State Title V MCH Programs, 1990

Service	Percent of States Offering Service	Number
Specialty medical services	56%	18
Case Management	53%	17
Primary Health Care	47%	15
Sex/Family Life education	34%	11
Home Health service	28%	9
Family Supports	28%	9
Individual transition Planning	22%	7
School health Clinics	19%	6
Drug prevention	16%	5
Follow-up of former clients	12%	4
Mental health services	12%	4
Self-advocacy training	12%	4

- Nearly all state Children with Special Health Care Needs programs (98 percent) report that specialty medical services for adolescents are available. Primary health care availability, however, falls to 25 percent through Children with Special Health Care Needs programs and 47 percent through Maternal and Child Health programs.
- Eighty-nine percent of Children with Special Health Care Needs programs report providing some form of case management services for youth with special health care needs.
- Only 43 percent of state Children with Special Health Care Needs programs indicate that individual transition planning services are available for teens; these services decline to about half that frequency (22 percent) for Maternal and Child Health programs.

- Very few state Children with Special Health Care Needs programs provide for drug abuse prevention (7 percent), mental health services (9 percent), tracking or follow-up of former clients (14 percent), or school-based health services (9 percent) for adolescents with disabilities. Maternal and Child Health programs do not appear to provide these services in any greater frequency. In many of the states there is no reason to believe that the majority of youth with chronic and disabling conditions receive such services at all.
- Where they exist, health promotion services appear to be the domain of Adolescent Health Coordinators.
- Of the 33 states with Adolescent Health Coordinators, 20 responded to the survey, and of those, 65 percent (13) reported providing sex/family life education; 55 percent (11) provide drug abuse prevention; and 50 percent (10) provide case management services to youth with chronic and disabling conditions.

Table 2

Services Offered by State Title V CSHCN Programs, 1990

Service	Percent of States Offering Service	Number
Specialty medical services	98%	43
Case Management	89%	39
Family supports	64%	28
Individual transition planning	43%	19
Home Health service	39%	17
Primary health care	25%	11
Sex/family life education	18%	8
Self-advocacy training	18%	8
Follow-up of former clients	14%	6
School health clinics	9%	4
Mental health services	9%	4
Drug prevention	7%	3

Table 3

Services Offered by State Adolescent Health Coordinators, 1990

Service	Percent of States Offering Service	Number
Sex/family life education	65%	13
Drug prevention	55%	11
Case management	50%	10
School health clinics	40%	8
Family supports	35%	7
Individual transition planning	35%	7
Career planning/assessment	30%	6
Self-advocacy training	15%	3
Post-graduation follow up	10%	2

- States with Adolescent Health Coordinators appear to provide more of the social and emotional support services than in states where such coordinators do not exist. For example, 35 percent report providing family support with an equal number providing individual transition planning; 30 percent offer career planning and assessment; 15 percent have self-advocacy training programs; and 10 percent undertake post-graduation follow-up.

Special Education Programs; Developmental Disabilities Councils; and Mental Retardation/Developmental Disabilities Programs

Departments of Special Education report a wide range of educational, vocational and psychosocial services to adolescents with disabilities. Many of these services, provided in most cases by local school districts, extend beyond the core educational curriculum, and are mandated by federal and state legislation. The Individuals with Disabilities Education Act (IDEA, formerly the Education for All Handicapped Act, P.L. 94-142) mandates each state to provide a free appropriate education in the least restrictive setting and based on an individual educational plan. Amendments to IDEA added a new definition of transition and the requirement that transition services and planning be added to individual student plans beginning at age 14 or younger.

"Federal program requirements appear to conflict with one another. Common applications, eligibility requirements and treatment standards would be desirable."

Table 4

Services Offered by State Special Education Programs, 1990

Service	Percent of States Offering Service	Number
Adaptive equipment	89%	32
Supported employment	89%	32
Career planning/assessment	81%	29
On-the-job training	80%	29
Individual transition planning	78%	28
Drug prevention	75%	27
Case management	72%	26
Job placement	67%	24
Personal/vocational adjustment counseling	64%	23
Job fairs	61%	22
Sex/family life education	58%	21
Post-graduation follow-up	53%	19
Family supports	53%	19
Self-advocacy training	44%	16
Financial planning	36%	13

For the most part, state education agencies set policy, maintain data systems, prepare state plans to secure federal funds for services, develop rules and regulations, monitor local education programs for compliance, and provide information, training and technical assistance to the local school district or education agency.

- At least 80 percent of all states provide four services: adaptive equipment (89 percent), supported employment (89 percent), career planning and assessment (81 percent) and on-the-job training (80 percent).
- Individual transition planning (78 percent), drug prevention (75 percent) and case management (72 percent) are all offered by more than 7 out of every 10 of the state special education programs.
- Many services are assumed by or deferred to special education. For example, psychosocial/vocational services including personal/vocational adjustment counseling, job placement, sex/family life education, family supports, self-advocacy training and financial planning were all reported as available by special education programs. (See Table 4.)
- With the exception of self-advocacy training (44 percent) and financial planning (36 percent), all the other psychosocial/vocational services listed above were offered by at least half of the states and, for the majority of those services, by over two-thirds of the states' special education programs.

Developmental Disability Councils are primarily planning and advocacy agencies. They often set state policies and agendas for mental retardation and developmental disabilities programs and services. They are not usually direct service providers.

Mental retardation/developmental disabilities programs are usually responsible for planning, administrating, coordinating, monitoring and evaluating the delivery of services for individuals with disabilities. They may also develop and manage programs that ensure that persons with disabilities receive supervision, support and training.

■ Developmental Disabilities Councils report that programs such as supported employment, family support, and case management are all offered in at least 70 percent of the states by various provider agencies.

Table 5

Services Offered by State Developmental Disabilities (DD) Councils, 1990

Service	Percent of States Offering Service	Number
Supported employment	76%	28
Family supports	70%	26
Case management	70%	26
Individual transition planning	65%	24
Career planning/assessment	57%	21
Personal/vocational adjustment Counseling	54%	20
On-the-job training	51%	19
Job placement	51%	19
School nurse/school health clinic	46%	17
Sex/family life education	38%	14
Self-advocacy training	35%	13
Drug prevention	30%	11
Post-graduation follow-up	30%	11
Financial planning	14%	5

■ Seventy-seven percent or more of all state Mental Retardation/Developmental Disabilities programs provide case management services (85 percent); family support (80 percent); adaptive equipment (77 percent); and supported employment (77 percent).

