NORTH PENN COMMUNITY HEALTH FOUNDATION SPECIAL POPULATIONS NEEDS ASSESSMENT

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May, 2003

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PHILADELPHIA HEALTH MANAGEMENT CORPORATION

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EXECUTIVE SUMMARY

This report summarizes the findings from an assessment of the health care and social service needs of North Penn area residents with special needs. The special needs populations which are included in this report are the seriously mentally ill, mentally retarded adults and children and developmentally delayed children, the physically challenged, substance abusers, and cancer survivors. This assessment was conducted for the North Penn Community Health Foundation (the Foundation) by the Philadelphia Health Management Corporation (PHMC), a private non-profit public health organization, in the Winter of 2002-2003.

METHODS

The information collected and analyzed for this assessment includes statistical information on the number of individuals with special needs in the service area and information from 12 key providers and advocates in the community with knowledge of the special needs population. These informants discussed the special needs of children, adults and older adults with mental illness, mental retardation, physical disabilities, substance abuse problems, and cancer. Three focus groups of 35 residents with special needs were also conducted to provide information from the consumer perspective. The 35 participants were recruited from a variety of community organizations, including the Easter Seals, Penn Foundation, Ken-Crest Services, Indian Creek Foundation, and the Wellness Place for the Cancer Community. The three groups included parents of children with serious developmental delays, mental retardation or physical problems, seriously mentally ill and dually diagnosed adults, and cancer survivors.

Statistics on the size of the special needs population were estimated using information from a variety of the most recent sources available:

- 2000 U.S. Census;
- U.S. Bureau of the Census 1996 Survey of Income and Program Participation;

- U.S. Department of Health and Human Services, National Household Survey on Drug Abuse, 2001;
- The Epidemiological Catchment Area Study, 1993;
- U.S. Centers for Disease Control, Youth Risk Behavior Surveillance, 1999;
- Commonwealth of Pennsylvania Department of Health, Cancer Incidence and Mortality, 1997-2000; and
- Pennsylvania Department of Education, Bureau of Special Education: Special Education Statistical Summary 2001-2002.

Estimates of the number of persons with mental and physical disabilities and substance abuse/dependence were derived by multiplying the number of persons in the North Penn area by the percentage of persons in the nation with specific disabilities according to the Census, Survey of Income and Program Participation, National Household Survey on Drug Abuse, and National Institutes of Mental Health. Calculations used population figures for the North Penn area from the 2000 U.S. Census of Population and Housing.

KEY FINDINGS

There are 270,104 residents in the North Penn area:

- 46,734 are children aged 0-11 (17.3%);
- 22,421 are teenagers aged 12-17 (8.3%);
- 164,306 are adults aged 18-64 (60.8%); and
- 36,643 are older adults aged 65+ (13.6%).

A substantial number of North Penn area residents have special needs. More specifically:

- 32,500 out of 247,960 residents aged 5 and over (13.0%) have either a physical, mental or emotional disability which affects their ability to go outside their home or to work at a job;
- 1,437 residents out of 270,104 (0.5%) were diagnosed with cancer and more than 500 persons died from cancer in 2000;
- 11,700 of a total of 222,569 residents aged 12 and over (4.3%) have had a substance abuse problem in the past year; and
- 53,450 of a total of 200,949 (26.6%) adults were caregivers for the chronically ill, disabled, or aged family members and friends during the past year.[1]

Most of the needs of the different special populations in the North Penn area which were identified by key informants and focus group participants were surprisingly similar: affordable housing, transportation, more information about available services, greater access to respite for caregivers, and increased efforts

[1]National Family Caregivers Association, 2000.

to decrease the stigma associated with their special needs. Many of these issues, which are identified below, such as poor public transportation, decreased public funding for services, and the lack of sufficient affordable supportive housing, are the result of national economic and social problems. Directly addressing these issues is not within the scope of the Foundation's mission. However, local efforts can still be made to improve the quality of life for residents with special needs by improving coordination and collaboration between government and providers, encouraging the recruitment and retention of volunteers to provide some services, and conducting more targeted outreach and education locally.

A short summary of the needs of the chronically mentally ill, mentally retarded children and adults and developmentally delayed children, the physically disabled, substance abusers, and cancer survivors is given below, followed by recommendations for the Foundation.

CHRONICALLY MENTALLY ILL

A serious mental illness is a diagnosable mental, behavioral, or emotional disorder that substantially impairs one's ability to function. Anxiety disorder, schizophrenia, and mood disorder are examples of serious mental illnesses, which are usually chronic in nature. At any one time, an estimated 31,000 out of 200,949 adults in the North Penn area suffer from symptoms of a diagnosable mental illness in the past month; this represents approximately 15% of the adults living in the North Penn area. A slightly higher percentage of children and adolescents, 20.9%, will suffer symptoms of a diagnosable mental disorder over the period of an entire year, which represents about 7,300 out of 35,048 children and adolescents aged 9-17 in the North Penn area. This number includes children whose mental illness ranges in severity, and thus accounts for a seemingly large percentage. It is also important to note that mental illness in children changes over time; many children show significant improvement over time. Several barriers to mental and physical health care and supportive social services for the chronically mentally ill were identified:

Barriers

Lack of information. Key informants and focus group participants agreed that the general population does not know where to go to obtain information about mental health services. Individuals who become affected by a mental illness, because they are either diagnosed with a mental illness or care for someone with a mental illness, usually begin their search for help only when a crisis occurs.

Inadequate funding. Insurance is the primary factor determining access to mental health services. All individuals, regardless of the type of insurance they have, private or public, are negatively affected by the lack of parity between mental health care and physical health care. Recently, many services and staff

have been reduced due to cutbacks by government and private insurers. The result is inadequate staffing and frequent turnover in staff, leading to waiting lists for appointments. A key informant explained that it is difficult to get an appointment for mental health services within 7 days. Most residential and case management programs experience significant turnover in staffing, resulting in a lack of access to services. Focus group participants also identified a need for longer partial hospitalization stays, which have been reduced due to changes in Medicaid managed care insurance coverage. Many focus group participants also felt that the selection of physicians and dentists who participated in Medicaid managed care plans were located in areas that present transportation barriers.

Stigma. Key informants and focus group participants both believed that chronically mentally ill adults may also not get treatment, or get delayed treatment, for serious physical conditions due to the fact that many primary care physicians and subspecialists do not take their physical complaints seriously. Conversely, many primary care physicians prescribe medication to treat common mental illnesses, such as depression. In fact, nationally, primary care physicians account for 65% of all prescriptions for psychotropic drugs. Several factors and outcomes weigh into this statistic. Patients may prefer to see a primary care physician rather than a psychiatrist because of the stigma associated with seeking psychiatric care. Second, in some cases it is easier to see a primary care physician due to low insurance reimbursement for mental health care. Third, primary care physicians receive incentives from managed care organizations for retaining mental health patients. Lastly, primary care physicians are not necessarily trained in psychiatry, and thus, patients may not receive the best and most advanced mental health care. Pressure by advocates to authorize psychologists to prescribe medication and to provide parity in mental health care coverage has also increased due to these trends.

Poor job opportunities. Job opportunities are often limited for those with mental health illness due to commonly held misconceptions about capability, reliability, and safety. There is a need to identify appropriate jobs for those with mental health illness and to educate employers to consider persons with mental health illness for positions.

Respite care. Key informants said that there is a need for short and long-term respite care for those caring for persons with mental illness, especially for caregivers of individuals with severe mental illness.

Lack of supportive housing. There is limited affordable, safe housing for the chronically mentally ill in the North Penn area, particularly for the chronically mentally ill who also have other special needs. Residents are often resistant to having group homes or other assisted living situations for those with severe mental illness in their community.