■ The following services are provided by 38 percent or less of the state Mental Retardation/Developmental Disabilities programs: sex/family life education (38 percent); self-advocacy training (31 percent), financial planning (28 percent); drug abuse prevention (28 percent); and post-graduation follow-up (26 percent). These represent less "traditional" services.

- In an area gaining increasing attention by the medical and health professions, only 26 percent of the state Mental Retardation Developmental Disabilities programs provide services to help teens' transition to adult health care.
- Perceptions of what services are available and *actual* availability are often subject to wide discrepancy among different programs. However, this is not the case with Mental Retardation/Developmental Disabilities Programs. *A high level of agreement* exists between what services Developmental Disabilities Councils believe are available and what is reported by Mental Retardation/Developmental Disabilities programs as available for teens with chronic conditions.

Table 6

Services Offered by State Mental Retardation/Developmental Disabilities Programs (MR/DD), 1990

Service	Percent of States Offering Service	Number
Case management	85%	33
Family supports	80%	31
Adaptive equipment	77%	30
Supported employment	77%	30
Mental health services	72%	28
Individual transition planning	67%	26
Home health services	62%	24
Job placement	56%	22
Career planning/assessment	46%	18
On-The-job training	46%	18
Personal/vocational adjustment counseling	46%	18
Sex/family life education	38%	15
Self-advocacy training	31%	12
Financial planning	28%	11
Drug prevention	28%	11
Post-graduation follow-up	26%	10
Transition to adult health care	26%	10
Job fairs	13%	5

What Programs are Emphasized?

Vocational Rehabilitation Services

Vocational Rehabilitation Services deal with both competitive and supported employment outcomes. Young adults with disabilities receive counseling and guidance based on individual written rehabilitation plans. Historically, Vocational Rehabilitation Services have focused on older age groups. While these services are theoretically available to adolescents, many may not have easy access to the programs.

- All states surveyed provide career planning and assessment (100 percent); the vast majority provide for: evaluation (98 percent), job placement (98 percent), and on-the-job training (95 percent) to teens and young adults with disabling conditions.

- Almost 9 out of every 10 states report providing personal and vocational adjustment counseling (92 percent), adaptive equipment (90 percent), education at post-secondary institutions (90 percent), and supported employment (88 percent) to youth with disabilities.

Table 7

Services Offered by State Department of Vocational Rehabilitation (DVR) Programs, 1990

Service	Percent of States Offering Service	Number
Career planning/assessment	100%	40
Evaluation	98%	39
Job placement	98%	39
Personal/vocational adjustment counseling	92%	37
Adaptive equipment	90%	36
Education at post-secondary educational institutions	90%	36
Supported employment	88%	35
Case management	80%	32
Services located in jr./sr. high school	62%	25
Family supports	60%	24
Support payments	60%	24
Job fairs	52%	21
Self-advocacy training	40%	16

- While only 40 percent of states report offering self-advocacy training, that is still twice the frequency of Children with Special Health Care Needs programs (18 percent), and more than three times that of Maternal and Child Health programs (12 percent) offering a similar service.

One of the barriers to providing services for adolescents is their low priority compared with other age groups. To measure the priorities assigned various age groups, agency directors were asked how they would rank the current program emphasis of health, education, policy development and employment-related concerns in five specific age groups. The same question was then posed asking the respondents to identify what the program emphasis should be assuming additional resources were available.

Maternal and Child Health & Children with Special Health Care Needs Programs

- An overwhelming 91 percent of Maternal and Child Health directors and 86 percent of Children with Special Health Care Needs directors report that the birth to 2 years age group received their most extensive program emphasis for health-related concerns

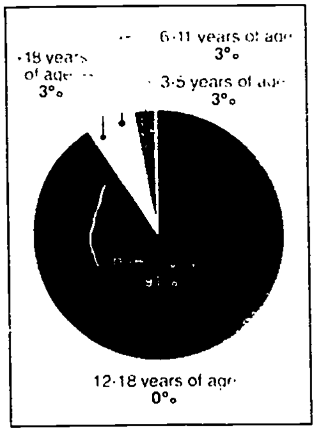
- No Maternal and Child Health or Children with Special Health Care Needs respondents selected the adolescent (12 to 18 years) age category as a primary focal group

- The focus on infants and young children reflects both a philosophical and a programming priority. When asked what the emphasis should be, the adolescent age category fared only slightly better than with fewer resources.

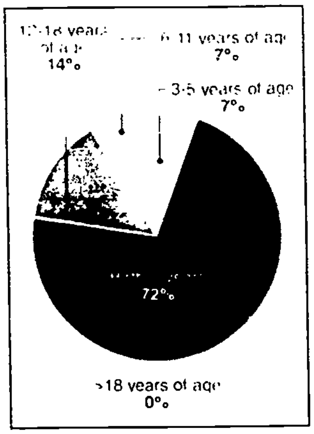
- Even if funding were available for their programs 72 percent of Maternal and Child Health and 82 percent of Children with Special Health Care Needs directors still felt it appropriate that the birth to 2 age group should be given top priority

- With increased funding Maternal and Child Health and Children with Special Health Care Needs, directors reported that adolescents would have a somewhat higher program priority

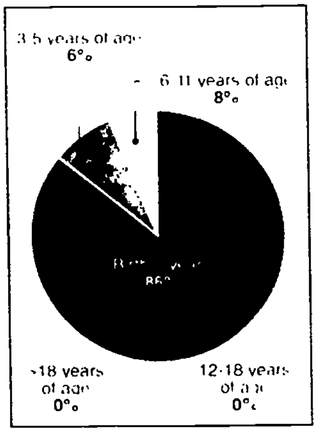
MCH Programs.
Current Emphasis
By Age Group, 1991



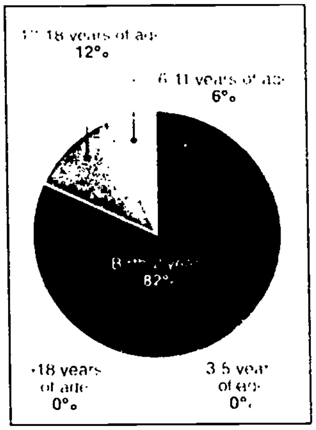
MCH Programs:
Given Increased Funding,
What *Should* be Emphasis
By Age Group 1991



CSHCN Programs.
Current Emphasis By Age Group, 1991



CSHCN Programs
Given Increased Funding
What *Should* be Emphasis
By Age Group, 1991

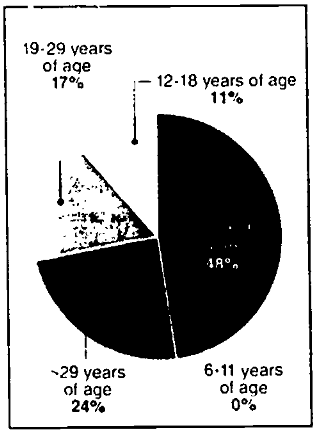


Developmental Disabilities Councils and Mental Retardation/Developmental Disabilities Programs:

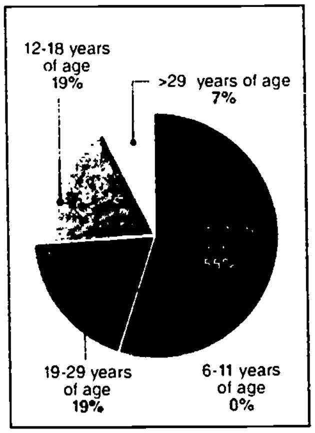
Because Mental Retardation/Developmental Disabilities programs have traditionally had responsibility across the life span, a broader range of program priorities exists. Nevertheless, adolescents still fared poorly against every age group with the exception of those 6 to 11 years-of-age.

- Just under half of Developmental Disabilities Council directors (48 percent) selected the birth to 5 age group as its most extensive program emphasis with respect to policy development.
- The age group of 19 to 29 years and those who are older than 29 years accounted for 41 percent of the council directors' priorities.
- About 1 in 10 of Developmental Disabilities Council directors selected the adolescent age group as its priority choice.
- Even with more funding, council directors would still increase their support for the birth to 5 age group (48 percent to 55 percent). With such hypothetically-expanded funding, the 12 to 18 year age group did increase in priority from 11 percent to 19 percent.
- Two out of every three (67 percent) Mental Retardation/Developmental Disabilities directors report that the 19 to 29 year olds and those over age 29 currently receive the most extensive program emphasis.
- None of the Mental Retardation/Developmental Disabilities directors who responded to the survey selected adolescents as the age group currently receiving the most extensive program emphasis.
- Even given increased funding, only about 1 in 10 (11 percent) directors of Mental Retardation/Developmental Disabilities programs believed adolescents should actually be their top priority. Rather, priorities would remain with the birth to 5 age group for nearly half (46 percent) of the respondents from mental retardation programs.

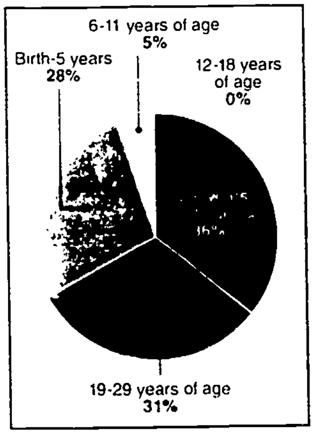
Developmental Disabilities Councils: *Current* Emphasis By Age Group, 1991



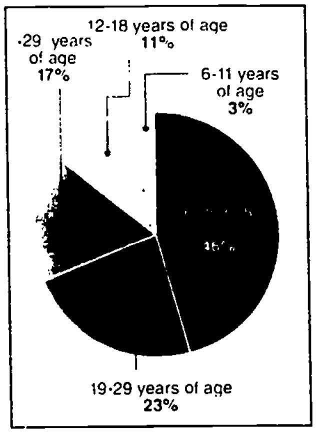
Developmental Disabilities Councils: Given Increased Funding, What *Should* be Emphasis By Age Group, 1991



Mental Retardation/Developmental Disabilities Programs: *Current* Emphasis By Age Group, 1991



Mental Retardation/Developmental Disabilities Programs: Given Increased Funding, What *Should* be Emphasis By Age Group, 1991



Special Education and Vocational Rehabilitation Services

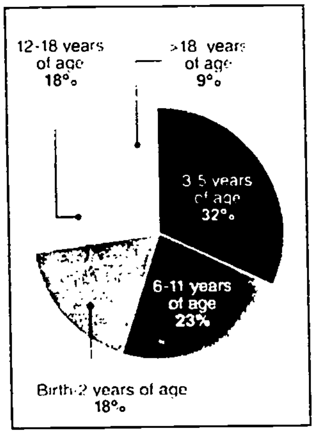
Pre-adolescent and younger children are clearly the top priority of current Special Education programs. Much of that priority is the result of the focus on early intervention seen in the federal legislation passed in the last two decades.

- Three age groups—birth to 2 (18 percent), 3 to 5 years (32 percent), and 6 to 11 years of age (23 percent)—account for nearly 3 out of every 4 Special Education director selections as current program priority.
- Increased funding makes an insignificant difference (from 18 percent to 20 pecent) in the priority that Special Education directors give to the adolescent population.

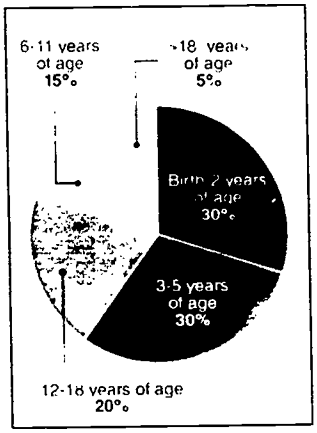
With Vocational Rehabilitation directors, the opposite is true: groups older than adolescents (19 to 29 and 30 to 39) account for more than 8 of 10 directors' selections for existing program priority. The mandates of federal legislation—especially the Rehabilitation Act of 1973 and subsequent amendments—account, in part, for this emphasis on adult populations. Vocational Rehabilitation directors said they'd make the most dramatic changes in programs if additional monies were available.

- Slightly more than half (52 percent) of Vocational Rehabilitation directors believe adolescents *should* be their department's most extensive program emphasis, an increase of 400 percent.
- That dramatic 400 percent shift may suggest Vocational Rehabilitation directors' appreciation for the crucial transition period from school to the adult world of work and the need for vocational skills to make that transition successful.