MENTALLY RETARDED AND SPECIAL EDUCATION

Mentally retarded children and adults in the North Penn area are served by both the private and public systems. An estimated 1,781 children and adults in the North Penn area are mentally retarded; this represents just 0.7% of North Penn area residents. About 400 out of 58,278 children 0-15 years old; 195 out of 27,924 residents who are 15 to 24 years old; 1,030 from a total of 147,259 adults aged 25-64; and 147 out of 36,643 adults aged 65+ are mentally retarded. About 4,500 children in North Penn area school districts are receiving special education for a specific learning disability. About 157 children in North Penn area school districts have autism. Key informants and focus group participants identified the major barriers that individuals with mental retardation, autism, developmental delays, and learning disabilities face:

Barriers

Lack of information. Parents of children receiving early intervention services in Montgomery County felt very strongly that not enough information about early intervention services and its policies and procedures was available to parents whose children might be in need of services. They also felt that there was a lack of information on how to navigate "the system" to obtain the medical services they felt their children needed. The lack of information that pediatricians were able to give to the families of children with special needs, particularly in cases of Pervasive Developmental Disorder and Autism, was also a problem for many early intervention parents.

Administrative delays. Parents of developmentally delayed children often experienced delays of nine months to one year in obtaining services for their children because of the time involved in completing their child's evaluation. The evaluation must be completed before the Individual Family Service Plan or Individual Education Plan can be written and services begun. Montgomery County families stated that evaluations are conducted in a piece-meal fashion and that delays often occur. Parents often felt frustrated because they felt that precious time was being wasted and they were unable to help their children receive the critical services that they needed.

Restrictive eligibility requirements. Key informants also felt that several subgroups within the mentally retarded and developmentally delayed population are at risk for not receiving needed services when they age out of the system and no longer meet eligibility requirements. For example, individuals with autism who have an IQ above 70 are not eligible for services through County Offices of Mental Retardation. Therefore, high-functioning autistic individuals will not receive County mental retardation services, despite the fact that they may be helpful.

A second subgroup who potentially face a lack of services are persons with mental retardation who are living with aging parents and are not currently receiving County-funded services. This group may eventually have difficulties receiving services when their parents are no longer able to care for them and then apply for County-funded services, since there is a waiting list for these services. In Pennsylvania, there are an estimated 36,770 mentally retarded individuals living with parents aged 60 and over.

There is also a growing population of mentally retarded children who receive primary medical care through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program and are nearing adulthood. When they reach age 21 they will no longer be qualified for EPSDT services, but they still need regular check-ups and screenings. Children who are served through the County mental retardation system who graduate from high school also become ineligible for other services. Sometimes these young adults receive assistance with employment and job training from the Office of Vocational Rehabilitation. However, these services are usually less intensive than those provided by the school.

Lack of activities for children. Many focus group participants wanted their developmentally delayed or physically handicapped children to be mainstreamed as much as possible. However, most playgrounds are not handicap accessible, forcing families with both physically challenged and non-physically challenged children to forgo visiting a playground altogether. In addition, there are few activities especially adapted to the growing number of children with autism or Pervasive Developmental Disorder. Participating in group activities is difficult for these children, so that activities have to be specially designed for them. Summer activities, especially for younger school aged children with special needs, are particularly needed also.

Lack of respite care. Short and long term respite care, both in the home and at off-site locations, is greatly needed for caregivers of mentally retarded and/or developmentally delayed children and adults. Affordable day programs for older adults with mental retardation are particularly needed. Several types of caregivers need respite care more than others: single parents, parents of mentally retarded adults, parents with other children, and parents of mentally retarded individuals with complex medical problems or severe behavioral problems. These subgroups, more than others, need respite care because they experience more stress and carry more responsibility. Single parents have no one with whom they can share caregiving. Parents with several children must care for their child with special needs and, in addition, care for their other children. Children who have multiple problems require even more care, and it is difficult to find caregivers who have the necessary skills and training.

Lack of transportation. Since many mentally retarded adults do not drive, the limited public transportation in the suburban and rural areas of both Bucks and Montgomery Counties is a barrier to accessing services.

Lack of supportive housing. Key informants from both counties said that there is a need for affordable housing and community living arrangements for mentally retarded adults. One key informant explained that there are also not enough licensed personal care facilities to care for adults with mental retardation. Adults aged 65 and over are also in need of specialized housing. They have many of the same needs as other older adults but their needs are often less likely to be met because few residential programs or nursing homes are equipped to care for older adults with mental retardation. Also, children with severe autism who cannot live with their families are particularly difficult to place since they often have multiple issues.

PHYSICALLY DISABLED

In the North Penn area, 7,436 individuals of a total of 251,766 adults and children aged five and over have a sensory, physical, or self-care disability. Among age subgroups of the North Penn area population, about 7,260 of a total of 208,171 of adults and children aged 16 and over (3.5%), have a physical, sensory or self-care disability. Only 173 out of 43,595 children aged 5-15 have one of these disabilities. The most common type of disability is a physical disability, which affects nearly 5,000 persons, representing nearly 2.0% of the total population aged five and over. Not surprisingly, most adults with a physical disability are elderly. Sensory disabilities, such as hearing or vision impairment, affect 2,440 persons aged 5 and over in the North Penn area; this represents 0.9% of the total population.[2]

Barriers

Lack of access to public places. All key informants agreed that one of the most serious problems, if not the most serious, is the lack of physical access to public places. Despite passage of the Americans with Disabilities Act, many buildings are not wheelchair accessible; bathrooms do not always accommodate the needs of those with disabilities; and parking lots do not always have ample parking spaces for those with physical disabilities. This disregard for the needs of individuals with disabilities hampers every aspect of their lives, from leisure activities to professional employment and basic transportation.

Discrimination. Key informants cited discrimination as another major problem. They explained that society is generally ignorant about persons with disabilities.

[2] These numbers reflect the number of persons who have only one of these three disabilities: physical, self-care, or sensory. It is important to note that the number of persons in the North Penn area who are disabled is probably higher because many individuals have more than one disability or have disabilities other than the three specific disabilities discussed above.

Currently, many of the disabled who want to work are unable to find employment. Consequently, the rate of unemployment among disabled persons is higher than national figures. Key informants believe that this pattern suggests that employers discriminate against the disabled. Even when disabled persons cross the initial hurdle of finding employment, they must continue to struggle for equal treatment once employed. For example, key informants felt that persons with disabilities are sometimes treated as children in the workplace. In other instances, supervisors are hypersensitive to their errors and blame the disability for mistakes. Sometimes, employers promise to make certain accommodations for persons with disabilities and then do not follow through.

Poor quality health care. Key informants felt that there is a great need to educate primary care physicians about medical issues related to physical disability. One key informant said that the disabled either have to find a physician who specializes in their condition or educate the primary care physician themselves about their disability and medical condition. Another key informant felt that physicians often do not treat disabled patients with respect.

Lack of access to transportation. Transportation continues to be a major obstacle for persons with disabilities. Para transit, which serves the disabled, has two drawbacks: it operates within a defined route and is designed specifically to transport individuals to medical appointments. Transportation is especially difficult for disabled older adults due to their increased levels of disability.

Lack of affordable housing. Like many others living in the North Penn area, those with physical disabilities struggle to find affordable homes. Many people would like to live on their own, but cannot afford it. In addition, it is often difficult to find a home that accommodates the needs of a person's physical disability and renovating a home can be quite costly. Another issue, which is linked to the availability of housing, is that there is no service that is specifically designed to help the disabled move from one location to another.

SUBSTANCE ABUSERS

In the North Penn area an estimated 11,700 residents aged 12 and older abuse legal and illegal substances. This represents 4.3% of the total population. Alcohol is the most commonly abused substance. Among the 13,800 high school students in the North Penn area, an estimated one-half currently use alcohol (6,900); one-third currently smokes cigarettes (4,800); and one-quarter currently use marijuana (3,690). Key informants believe that most individuals in need of drug and alcohol treatment know how to find information about services. While most are aware of available services, there are several populations that are largely unfamiliar with drug and alcohol abuse treatment: the deaf and hard of hearing; racial and ethnic minorities, particularly Latinos and Asian-Americans;

and those with a dual diagnosis of drug and alcohol addiction and mental illness. Key informants note that most individuals have access to the services they need.