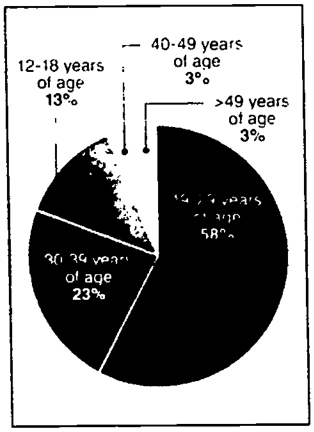
Special Education Programs
Current Emphasis By Age Group, 1991



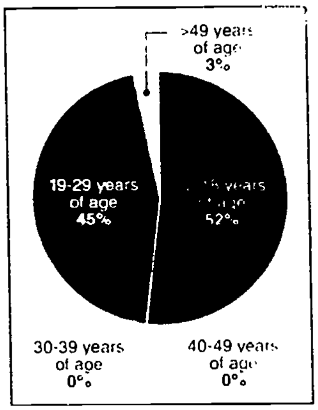
Special Education Programs, Given Increased Funding: What *Should* be Emphasis By Age Group, 1991



Vocational Rehabilitation Programs: *Current* Emphasis By Age Group, 1991



Vocational Rehabilitation Programs, Given Increased Funding, What *Should* be Emphasis By Age Group, 1991



Who Should Provide Services to Adolescents With Chronic Illness or Disability?

Directors of the programs surveyed in this study do more than plan, coordinate or provide services. They usually have some role in shaping and influencing policy. The directors' perception of who should be primarily responsible for providing services may be an important factor in what services an agency or program actually offers. To measure that perception, we asked the directors of all six state programs and the Adolescent Health Coordinators who *should* be responsible for providing services in 11 areas. Directors could assign primary responsibility for a particular service to one of five programs or departments:

- Maternal and Child Health Programs
- Children with Special Health Care Needs Programs
- Department of Vocational Rehabilitation
- Department of Education (including Special Education)
- Other (and asked to specify)

Combined results for all programs are represented in Table 8.

- Seventy-two percent agreed that vocational counseling is the responsibility of the Department of Vocational Rehabilitation.
- The services least available to teens with disabilities tend to be those where primary responsibility is most dispersed among the five program choices such as: transition to adult health care, financial planning, self-advocacy, and support with family relationship problems.
- Many agency directors expect the Department of Education to provide services to adolescents with chronic illness and disability, even when the education system may not necessarily be the most appropriate choice. Departments of Education are reported to be the first choice to provide services including: financial planning, drug prevention, self-advocacy, health education, family relationships and health services in schools and school health clinics.
- The Department of Education appears to be a catch-all when a specific service does not clearly fall under another agency's priorities.
- There is little agreement among state-level public program directors with respect to program responsibility for many activities related to young people with disabilities. This may suggest a lack of understanding of the limits of some programs, lack of knowledge of what other programs actually provide, and a strong rationale for the need for greater interagency collaboration among programs and agencies.

> ***"We have training materials and resources. We need to put them into practice."***

Table 8

ALL DIRECTORS

For each of the following issues, who do you believe *should* be primarily responsible for the provision of services to adolescents with chronic illnesses and disabilities?

AGENCY/PERCENT*

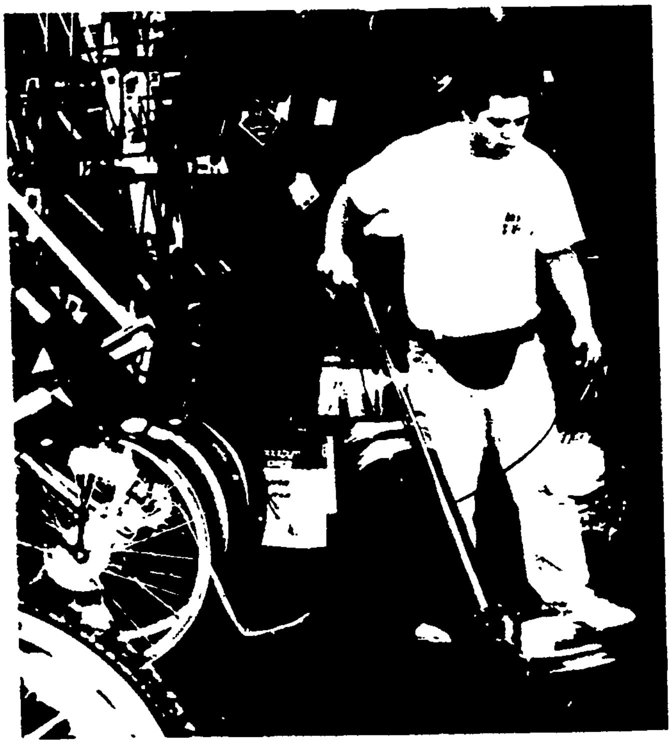
Issue	MCH	CSHCN	VR	Dept. of Ed.	Other	No Response
Health services in schools	28%	17%	0%	47%	3%	5%
Transition to adult health care	23%	33%	12%	14%	13%	5%
Financial planning	4%	14%	19%	28%	21%	14%
Vocational Counseling	0%	1%	72%	22%	2%	3%
Vocational skill development	0%	1%	58%	36%	3%	2%
Sexuality/family life education	22%	5%	1%	59%	8%	5%
Drug prevention	12%	4%	1%	63%	15%	5%
Self-advocacy	2%	25%	7%	30%	28%	8%
Health education	17%	15%	1%	60%	4%	3%
Family relationships	15%	21%	1%	32%	21%	10%
School Health clinics	41%	7%	0%	44%	4%	4%

(*Responses with multiple answers (i.e. more than one per horizontal row) were eliminated from this analysis.)

Transition to Adulthood

Transition to adulthood can be painful and awkward, but it is a significant and vitally important time, even for healthy adolescents. For those with chronic and disabling conditions, it is all that and perhaps more. Just what do state program directors consider the most significant factors in their state that limit the successful transition of youth with chronic illness or disability to adulthood? They were asked to select from a pre-selected list of nine factors:

- education
- parent involvement
- peer relations
- vocational / employment training
- insufficient transition planning
- health care financing / insurance coverage
- availability of health care services
- inadequate community living options
- transportation / location of services.



Based upon the above choices, the three primary barriers to transition generally identified by all include:

- insufficient transition planning
- transportation / location of services
- vocational / employment training.

Individual directors' views on the key barriers to successful transition varied considerably. Interestingly enough, despite the fact that health insurance has become a major national issue, it was infrequently cited as a barrier to transition.

Table 9

Factors that Limit Successful Transition

Factor	Percent of all program directors rating most important	Number
Insufficient transition planning	46%	115
Transportation / location at services	45%	112
Vocational / employment training	45%	112
Inadequate community living options	38%	95
Health care financing / insurance coverage	24%	60
Education	16%	41
Parent involvement	14%	36
Availability of health care services	13%	33
Peer relations	7%	17

Combined results for all programs are represented in Table 9. Results from Maternal and Child Health and Children with Special Health Care Needs directors are represented in Table 10

Table 10

Factors that Limit Successful Transition MCH & CSHCN Directors

Factor	Percent of MCH & CSHCN of "Most Important"	Number
Health care financing/ insurance coverage	47%	36
Insufficient transition planning	46%	35
Vocational/employment training	46%	35
Transportation/location of services	37%	28
Inadequate community living options	36%	27
Education	24%	18
Availability of health care services	20%	15
Parent involvement	12%	9
Peer relations	5%	4

- Maternal and Child Health and Children with Special Health Care Needs directors selected health care financing and insurance coverage as the single most important factor; for all directors, insurance was *fifth* on the list.
- Mental Retardation/Developmental Disabilities directors, Developmental Disabilities Councils and Vocational Rehabilitation directors viewed vocational/employment training, transition planning, transportation and community living options as most important; health care financing/insurance coverage and availability of health care were *least* important.
- Adolescent Health Coordinators considered the reverse to be true: Health concerns were viewed as two of the three most important factors limiting successful transition.
- The importance of transition planning was a significant theme for all directors. *Insufficient* transition planning, one of the three most important factors, was consistently listed by directors, and 46 percent of all directors (more than any other factor) listed it as *the* most important of the three priority factors.
- Generally, public sector programs view health care financing and insurance coverage as a more important cause in limiting successful transition than the availability of health care services. In other words, the data suggest access to health care is a far greater problem than availability of health care

"Intensive transition and vocational preparation programs are needed to prepare students for all areas of adult life."

Table 11

Do severe chronic illnesses without overt physical disability present youth with any particular problems with regard to employment?

Response	Percent	Number
Usually	42%	89
Some of the time	31%	64
Always	9%	18
Rarely	3%	7
Don't know	13%	27
No response	2%	4

(Combined results from six of the seven program directors-MR/DD directors not asked question)

Hidden Disability and Employment

Employment-related problems are a significant issue in the lives of adolescents, especially for those with severe chronic illness without overt manifestation of physical disability (such as epilepsy, diabetes, cystic fibrosis, hemophilia, rheumatic heart disease). Six of the seven program directors were asked about the frequency of employment-related problems for adolescents with non-visible conditions. Because cognitive disabilities were excluded from this question, Mental Retardation Developmental Disabilities program directors were not queried. Data are summarized in Table 11.

- Ninety-five percent of Vocational Rehabilitation directors felt that severe chronic illness causes problems for adolescents on some occasions.

- Sixty-eight percent of Maternal and Child Health directors felt that adolescents with non-visible conditions face some employment-related problems. An even higher percent of Children with Special Health Care Needs directors (81 percent) believe adolescents with hidden disabilities will face employment problems

The same groups of directors were then asked to determine how successfully the employment-related concerns of adolescents with severe chronic illness were being addressed by regular and special educational services, vocational educational and Departments of Vocational Rehabilitation. The responses of Title V Maternal and Child Health and Children with Special Health Care Needs program directors were of particular interest, primarily due to the high number of *"don't know"* responses received.

- *"Don't know"* responses were extremely high: 36 percent of Maternal and Child Health directors responded that they did not know the success of regular and special education; 52 percent said they didn't know vocational education's impact; and 44 percent gave a similar response for Departments of Vocational Rehabilitation.

- Children with Special Health Care Needs directors' *"don't know"* responses were even higher: 54 percent responded *"don't know"* as to the impact of regular and special education; 51 percent with respect to vocational education; and 42 percent for Departments of Vocational Rehabilitation.

- Adolescent Health Coordinators' lack of knowledge about the impact of other agencies was higher still: 57 percent of responding coordinators didn't know how regular and special education services were addressing such problems, and 64 percent reported *"don't know"* for both vocational education and Department of Vocational Rehabilitation services.

- Developmental Disabilities council directors may be either better informed or more opinionated: their reported *"don't knows"* were 29 percent for regular and special education; 32 percent for vocational education; and 33 percent for Department of Vocational Rehabilitation Services.

- What is clear is that lack of information and awareness across agencies is the norm, not the exception, for agencies and programs in this crucial area concerning youth with chronic conditions.

> ***"Invisible disabilities often can carry as great or greater a stigma."***

Table 12

Is there a need for interagency efforts to meet needs of adolescents with chronic illnesses and disabilities (all programs), 1990?

Response	Percent	Number
In general, yes	87%	216
In some cases	10%	26
In general, no	<1%	1
Don't know	2%	4
No response	<1%	1

Table 13

Does your program participate in any interagency agreements, programs, or activities related to adolescents with chronic illnesses and disabilities (all programs), 1990?

Response	Percent	Number
Yes	64%	159
No	29%	71
Don't know	6%	16
No response	1%	2

Apart from the apparent lack of knowledge as to how employment-related problems are actually being addressed, the data suggest the respondents to this survey perceive that the programs in regular and special education, vocational education and the Department of Vocational Rehabilitation are not successfully meeting the needs of young people with disabilities. On average, agency directors evaluated the program successes in other state agencies as follows (1=high 10=low):

- Special Education: 6.9
- Vocational Education: 6.4
- Vocational Rehabilitation: 5.7

A multidisciplinary, interagency approach requires a certain level of knowledge of other fields and programs. The apparent lack of information (reflected by the high rate of *"don't know"* responses with respect to the extent educational programs and Vocational Rehabilitation services successfully address certain employment problems) suggests a need for more interagency collaboration and a greater commitment to the concept of the multidisciplinary approach to adolescent problems. If programs are truly to use all resources available to serve teens with disabling conditions, then they must know where the programs are succeeding and where they are not.