Key informants identified the top barriers for those with substance abuse:

Barriers

Treatment for those with medical and substance abuse problems. Individuals with both chemical addictions and serious medical conditions have difficulty finding a provider. Often, those who abuse alcohol have medical problems involving the central nervous system and the gastrointestinal system. Cocaine abusers may experience malnutrition, myocardial infarction, and stroke. Injection drug users are at greater risk for contracting Human Immunodeficiency Virus, tuberculosis, sexually transmitted diseases, abscesses, and bacterial endocarditis. The problem of finding a provider when one has medical comorbidity becomes magnified if the individual is elderly, as the elderly are poorly served by the drug and alcohol system. In addition, persons with brain damage due to many years of untreated alcoholism are often not appropriate for treatment programs used for younger, non-brain damaged substance abusers. These individuals are better served in a nursing home environment, which is rarely available, except in an expensive private pay situation.

Treatment for those with dual diagnosis. There are few services that cater to dually diagnosed individuals with substance abuse problems and mental health disorders. Approximately, 3.3% of adults 18 and older with mental illnesses also have substance abuse disorder. This figure represents 1,326 adults in the North Penn area. The number of services for dual diagnosis clients should improve in the near future, as both drug and alcohol and mental health facilities are applying for licenses to provide both services. In the meantime, this group is largely underserved.

Lack of affordable housing and employment opportunities. One key informant explained that lack of housing and employment are the two needs that affect the largest number of substance abusers. Drug and alcohol treatment clients have great difficulty finding jobs, as employers rarely hire people with addictions. They also have trouble finding affordable housing that is in safe and relatively drug-free neighborhoods. Safety is of primary importance, as it is necessary for people with addictions to remove themselves from tempting environments. Both the lack of affordable housing and employment opportunities increases the likelihood of relapsing to addiction.

CANCER SURVIVORS

A substantial number of North Penn area residents, approximately 1,400 adults and children, are diagnosed with cancer each year. Among children 0-14 years old, the most common are those of the brain and nervous system cancer, thyroid

cancer, non-Hodgkin's lymphomas, Hodgkin's lymphomas, and leukemia. These cancers affect a total of 30 children annually. Among adults, the most common cancer sites are the colon and rectum, lung, prostate, female breast, and urinary tract and bladder.

Cancer patients do not usually lack access to adequate health care, but key informants and focus group participants felt that the medical care system itself does not often provide the supportive services that are needed. For example, key informants and focus group participants felt that cancer patients have an unmet need for counseling due to the emotional trauma that accompanies a possibly life-threatening illness. However, many organizations offer support services for cancer patients and their caregivers. For example, the Wellness Place for the Cancer Community, the North Penn Visiting Nurse Association, Abington Memorial Hospital, Doylestown Hospital, Gilda's Club, local YMCAs, Grandview Hospital, Warminster Hospital, and the Phoenixville Hospital all offer support programs and counseling for cancer survivors and their families. In addition, a growing number of cancer patients and caregivers are joining online support groups.

Key informants and focus group participants identified these key barriers for cancer survivors and their families:

- Lack of knowledge of supportive services
- Lack of sufficient nursing services for survivors recently discharged from hospital and those who live alone;
- Stigma against discussing cancer;
- Lack of information about diet and nutrition;
- Lack of respite care;
- Lack of supportive services especially designed for children and their families.

More outreach and education to the general public and those diagnosed with cancer is needed, especially to overcome the stigma associated with cancer. In addition to emotional support and counseling, other services for cancer survivors and their families which focus group participants felt were needed in the North Penn area are: **more respite care** services for family members, **more visiting nurses** who can provide home care beyond that which is covered by insurance, **volunteers to assist cancer patients** who have just been released from the hospital and live alone, **transportation to supportive programs** for those who are undergoing treatment and are too sick to drive themselves, **a dietician who can advise cancer patients**, and a **special facility for children** with cancer.

RECOMMENDATIONS

Most of the needs of the different special populations in the North Penn area which were identified by key informants and focus group participants were surprisingly similar: affordable housing and transportation, more information

about available services, greater access to respite for caregivers, and more efforts to decrease the stigma associated with their special needs. These needs are listed below, in addition to specific needs which were identified for each population. Many of these issues, which are identified below, such as poor public transportation, decreased public funding for services, and the lack of sufficient affordable supportive housing, are the result of national economic and social problems. Directly addressing these issues is not within the scope of the Foundation's mission. However, local efforts can still be made to improve the quality of life for residents with special needs by improving coordination and collaboration between government and providers, encouraging the recruitment and retention of volunteers to provide some services, and conducting more outreach and education locally.

The following table summarizes the issues which were identified for each population, the rationale for making these issues a priority, and suggested programmatic areas, followed issues which were common to all of the special needs populations.

SPECIAL POPULATION(S)	PRIORITY NEEDS	RATIONALE	POTENTIAL PROGRAM AREAS
Chronically Mentally Ill, Mentally Retarded, and Developmentally Delayed Children	Affordable supportive housing for adults More in-home and residential respite for caregivers More activities for children which are adapted to their needs and are handicapped accessible, especially in the summer and for autistic/PDD children	Adults need housing in the community to decrease institutionalization Caregivers will provide better care and use less public resources when they are less stressed Children will continue the gains made during the school year in programs offered in the summer	Encourage programs which decrease community opposition to supportive housing for the mentally ill and mentally retarded adults Encourage government and non-profits to attempt more supportive housing by providing information on the benefits of developing these ventures Encourage community volunteer efforts to provide consistent and quality in-home respite care, especially faith communities which are already providing care on a smaller scale. Assist non-profits and charitable organizations which already provide summer activities to expand their efforts to meet the demand.
Substance Abusers	More treatment programs for substance abusers with serious medical illnesses, older adult substance abusers, and chronically mentally ill substance abusers	These individuals are most in need of treatment but most likely to "fall through the cracks" since government agencies often only serve those in one diagnostic category	More facilities are treating chronically ill substance abusers, but government and providers need encouragement to serve these populations by forming collaborations to work together.
Cancer survivors	More outreach to cancer survivors to encourage participation in existing supportive programs Specialized supportive services for children with cancer and their caregivers	Decreasing stress may improve treatment outcomes	Assist collaborations between the medical community and supportive providers to increase outreach

ALL SPECIAL NEEDS POPULATIONS	More funding for public services to decrease administrative delays, provide needed services, and improve the quality of treatment	Without access to quality, appropriate services which are provided in a timely manner, many adults and children with special needs become more ill.	Encourage providers and government to collaborate to identify areas where administration could be more efficient and funding allocated to higher priority areas
ALL SPECIAL NEEDS POPULATIONS	More affordable, accessible transportation to non-medical appointments	Many do not drive; public transportation is poor and not always accessible	Encourage the expansion of volunteer transportation programs, especially in faith-based communities that have existing programs Encourage potential grantees to address the issue of transportation and fund van services where needed
ALL SPECIAL NEEDS POPULATIONS	Decrease the stigma associated with the special needs populations	Stigma prevents people with special needs from living fully in the community	Assist government and non-profits to educate the general public, medical community, and potential consumers of services and their caregivers
ALL SPECIAL NEEDS POPULATIONS	More information on available services for the general public, medical and treatment communities, and those with special needs and their caregivers	Increased access to needed services prevents more serious illness and conditions	Assist government and non-profit providers to publicize services, including a “cook book” approach for obtaining services for each special population

INTRODUCTION

This report summarizes the findings from an assessment of the health care and social service needs of North Penn area residents with special needs. The special needs populations which are included in this report are the chronically mentally ill; mentally retarded adults and children and developmentally delayed children; the physically disabled; substance abusers; and cancer survivors. This assessment was conducted for the North Penn Community Health Foundation (the Foundation) by the Philadelphia Health Management Corporation (PHMC), a private non-profit public health organization, in the Winter of 2002-2003. The Foundation's service area includes the following 24 communities in Montgomery and Bucks Counties.