The data suggest a strong perceived need for improved interagency efforts.

- Virtually all (97 percent) directors report a need for interagency efforts to meet the needs of adolescents with chronic illnesses and disabilities.
- Fewer than two-thirds (64 percent) of all the program directors report actually participating in interagency agreements, programs or activities related to youth with disabling conditions.
- Only half (50 percent) of Maternal and Child Health programs and Adolescent Health Coordinators participate in interagency agreements that relate to adolescents with chronic illness and disability. For Children with Special Health Care Needs programs, the corresponding frequency is 68 percent.

Data are represented in Tables 12 and 13.

Interagency efforts are generally believed to be a key to a real multidisciplinary approach to the complex array of problems faced by adolescents with chronic illness and disability. The benefits, both potential and real, seem obvious.

- Over one-fourth (27 percent) of directors indicated that interagency collaboration helps coordinate service and share information.
- One in 5 believe that improved delivery services are a benefit derived from interagency efforts.
- Eighteen percent of all program directors reflected a belief that interagency collaboration enhances technical assistance, communication and planning.
- Thirteen percent of the directors stated that interagency collaboration helps avoid duplication, reduces costs and provides for an efficient use of agency resources.

What About the Future? Research, Legislation, Policy and Future Program Development

The existence of interagency agreements on paper does not, of course, imply effectiveness. A number of factors intervene to prevent such agreements from being fully implemented:

- Paper agreements are rendered meaningless by lack of coordination.
- Resolving *"turf"* issues consumes time and effort which could be going to service coordination and delivery.
- Lack of leadership and/or a superficial commitment to interagency collaboration renders even the most skillfully-drafted agreement meaningless and ineffective.
- A lack of formal mechanisms to assure the collaborative process translates into inefficiency, with numerous issues and problems falling between bureaucratic cracks.
- People are needed to staff and coordinate interagency collaboration efforts; such agreements are rarely, if ever, self-executing. Staff shortages due to budget restraints and limited resources impede the effectiveness of many interagency agreements.

Special Studies:

A principal means of assessing needs and defining the problems of adolescents with chronic illness and disability is, of course, to conduct special studies. Few public programs, however, have undertaken needs assessments targeted to youth. One in four Developmental Disabilities Councils has undertaken special studies of youth with chronic and/or disabling conditions, significantly more data collection than has been developed by the other agencies surveyed (Maternal and Child Health and Children with Special Health Care Needs were not questioned).

Future Priorities:

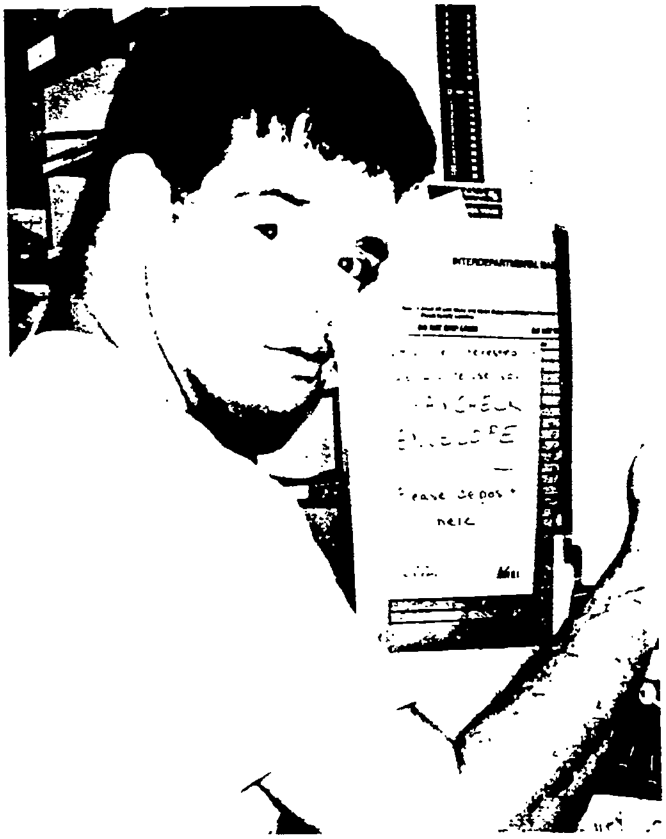
All seven agencies were questioned about the three top priorities for the future in delivering their services to adolescents with chronic illness and disability.

- The most frequently cited priorities (20 percent) were: expansion of services, improved coordination of services, and the integration of service delivery systems.
- The second most frequent choice among program directors was providing more support services, such as case management, transportation, school-based health programs, independent living assistance and respite care to families.
- The third most frequently listed priority by all program directors was the availability of transition services and planning for youth with chronic and disabling conditions.
- Expanded training and supported employment opportunities for teens with chronic illness and disability was an important priority, especially for directors of Special Education and Vocational Rehabilitation.
- One in every eight responses acknowledged the need for more funding.

Legislation - Does it Enable Services or Act as a Barrier?

The agencies surveyed were asked if they encountered state legislation beyond federal requirements that either enabled or acted as a barrier to service provision for youth with disabilities.

- Overall, 27 percent of the directors reporting indicated that their state had legislation which enabled the delivery of services to adolescents with disabling conditions.
- Just 15 percent of the directors report that there was specific state legislation which acted as a barrier to the delivery of services. An additional 25 percent were uncertain.



- Directors of Special Education (44 percent), Mental Retardation Developmental Disabilities Programs (36 percent) Developmental Disabilities Councils (33 percent); and Vocational Rehabilitation Departments (28 percent) were all much more likely to report having state legislation that enabled the delivery of services than were Maternal and Child Health and Children with Special Health Care Needs programs or Adolescent Health Coordinator positions.

- Twice as many directors (54 percent) believed there was no legislation which enabled the delivery of services. Twenty-seven percent felt there were such laws.

- The impact of enabling legislation where it exists on the delivery of services to adolescents is far greater in Special Education Development Disabilities Councils, Mental Retardation Developmental Disabilities programs and Vocational Rehabilitation Services than on Title V programs (Maternal and Child Health Children with Special Health Care Needs and Adolescent Health Coordinators).

- Of the directors who report having enabling legislation, slightly over half (53 percent) report such legislation has moderate or little impact. Twenty-four percent report the law's impact on services as great. About an equal number (23 percent) either did not know the impact or did not respond.

Policy Issues

Each agency or program was asked to specify policy issues related to services for adolescents with chronic illness or disability that were currently being discussed in their state. This was a subjective question and relied on the respondent perceptions of *what was going on.*

- Some 18 percent of directors indicated that policy discussions were in progress on systems planning; state federal mandates, school services, expansion of services interagency collaboration information sharing and HIV programs.

- Additionally, 18 percent of directors acknowledged discussions regarding the range of support services family support, respite care independent living, community-based support services case management, and integration inclusion issues.

- Seventeen percent of all director responses indicated transition issues were currently being discussed.

- Seven percent of the respondents indicated that no policy issues related to services for youth with disabilities were currently being discussed in their state.

> *"Various agencies deal with pieces of the needs of this population–approaches are fragmented, uncoordinated and the buck is often passed resulting in kids falling through the cracks."*

Future Program Services Development

The directors of each program were asked what types of programs or services for adolescents with chronic illness and disability they would like to see developed in their state if given increased support

- About 1 in 3 (36 percent) of the directors responded that they would like to see more community- and school-based services made available to teens with disabilities and their families, such as school health services, independent living programs, recreational services and employment services.

- More transition programs in health care and in planning and employment were needed to help the teenager move from school into the adult world according to 18 percent of respondents

- Fifteen percent of the directors would like to use increased financial support for program or systems improvement, making interagency collaboration and coordination of services more effective, and instituting a strong needs assessment initiative

- Only 2 percent of the directors surveyed would put more resources into case management.

The need to provide a greater array of transition services and planning was a consistent theme across all programs. Maternal and Child Health directors and Adolescent Health Coordinators ranked this first; directors of Special Education, Developmental Disabilities Councils and Vocational Rehabilitation programs ranked it second; and Children with Special Health Care Needs and Mental Retardation/Developmental Disabilities directors ranked it third.

One in every seven public sector programs surveyed agreed that more and better transition planning and services are needed across the board, from pediatric care to adult health-care, and from school to employment and independent living

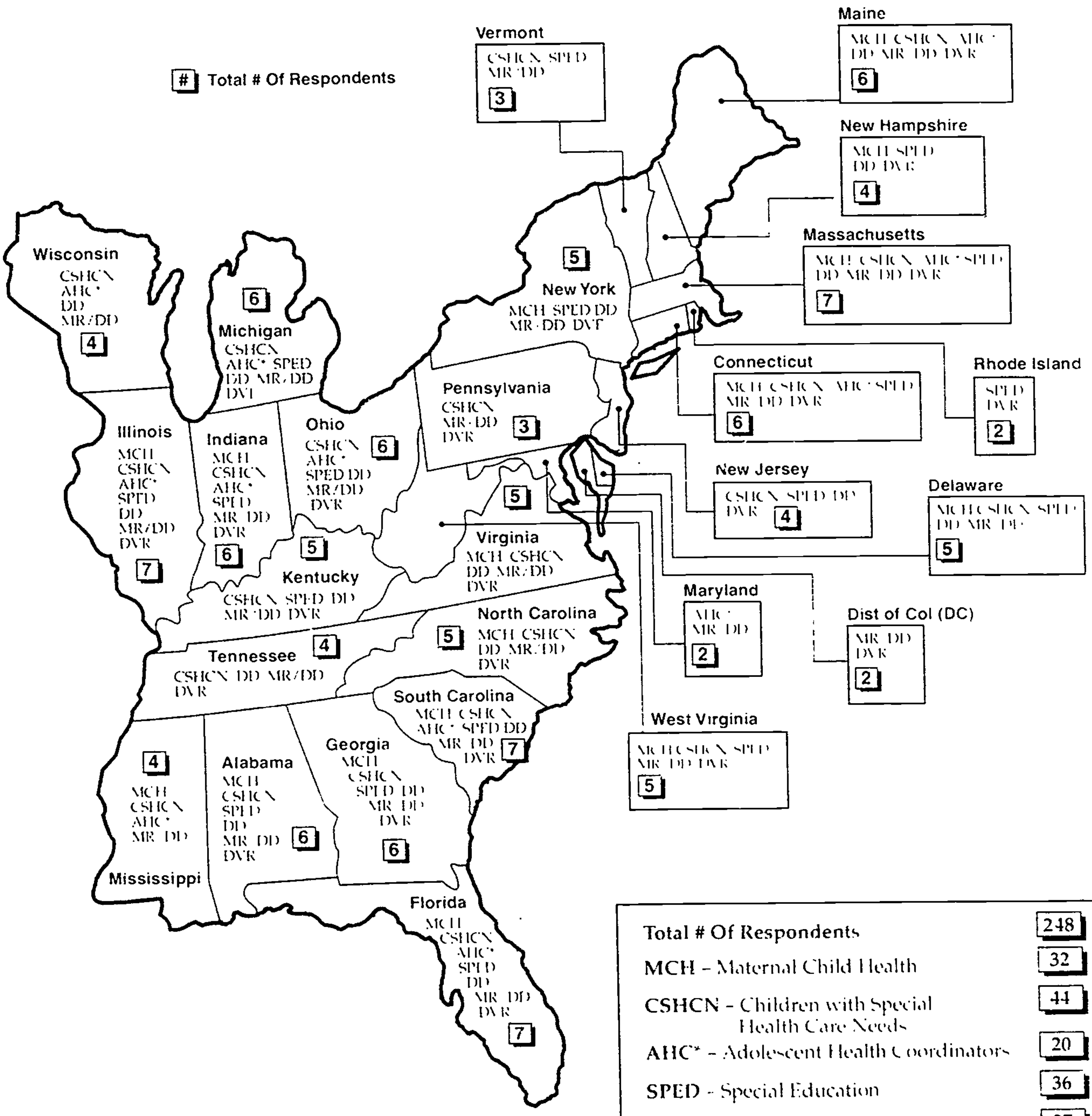
The correlation was high between what directors would like to see developed if more support was provided, and what were listed as the most important factors that limited the successful transition of youth with disabilities to adulthood. For example, more transition services are consistently rated as a highly desirable development; insufficient transition planning was viewed as one of the three most important factors in limiting the successful transition of adolescents to adulthood.

More community-based service with greater access was the most frequent choice of directors, and such basic service issues as mobility and the location of services was one of the three most important factors that limit successful transition.