North Penn Community Health Foundation Service Area	
Montgomery County	**Bucks County**
Franconia Township	Silverdale Borough
Souderton Borough	Hilltown Township
Hatfield Township	New Britain Township
Hatfield Borough	New Britain Borough
Lansdale Borough	Chalfont Borough
Montgomery Township	Doylestown Township
Horsham Township	Doylestown Borough
Lower Gwynedd Township	Warrington Township
Whitpain Township	Telford Borough
Worcester Township	
Upper Gwynedd Township	
Towamencin Township	
Lower Salford Township	
North Wales Borough	
Ambler Borough	
Telford Borough	

The information collected and analyzed for this assessment includes statistical information on the number of individuals with special needs in the service area and information from 12 key providers and advocates in the community with knowledge of the special needs population. These providers discussed the special needs of children, adults, and older adults with mental illness, mental retardation, physical disabilities, substance abuse problems, and cancer. Three focus groups of 35 residents with special needs were also conducted. These sources are described in more detail in Methods, the next section of this report. The Methods section is followed by the Findings section of the report, which presents information on the number of individuals in each special needs population and the particular issues which impact on their quality of life.

Recommendations which address these issues in detail are included in the final section of the report.

METHODS

Statistical information on the size of the special needs population was collected and analyzed from a variety of the most recent sources available:

- 2000 U.S. Census;
- U.S. Bureau of the Census 1996 Survey of Income and Program Participation;
- U.S. Department of Health and Human Services, National Household Survey on Drug Abuse, 2001;
- The Epidemiological Catchment Area Study, 1993;
- U.S. Centers for Disease Control, Youth Risk Behavior Surveillance, 1999;
- Commonwealth of Pennsylvania Department of Health, Cancer Incidence and Mortality, 1997-2000; and
- Pennsylvania Department of Education, Bureau of Special Education: Special Education Statistical Summary 2001-2002.

Except where otherwise noted, estimates of the number of persons with mental and physical disabilities and substance abuse/dependence were derived by multiplying the number of persons in the North Penn area according to the 2000 U.S. Census by the percentage of persons in the nation with specific conditions.

Information on the specific needs of special populations in the North Penn area was collected from 12 key individuals in the North Penn community (See Appendix A for a list of key informants). These informants discussed the special needs of children, adults and older adults with mental illness, mental retardation, physical disabilities, substance abuse problems, and cancer. The interviews followed a written interview guide and were conducted in person and by telephone. Question topic areas included unmet needs, needs of caregivers, and access to services (See Appendix B for the Key Informant Guide).

Three focus discussion groups of North Penn area residents were also held. The 35 participants were recruited from a variety of community organizations, including the Easter Seals, Penn Foundation, Ken-Crest Services, Indian Creek Foundation, and the Wellness Place for the Cancer Community. The three groups included parents of children with serious developmental delays, mental retardation, or physical disabilities; seriously mentally ill and dually diagnosed adults; and cancer survivors. The discussion groups lasted 1-2 hours, were audiotaped, and were led by a trained facilitator and a co-facilitator. The discussion followed a written guide. (See Appendix C for the Focus Group Discussion Guide). Focus group participants were compensated $30 each for their time.

FINDINGS

This section of the report summarizes the findings from an analysis of statistical information on the number of individuals with special needs in the North Penn area. This section also describes the specific health and social service needs of the North Penn area's special populations based on information from the 12 key informants who were interviewed and three focus discussion groups which were conducted for this report.

There are 270,104 residents in the North Penn area:

- 46,734 are children aged 0-11 (17.3%);
- 22,421 are adolescents aged 12-17 (8.3%);
- 164,306 are adults aged 18-64 (60.8%); and
- 36,643 are older adults aged 65+ (13.6%).

A substantial number of North Penn area residents have special needs.

- **32,500 out of 247,960 residents aged 5 and over (13.0%) have either a physical, mental or emotional disability which affects their ability to go outside their home or to work at a job:**
- **1,437 residents out of a total of 270,104 (0.5%) were diagnosed with cancer and more than 500 persons died from cancer in 2000;**
- **11,700 individuals of a total of 222,569 residents aged 12 and over (4.3%) have had a substance abuse problem in the past year[1]; and**
- **53,450 of a total of 200,949 (26.6%) adults were caregivers for the chronically ill, disabled, or aged family members and friends during the past year.[2]**

Many individuals who are disabled may have additional special needs or difficulties accessing health care and social services due to the fact that they lack health insurance and/or have a low level of educational attainment or income. Nationally, severely disabled individuals are more likely to be in fair or poor health but less likely to be covered by private insurance than non-disabled individuals. Disability status is also associated with lower levels of educational attainment, an increased likelihood of receiving welfare benefits, of having low levels of income, and of being more likely to live in poverty. Severely disabled individuals without private insurance coverage for health care may be totally or

[1] It is important to note that they actual number of North Penn area residents with substance abuse problems is probably underreported.
[2] National Family Caregivers Association, 2000.

partially insured through a public program, such as Medicare, Medicaid, Social Security, or SSI. Therefore, due to their lack of economic resources and education, disabled individuals may experience additional barriers to accessing health care and social services. These barriers, which are discussed in the following sections of this report, include those created by social stigma, linguistic, cultural, and literacy differences, as well as economic differences causing problems with obtaining transportation and services which must be paid for out of pocket.

The following sections present information on each of the special populations in the North Penn area.

CHRONICALLY MENTALLY ILL

> "Mental illness is the term that refers collectively to all diagnosable mental disorders. Mental disorders are health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning…Alterations in thinking, mood or behavior contribute to a host of problems – patient distress, impaired functioning, or heightened risk of death, pain, disability or loss of freedom." (American Psychiatric Association, 1994).

Mental illness is a common, yet often unrecognized, illness. Estimates of the number of mentally ill adults vary based upon the definition of mental illness that is used. A mental disorder is usually defined as an illness which is diagnosable under the criteria published in the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV*). Generally, only conditions which are composed of a cluster of signs and symptoms, which taken together, impair a person's ability to function are considered to be a diagnosable mental disorder. There are a total of 47,500 adults and children aged 9-17 in the North Penn area with symptoms of a mental disorder in the past year (21.0%). At any given point in time, approximately 20% of adults in the North Penn have had symptoms of a mental illness in the past year.[3] This figure represents 40,000 of a total of 201,000 adults in the North Penn area. A similar percentage of children (20.9%) have had some symptoms of mental disorder in the past year; this represents approximately 7,300 out of 35,000 children aged 9-17 (Table 1). This number includes children whose mental illness ranges in severity, and thus accounts for a seemingly large percentage. It is also important to remember that mental illness in children changes over time; many children show significant improvement over time.

Anxiety disorder is the most common mental illness among adults (Table 2). Anxiety disorders, including phobias, panic disorder, and obsessive-compulsive disorder, affect about 14,000 North Penn area adults in any month, representing 7.3% of the adult population.[4] Among these disorders, phobias affect the greatest number, about 1,000 adults in North Penn. The second most common mental illness among all adults is affective disorder (also known as mood disorder). Affective disorders include manic disorder, major depressive episode, and dysthymia. About 10,250 North Penn area adults have symptoms of an affective disorder in any one month. This represents 5.1% of the adult population

[3] L.N. Robbins & D.A. Regier, *Psychiatric disorders in America: The Epidemiologic Catchment Area study.* 1991.

[4] Regier et al. (1993) calculated totals of mental illness cases for a one-month time frame. Study subjects were asked if they ever had symptoms of particular mental illnesses and if these symptoms were also present in the past month. Affirmative responses to both questions categorized them as having the mental illness for the past month. Advantages of using a one-month time frame include the minimizing of recall bias, as well as a reduction in mental illness symptoms due to one-time events, such as divorce or bereavement.

in the North Penn area. Dysthymia, which is described as a depressed mood that is less chronic than major depression, is the most common affective disorder, affecting 6,630 adults (3.3%).

Generally, adults in the 25-44 age group have the highest rates of mental illness. For example, during a one month time frame, a total of about 14,580 out of 84,304 adults aged 25-44 have symptoms of a mental illness (17.3%). In comparison, 16.9% of adults age 18-24, 13.3% of adults aged 45-64, and 12.3% of adults aged 65+ have symptoms of a mental illness in any one month. These percentages represent 2,880 of 17,000 adults aged 18-24; 8,370 of 63,000 45-64 year olds, and 4,500 of 36,600 adults aged 65 and over.

However, severe cognitive impairment and substance abuse disorder are more common, respectively, in the oldest and youngest age subgroups of adults. For example, rates of severe cognitive impairment, which includes illnesses such as Alzheimer's Disease and other dementias, increase with age: adults aged 65 and over have the highest rate of severe cognitive impairment (Table 2). Approximately 4.9% of adults aged 65 and older have severe cognitive impairment, compared to 1.2% of 45-64 year olds, 0.4% of 25-44 year olds, and 0.6% of 18-24 year olds. Substance abuse disorder is most common among the youngest age subgroup of adults, 18-24 year olds. About 1,160 adults in this age group have a substance abuse disorder, which represents 6.8% of this population. The rate of this disorder decreases with age: 4.8% of adults aged 25-44, 2.1% of adults aged 45-64, and 0.9% of adults aged 65+ are affected by substance abuse disorder in any one month. About 1,320 adults in North Penn have both a substance use disorder and a mental illness in any one month. This represents 3.3% of the adult population.

Patterns of mental illness among children are similar to those seen in adults. As stated earlier, a similar percentage of adults and children have a mental illness (about 20%). Like adults, anxiety disorder is the most common mental illness among children 9-17 years old (Table 1). It affects about 4,500 out of 35,048 children; this represents 13% of this population subgroup.

Mood (affective) disorder is also another common mental illness among children, affecting an estimated 6.3% of 9-17 year olds, or approximately 2,170 children (Table 1). Depression is the most common type of mood disorder in children aged 9-17. It affects an estimated 1,700 North Penn area children. Another common mood disorder is reactive depression,[5] in which depressed feelings are short-lived and occur in a normal response to specific experiences, such as rejection, divorce, or loss. It is possible that many of the 9 to 17 year olds diagnosed with a mood disorder have a specific diagnosis of reactive depression.

Not surprisingly, depression leads to an elevated risk of suicide. Suicide in children and adolescents is extremely rare in the North Penn area. Yet, any

[5] The figure and percentage of reactive depression in children was not available.

depression in children is cause for serious concern. An estimated 20% of high school students in the North Penn area have seriously considered attempting suicide in the past year (Table 3). This represents 2,664 of 13,804 high school aged adolescents. An estimated 14.5% have made a suicide plan in the past year; 8.3% have attempted suicide one or more times; and 2.6% have required medical attention for a suicide attempt. These figures represent, respectively, 2,001, 1,146, and 359 high school students in the North Penn area. Emotional problems are particularly common during adolescence; the incidence of suicide attempts reaches a peak during the high school years. These figures, therefore, may represent a relatively high estimate of the number of suicides attempted by children.

Disruptive disorders include oppositional defiant disorder, which is characterized by defiance, disobedience, and hostility, and conduct disorder, which is an abnormally high engagement in fighting, bullying, cruelty, and vandalism. In the North Penn area, approximately 3,610 children aged 9-17 (10.3%) have a disruptive disorder (Table 1). It is the second most common mental disorder in this age subgroup.

Key informants and focus group participants identified several barriers to mental and physical health care and supportive social services:

- **Lack of information**
- **Inadequate funding**
- **Stigma**
- **Poor job opportunities**
- **Lack of respite care**
- **Lack of supportive housing**

These barriers are described in more detail below.

Barriers

Lack of Information

According to PHMC's 2000 Southeastern Pennsylvania Household Health Survey, only 28.5% of adults who report that they have a mental illness receive any kind of mental or addictive services. This means that only 11,454 adults out of a total of 40,190 who report that they have a mental illness in North Penn have received treatment for their condition in the past year. Key informants and focus group participants agreed that North Penn area residents are generally not aware of available services. Individuals who become mentally ill because they are either diagnosed with a mental illness or individuals who care for someone with a mental illness usually begin their search for help only when a crisis occurs. Frequently used resources for information are insurance companies, parent support groups, and the school district. Individuals who are more seriously impaired experience the greatest barriers. One provider said that “probably not

enough [clients have access]. Especially the severely mentally ill." Focus group participants also felt that seriously mentally ill adults were not aware of services in the area that could help them. One chronically mentally ill woman who had been homeless and incarcerated in the past and now resided in a program for dually diagnosed formerly homeless women remarked that:

> "I been there (residential program) for a year, but I came there from jail. And I was homeless before I went to jail. If you ever … know anything about jail, people who are mentally ill and are in jail… it's terrible… And then somehow the Grace of God I came here and they've been taking good care of me here. My point is this, people that are mentally ill, when you're sick you can't really think of what to say or do. Like, people don't tell you…down in Lower Bucks County I couldn't get help. I wound up going to jail and then coming here. You're talking about emergency situations, I went to the hospital quite a few times, you'd think that they would notice that… Once you're in the system you sit here and eat pizza and drink coffee, but when you're out there it's not like that. You might look at me now, I have pigtails in my hair and I got clean clothes on, but a year and a half ago that's not what I looked like. I stunk, I was homeless, mentally ill, homeless, sick, and alcoholic and I wound up in jail… And you're lucky to get to a place like this. It's not eating pizza and drinking coffee for the mentally ill."

Other barriers to obtaining information include language differences and a lack of internet access. According to one key informant, "low literacy clients have the most trouble finding services. Those who do not speak English have trouble, and those without access to the internet have trouble."

Inadequate Funding

One key informant explained that insurance coverage is the primary factor determining access to mental health services. All individuals, regardless of the type of insurance they have, private or public, are negatively affected by the lack of parity between insurance coverage for mental and physical health care.

This issue of low reimbursement for mental health care is currently a major policy issue. Advocates struggle to prove that mental health care should be reimbursed at a rate equal to physical health care. Mental health care professionals must prove to payors that their services are valuable and effective. Some point out that insurance reimbursement is beginning to rise. However the cutbacks over the last decade were so substantial that it will take years before the level of reimbursement is raised to a reasonable level.

As the policy debate continues, a surprising trend has emerged. As a result of this low reimbursement landscape, many consumers with mental health issues have relied on their primary care physician for care rather than on a mental

health specialist. In fact, primary care physicians now write 65% of all prescriptions for psychotropic drugs.[6,7] It is easier to get reimbursement for primary care visits than for mental health appointments. In addition, managed care organizations provide incentives to encourage primary care physicians not to refer patients to mental health specialists, but to remain responsible for patients with mental disorders.[8]

While these issues are debated among payors, advocates, and health care professionals, low insurance coverage and lack of state funding for Medicaid presents barriers to receiving care. For example, focus group participants who receive mental health services through Medicaid managed care worry that cutbacks will affect their access to case managers. Focus group participants explained that case managers are already hard to find. These focus group participants found the services of a case manager to be invaluable because case managers can coordinate treatment between different providers and systems and also act as an advocate for the consumer.

> "I was going to say that, really, people who have special needs need a social work contact that can act as a liaison between all these other professional people. So that if you have an issue and they think that you're too crazy to be reliable, then you should have some kind of a case worker or social work liaison that can speak up for you that knows how to get through the system to find out what kind of funds are available if you need medication that you're not covered (for) and that kind of thing. Because that would be effective. Unfortunately, even if we do speak up and try to get our needs met, you know, there's a terrible prejudice out there against people that have some kind of handicap, and it doesn't even necessarily have to be psychiatric. It can be a physical handicap. But we are looked at as being second class citizens. Unreliable, etc. etc. So if somebody who does have some kind of credibility could be there to speak up for us, then maybe we wouldn't have quite as hard a time getting our basic needs met."

> "It's very rare to have a case manager, like a case worker. I heard that if you get one you're supposed to try to keep them because they are very rare."