Additionally, the data suggest an equally strong correlation between future programs and service development and transitional factors. This consistency between what directors perceive as the most crucial of adolescent needs and the programs they would like to see developed in their states can only be viewed as a very positive phenomenon. The contingency, of course, is increased funding, and unfortunately that has been a consistently difficult problem for those programs who would serve youth with disabilities.

Appendix A

Response by Agency By State



Total # Of Respondents	248
MCH – Maternal Child Health	32
CSHCN – Children with Special Health Care Needs	44
AHC* – Adolescent Health Coordinators	20
SPED – Special Education	36
DD – Developmental Disabilities	37
MR/DD – Mental Retardation Developmental Disabilities	39
DVR – Department of Vocational Rehabilitation	40

*At the time of this [illegible] Coordinator position

National Center for Youth with Disabilities

The National Center for Youth with Disabilities is a collaborative project of the Society for Adolescent Medicine and the University of Minnesota's Adolescent Health Program. Established in 1985, the National Center for Youth with Disabilities is an information and resource center focusing on adolescents with chronic illnesses and disabilities and the issues that surround their transition to adult life.

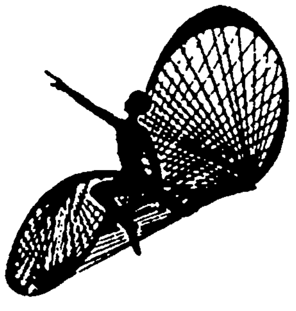
The Center's mission is to:

- Raise awareness of the needs of adolescents with chronic illness and disabilities.
- Expand the knowledge and involvement of those who provide services to youth.
- Promote programs and strategies which enhance the ability of adolescents and young adults to grow, develop, work, and participate in community life to their fullest capacity.

The National Center for Youth with Disabilities combines and shares information and knowledge to help advance thought and practice in a rapidly developing field. The Center provides easy access to current research findings and information on resources and advocacy efforts, and disseminates policy and program development information to agencies, health care professionals, educators, social workers, policymakers, parents and youth.

Programs and Services of the National Center for Youth with Disabilities:

- National Resource Library
- Publications
- Conferences and Workshops



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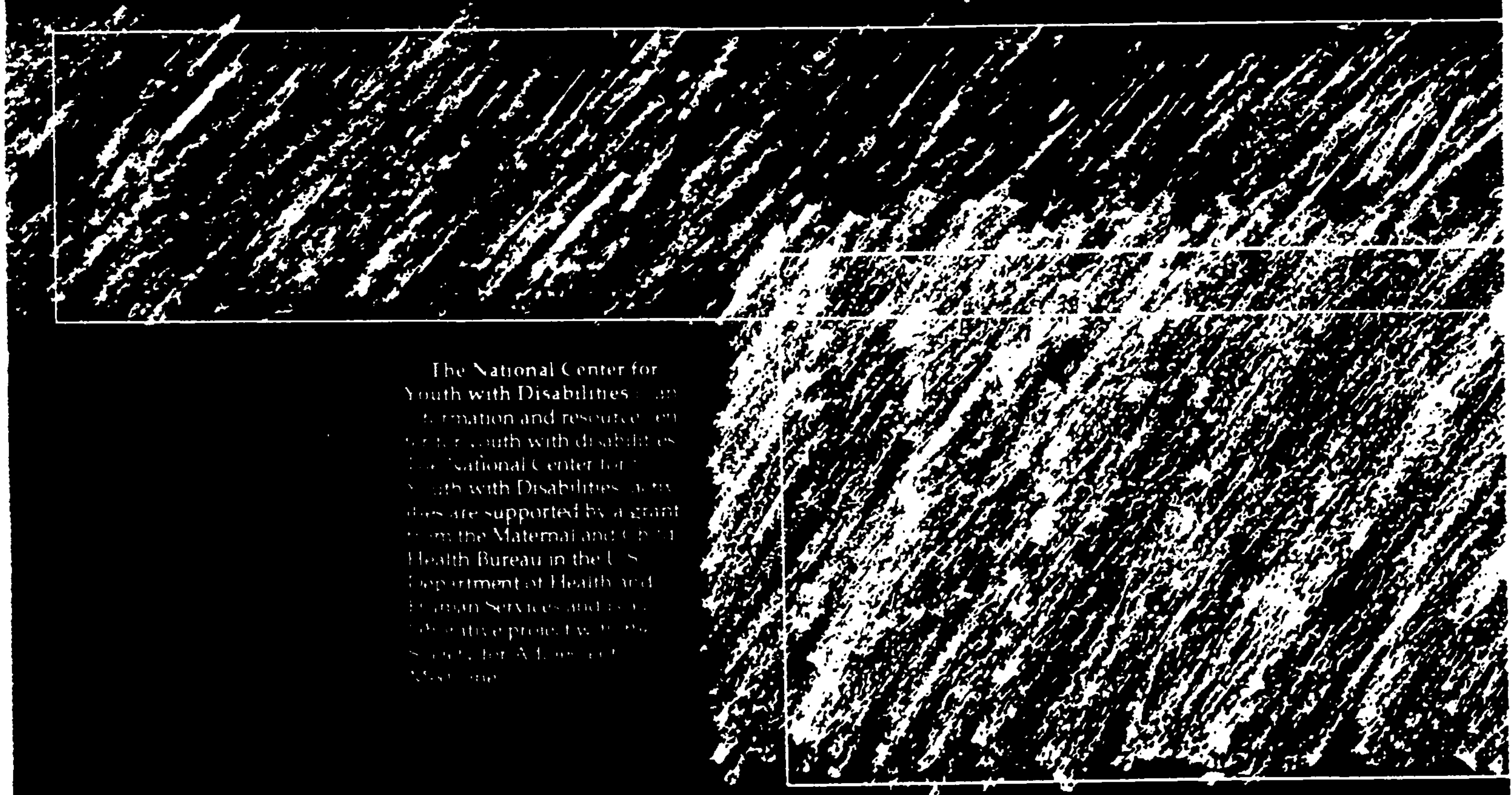

The National Center for Youth with Disabilities is an information and resource center for youth with disabilities. The National Center for Youth with Disabilities activities are supported by a grant from the Maternal and Child Health Bureau in the U.S. Department of Health and Human Services and is a collaborative project with the Society for Adolescent Medicine.