> "These people (case workers) are so overworked … that not all of our needs are met. We still have to do some of it ourself… Maybe they need more (case workers). But see, the thing is that's going on is the insurance

[6] National Ambulatory Medical Care Survey, 2001 (NAMCS)
[7] Percentage based on NAMCS information that was collected only from office-based settings and excludes visits in hospital settings, federal facilities, emergency departments, or outpatient hospital based clinics.
[8] Pincus et al., "Prescribing Trends in Psychotropic Medications." *Journal of American Medical Association*. Feb. 18, 1998.

> companies, the payments. If they're not going to pay, what can these companies, these people, these doctors, do?"

Another result of cutbacks in reimbursement and funding is inadequate staffing and frequent turnover in staff, leading to waiting lists for appointments. A key informant explained that it is difficult to get an appointment for publicly-funded mental health services within seven days. Most residential and case management programs experience significant turnover in staffing, resulting in a lack of access to services. Focus group participants also identified a need for longer partial hospitalization stays, which have been reduced due to changes in Medicaid managed care insurance coverage.

> "When we come out of the hospital, we need to be in a kind of partial program or some sort of thing, well, they're (insurance companies) cutting back on that…They're trying to close the Norristown State. Well, if they're going to close Norristown State, they need to build more partials, you know what I mean, to keep people in the community. To keep people with case workers, to keep things like that going. Because if you're going to take away something that's so big, you're going to have all these people out there. And I'm sorry to say that a lot of mentally ill people end up homeless, because a lot of people don't want to rent to them…sometimes they don't trust you living by yourself…and family sometimes don't understand your illness, don't want to be bothered, so a lot of them end up homeless. And then what you have is the cops arresting them, you know what I'm saying, because they're in a bad place or they're using a bathroom in the wrong place…They think they're cutting back on money but in the long run it's going to create a bigger problem, I can guarantee it."

Individuals with coverage through Medical Assistance (HealthChoices) are required to choose one of three managed care plans (AmeriChoice, Health Partners, and Keystone Mercy). Many focus group participants felt that primary care providers who participated in their health insurance plans were inconveniently located. Since many chronically mentally ill adults do not drive due to their illness, or are cannot afford a vehicle, the location of providers near public transportation is often a limiting factor in obtaining quality care or any care. In addition to obtaining transportation for regular appointments, obtaining ambulance service in a timely fashion can be difficult. Clients needing emergency transportation from an intake to an in-patient facility for a mental illness may face long delays. According to one key informant, clients with Health Choices have been known to wait 8-16 hours for a ride in an ambulance during a psychiatric emergency.

Many focus group participants felt that the physicians and dentists who were enrolled in the managed care programs provided poorer quality care than

physicians who accepted other types of insurance. As a result, they often went without important medical and dental care when they needed it.

> "I think with the Keystone Mercy insurance, which a lot of us have, doctors are few and far between. Specialists are even harder to find. And with dental care, boy, are they hard to find."

> "See the problem with Keystone Mercy that I found out … because I'm a diabetic … I had to see, like, a lot of specialists. And the problem with Keystone Mercy is that their doctors complain that they don't pay, you know, on time, they delay their payment. So, a lot of them (physicians) reject you if you have Keystone Mercy."

> "I know for a dental specialist, they were going to send me all the way up to Allentown, either that or Pottstown. I finally found a good one, it took me a long time."

> "Dental services around the area where I live, I called one and he doesn't accept that insurance. There's one that takes this insurance… but I heard that they're not even good dentists. What's the use if they're not going to do a good job."

> "I think pretty much with the dental thing it's like this, the only people who accept our insurance can't get real customers. We're getting the lowest service we could possibly get."

Some chronically mentally ill individuals are insured, but lack insurance for ancillary services, such as prescriptions and dental care, for one reason or another. These individuals often forgo taking needed prescription medication or important dental care or primary care until their problems are so serious that they are chronically ill.

> "I have Medicare and that's it. And the reason I didn't get the Keystone thing was because my psychiatrist won't accept it, and he's the most important person on my list. So, I'm stuck with not being able to get medication. I have to depend on hand-outs from my doctor, and if he doesn't have any, I don't get them. And I have blood pressure medication. I have medication for my knees which I am almost never able to take which means that I am in almost constant pain and stiff because I have arthritis on top of anything else. It's horrible. I've got four teeth missing out of my head and the rest of them are broken and falling out. It's terrible. It's a nightmare. And having to beg people for hand-outs of medication and stuff like that, I mean there are medications that I should be taking every day that I just can't pay for. You know what, … my SSD (Social Security Disability) check is too high to qualify for that (County

> indigent prescription program). It's not enough to survive and it's too high to qualify for that."

Children with mental disorders are particularly underserved by the publicly-funded system. School districts, who are mandated to provide services for disabilities which interfere with learning, have difficulty providing services to children with mental disorders. School district officials note that it is very difficult to give children with mental illness the appropriate services they need. Schools can provide basic counseling for children with mental disorders, but if the student needs medication or hospitalization, s/he will need outside services which may or may not be covered by the parents' insurance. In addition, according to mental health law, children aged fourteen and over can make decisions about their mental health treatment. The school has less authority and control over children with mental illness, and therefore has more problems providing services for this group.

Stigma of Mental Illness

Key informants and focus group participants both believed that chronically mentally ill adults may also not get treatment, or get delayed treatment, for serious conditions due to the fact that many physicians do not take their complaints seriously. As one key informant explained, many health care providers are not comfortable with those with mental illness and are not familiar with the nature of mental illnesses. Key informants noted that this is especially true for elderly adults with both physical and mental illnesses. A person with a mental illness may have a physical ailment, but as one key informant explained, their doctor may disregard their symptoms because they think the person is "crazy." For example, a person with schizophrenia and diabetes may have a seizure and hallucinate. In a person with schizophrenia the hallucinations may not be explored because they are considered symptoms of schizophrenia. Several focus group participants told of primary care physicians and specialists who dismissed their physical symptoms as being the result of mental illness:

> "One time I had a family doctor, and every time I went to him with a problem, he would use, "Well, you have a mental illness. So it was hard for me to say, "This is what's wrong." Until I finally changed doctors and they took tests and stuff and found out I had diabetes… But my family doctor, was like, you know, as soon as he found out that I was on medication for mental illness he was, like, "Well, it's your mental illness, there's no problem."

> "I went to a doctor for my son. My son had seizures…he had a fever and he was throwing up…and I was telling him the symptoms that my son had that he had a fever and he was throwing up. And I told him that I was borderline personality disorder and bi-polar because he was asking about my side of the family, my history. And he said, "Well, since you're

> borderline there's nothing wrong with your son. You can pack him up and go home."…I took him to another hospital and they took care of him. He had a virus."

> "I went to a dentist in Norristown, (name of practice), and the doctor's name was (name of dentist). And he filled this tooth right here and I told him I could feel the drill going in and he told me I had mental illness and I didn't know what I was talking about. And he wouldn't give me any more Novocain. He basically drilled right through my tooth …."

Although focus group participants felt that primary care physicians do not understand their mental illness, national statistics show that more and more primary care physicians are being consulted for mental health problems. As stated earlier, this trend is, in part, a result of the lack of full coverage for mental health care and managed care incentives for primary care physicians to retain patients. However, the stigma associated with consulting a psychiatrist also encourages patients with mental health problems to consult a primary care physician. Receiving mental health care from a primary care physician instead of a psychiatrist neutralizes the stigma of mental illness and may make patients feel more comfortable with their diagnosis and treatment.

Some policy analysts see this method of treatment as cost-effective and note that treatment from a primary care physician for patients without full-blown mental health disorders is quite acceptable. Moreover, as office-based psychiatry continues to treat mostly white and affluent individuals, non-white and non-affluent individuals benefit from access to primary care physicians. Yet this is just one side of the issue. Many researchers wonder how the patients fare. While toxicity and overdoses are rare results of mental health treatment in the primary care setting, researchers note that many prescriptions for serotonin reuptake inhibitors (SSRIs) for depression, one of the most commonly prescribed treatments by primary care physicians, are often not accompanied by formal diagnoses. Secondly, primary care physicians are less likely to be aware of technological advances and developments in depression treatment than mental health specialists. In addition, one recent study found that psychosis induced by SSRIs accounted for 8% of all general hospital psychiatric admissions over a recent 14-month period.[9] Clearly, there are both drawbacks and benefits to this new role for primary care physicians.

Poor Job Opportunities

Job opportunities are often limited for those with mental illness due to beliefs among employers about capability, reliability, and safety. One key informant pointed out that those with mental illness have a chronic disease, but they can still have a productive life. There is a need to identify appropriate jobs for those with mental illness and to educate employers to consider people with mental

[9] Pincus et al., 1998

illness for positions. Focus group participants also identified the need for vocational and social rehabilitation programs as being highly important:

> "Along with rehab you need vocational training and psychosocial (rehab). It takes time to get back into work. We need more programs like the Clubhouse…Social rehab."

Lack of Respite Care

Key informants said that there is a need for short and long-term respite care for those caring for persons with mental illness, especially for caregivers of individuals with severe mental illness. One key informant explained that families of children with severe emotional problems or autism who have inadequate social supports often become isolated. Parents need formal networks to bring them together for support, empowerment, and information-sharing.

Lack of Supportive Housing

According to one key informant, there is limited affordable, safe housing for the chronically mentally ill in the North Penn area. Like many areas experiencing suburban growth, the North Penn area's new housing is largely comprised of single-family homes. Housing has not been developed for those with special needs. Residents are often resistant to having group homes or other assisted living situations for those with severe mental illness in their community. One key informant explained that the general public is not educated about the mentally ill and are fearful. They typically ask, "Are these folks murders? Child pornographers?"

Key informants had two major suggestions for how the North Penn Community Health Foundation could help meet the needs of those with mental illness:
"recogniz(ing) that people with mental health and serious mental heath should be a priority population" and funding pre-existing collaborations, instead of creating new ones.

MENTALLY RETARDED AND SPECIAL EDUCATION

Mental Retardation

An estimated 1,781 out of 270,104 children and adults in the North Penn area are diagnosed as mentally retarded; this represents about 0.7% of North Penn area adults (Table 4). The percentage of individuals with mental retardation does not vary across different age subgroups of the population: 0.7% of 0-15 year olds (408), 0.7% of 15-24 year olds (195), 0.7% of 25 to 64 year olds (1,031), and 0.4% of adults 65 years and older (147). There are 299 children ages 6-21 in the North Penn area school districts who are receiving special education due to mental retardation (Table 5). This number is lower than the estimated total

number of mentally retarded children in the North Penn area because it includes only those who are both mentally retarded and receiving special education. It excludes children who may not be attending school or who may be institutionalized.

Learning Disabilities

Children with learning disabilities, a much less severe condition than mental retardation, are also entitled to special education services in the public schools. A learning disability is defined in the Individuals with Disabilities Education Act (IDEA) as a disorder in one or more of the basic psychological processes used to understand language, which impairs one's ability to listen, think, speak, read, write, spell, or do mathematical calculations. Learning disabilities are usually diagnosed when the child's level of achievement is substantially lower that what is expected according to their intelligence level or ability to learn. About 4,586 school aged children in the North Penn area have a specific learning disability and are receiving special education in school (Table 5). Often, children with learning disabilities also have mental health problems for which they need services. These children may feel frustrated by their learning difficulties and have low self-esteem.

Learning disabilities are much less common in adults because the condition is usually diagnosed and treated in childhood. An estimated 1.6% of North Penn area adults aged 25-64 (2,356 out of 147,259 adults) and 0.7% of adults aged 65+ (256 out of 36,643 older adults) have a learning disability.[10]

Autism

Autism Spectrum Disorders, including Pervasive Developmental Disorder (PDD), are neurological disorders that affect the ability to communicate, to form relationships with others, and to interact normally with the outside world. Autism is a disorder that affects one's ability to socialize. Children with autism have little in interest in social interactions and also have severe difficulty socializing. These children also have problems with verbal and nonverbal communication and with leisure and play activities. Nationally, between 2 and 6 children in 1,000 have an Autism Spectrum Disorder. In the North Penn area school districts, 157 children with autism are receiving special education (Table 5).

Service system for mentally retarded, learning disabled, and autistic

Mentally retarded children and adults in the North Penn area are served by both the private and public systems. County-funded mental retardation programs are available to children and adults with a cognitive deficit, an I.Q. below 70, and a diagnosis of mental retardation which originated before age 21. In Bucks County, the Office of Mental Health and Mental Retardation serves approximately 2,900 individuals with a primary diagnosis of mental retardation annually, and in

[10] U.S. Bureau of the Census 1996 Survey of Income and Program Participation.

Montgomery County, the Office of Mental Retardation serves approximately 3,000 individuals annually.

Some families are not served by the publicly-funded system and utilize their own resources to care for their mentally retarded child. Some of these are wealthy families who do not need public services and only use them when there is a crisis with their child. Other families who depend on their own resources may be waiting to receive public services, while others do not use public services and are not on a waiting list. Often families seek these services when the child reaches adulthood and/or the parents, who are aging (usually 60 or older) become concerned that they will not always be able to care for their child. These individuals then apply to the public system for assistance with obtaining independent, supportive living for their adult child. This group may be placed on a waiting list. In Pennsylvania, there are 36,770 individuals in this group. Unfortunately, because they have not yet entered the service system, their needs have not been recognized. In addition, families become frustrated with the long waiting period and simply stop trying to access services. Locally, Temple University maintains the waiting list for Bucks and Montgomery Counties, and is responsible for prioritizing a person's need for services, using a process for this called Prioritization of Urgency of Need (PUNS). There are three PUNS categories:

- Emergency: persons who need services immediately

  Example: A death in the family leaves a person with mental retardation without support.

- Critical: persons who need services within 1 year

  Example: A single caregiver would not be able to work without the provision of services.

  Example: An aging caregiver needs assistance in caring for child with mental retardation.

- Planning: persons whose need for services is more than one year away.

  Example: Person or caregiver would like additional services.

County-funded mental retardation services include home-based, residential, vocational, and employment services for mentally retarded adults and children. Since 1990, Montgomery County has been participating in a state initiative, Family Driven Support Services Program, an initiative funded by the Pennsylvania Department of Public Welfare and Montgomery County under Family Resource Services to provide family directed supports and self-determination for persons with mental retardation. In this program, families are

given a choice in what types of supports they want and who will provide these services. Eligible families may receive a stipend ranging from a minimum of $50 to a maximum of $1,200. Currently, over 800 families in Montgomery County receive Family Driven funds. Services which are typically purchased with these funds include: short term respite care, recreational services, family aides, therapeutic services, camps, and adaptive equipment. Similarly, the Bucks County Department of Mental Health-Mental Retardation also provides Family Driven Support Services to 190 individuals, in addition to home based services, case management, supported and community living arrangements, and vocational and employment training. This program is an indication of recent trends in social services to increasing individual choice.

Montgomery and Bucks Counties also provide Early Intervention services for developmentally delayed infants and preschool aged children up to age 5. Children in this age range are eligible if they who have a developmental delay of at least 25% in at least one of the following five areas: physical, language and speech, social and emotional, adaptive (self-care), cognitive development, or if they have a mental or physical condition that will likely lead to development problems. In Bucks County approximately 1,430 children ages 2-6 received early intervention services through an agency in the June 2001- July 2002 year. In Montgomery County, 1,570 eligible children receive early intervention services annually.

School aged children with mental retardation or developmental delays are eligible to receive supportive services in mainstream classrooms that are designed to improve their ability to learn. Services include speech therapy, occupational therapy, physical therapy, behavioral therapy, nursing services, aides, and adaptive equipment. School-based services for the mentally retarded also include college and job preparation programs. For example, job training begins between the ages of 16 and 21 years for high school students, depending on the school district. During this transition and training period, representatives from the Office of Rehabilitation often go to students' Individual Education Plan meetings, so they can become familiar with the student and begin arranging employment or further schooling. The Office of Rehabilitation also provides services to this population once they leave the school district. School districts try to track the progress of graduated students, yet once the student graduates, the school is no longer responsible for the former students' success. Despite the services employed to help these students transition into the workforce, school officials note that it is an incredibly difficult feat. Many agree that more attention should be directed towards this issue, as well as to the creation of better services.

Recently, the number of school children with autism or PDD has soared. Most school officials feel that they are well equipped to educate these children, although it is difficult to continually train educators and staff in new teaching techniques. It is also a challenge to provide special, unrestrictive education environments that meet each type of need. Low functioning mentally retarded

and autistic children are often placed in outside educational settings, such as the County Intermediate Unit or private school. Some school officials believe that there are not enough outside placements for these children.

Key informants and focus group participants identified the major barriers that individuals with mental retardation, learning disabilities, or autism face:

- **Lack of information**
- **Administrative delays**
- **Restrictive eligibility requirements**
- **Lack of activities for children**
- **Lack of respite care**
- **Lack of transportation**
- **Lack of supportive housing**

Barriers

Lack of Information

Parents of children receiving early intervention services in Montgomery County felt very strongly that not enough information about early intervention services and its policies and procedures was available to parents whose children might be in need of services. They also felt that there was a lack of information on how to navigate "the system" to obtain the medical services they felt their children needed.

> "I think nobody really tells you what's out there. That's the bottom line. You have to find it. It's a secret almost."

> "The one thing you could do just put out a newsletter…on a website or whatever, that just gives you a schedule of what the offerings are."

> "I was surprised meeting with other moms how many people don't even realize about what Pennsylvania offers you as far as free advocates…or even calling down to the educational law office if you have a question….it seems like a lot of people just miss that first block of the basics."

Other parents expressed anger at the difficulties they experienced in obtaining coverage for needed therapy and equipment from their insurance companies.

> "For me the issue hasn't been having the health care coverage, it's been the time-consumingness of the health care coverage…If I were going to ask for help with anything, it would be that…the amount of time the phone calls have taken up. You wouldn't believe it unless you were in my house…Diapers. Just to get the diapers. You know at three, because of their diagnosis we could get diapers. And to make the right phone calls, to have it transferred to the right person, to get the right answer, not the

> wrong answer, too many people not knowing the right answer, giving me the wrong answer within the insurance company. And we're waiting, and then getting the prescription and then having it sent to the wrong information to the wrong…so that six months have gone by before we even got it. And then once we get the first order, finding out from friends that it was being cancelled, the shipment, and there would be a new way, you'd have to go to the pharmacist. And calling them and saying, "I've heard it won't be arriving at my door." And them denying it saying, "No, no, it will come on Thursday." And Thursday coming and it's not coming and them saying it's not coming, they have a new policy. And having to start all over again. With the water therapy, I gave up, because I can't take the time any longer."

> "I know that with the horseback riding there's a lot of places in our area, but when I did my IEP she said If you're going to have all these services, that's a lot to get it covered…I still felt there was a limit for my kids and it's too expensive out of pocket. It's like $36 an hour each. The orthopedic surgeon himself told me he would write me the script but I can't get it covered. He doesn't understand why it works, but he absolutely sees that it works in the kids that get it."

The lack of information that pediatricians were able to give to the families of children with special needs, particularly in cases of Pervasive Developmental Disorder (PDD) and Autism, was also a problem for many early intervention parents. Parents felt that they had to research the best treatments for their children themselves and bring this information to their pediatrician, when they would have preferred their pediatrician to be more knowledgeable about these subjects. Developmental pediatricians are more knowledgeable about treatment issues, but often they only see their patients every six months. Key informants explained that many health care professionals have a limited understanding of mental retardation. This creates problems in several arenas. For example, parents often rely on their child's pediatrician for information on services and reports on their child's functioning. However, most pediatricians are not trained in special needs. They may not recognize the extent of the child's problem and often do not know of available services or of appropriate information resources. Hospital staff, too, is not usually equipped or trained in treating someone with mental retardation. For example, many severely mentally retarded patients cannot feed themselves or cannot speak to communicate their needs.

> "I take them to the regular pediatrician for other things but I find that I don't get…they're not very current. The regular pediatricians don't think to gather resources to find. You know, you have to find out yourself then ask them for referrals. The regular primary, they don't give you any kind of information unless you go there and say, "Can I get a referral for this?" You know, like water therapy. Because my kid can't swim and he doesn't like groups. So I can't have like a teenager teach him and four other kids

> how to swim because he can't do it…And that's in a lot of different types of situations."

> "I find myself going in and saying here's what I need. I need a referral for this. I find I'm doing the research and telling people what I need, and I'm kind of a novice at that. I think that's a universal problem."

Many key informants felt that one of the best things the Foundation could do to meet these needs was to provide education and training to professionals working with mentally retarded individuals and developmentally delayed children. Key informants suggested training physicians about mental retardation, including how to deal with all types of disabilities and providing information on the services which are available. Staff working in day care facilities also need training on how to work with children who have special needs. Key informants suggested that all training address ignorance. One key informant suggested that the Foundation assume some of the responsibility for training service staff. Agencies do train their staff, but are always in need of additional training, and any assistance with training would help reduce the burden on agencies.

Administrative Delays

Parents of developmentally delayed children often experienced delays from nine months to one year in obtaining services for their children because of the time involved in completing their child's evaluation. The evaluation must be completed before the Individual Family Service Plan or Individual Education Plan can be written and services begun. Montgomery County families stated that evaluations are conducted in a piece-meal fashion and that delays often occur. Parents often felt frustrated because they felt that precious time was being wasted, and they were unable to help their children receive the critical services that they needed.

> "I didn't know about the Intermediate Unit for several months. On a positive note, I'm very thrilled with the I.U., with the teachers there, the progress reports you get. The only complaint I have about that is the process of getting her in took about nine months… that nothing could happen concurrently. First she has to be evaluated for this, then a month goes by before. Everything had to be followed up. Now, let's schedule. Well, we don't do physical therapy evaluations during July and August. It took a full nine months to get her in. That's something, I really think administratively, that could be improved. I think nine months for a two and a half year old is a long time to wait for services."

> "He was two and a half and it was almost a year when we had services. He was three and a half."

> "When these kids need services they need them. You can't wait eight months to get them started."

> "It's not that the person we were dealing with was incompetent, she had a work load that was overwhelming."

Key informants also felt that services can be delayed due to problems getting a formal diagnosis of mental retardation. For example, in order to qualify for mental retardation services a person must have an IQ of 70 or lower. One key informant explained that children with a developmental delay need to see a developmental pediatrician to get a comprehensive evaluation and diagnosis of their condition. However, there are not enough developmental pediatricians in the community. According to one key informant, there is a 9 month to one year wait to see a developmental pediatrician at the Children's Hospital of Philadelphia (CHOP) Specialty Care Center in Bucks County. At CHOP in Philadelphia, the wait is approximately six months. This key informant has recommended that parents from the North Penn area bring their child to Sacred Heart Hospital in Allentown, Pennsylvania to see a developmental pediatrician, where the wait is only 3 months.

Another reason for delays in receiving services is that funding levels have not kept up with the demand for services, particularly in the area of services for autistic children and those with Pervasive Developmental Disorder. In recent years, the number of children with these diagnoses has soared. Because these children are also very difficult to treat in many cases, the strain on the system is even worse. For example, there is a shortage of classrooms for children with autism. Inadequate funding has also led to staff shortages and high staff turnover. A high staff turnover rate is detrimental to the quality of services provided to consumers. Key informants said that it is hard to retain staff for a variety of reasons. Minimum wage salaries is one cause, in that agencies pay little, but require staff to do very challenging work

Restrictive Eligibility Requirements

Key informants also felt that several subgroups within the mentally retarded population are at risk for not receiving needed services when they age out of the system and no longer meet eligibility requirements. Key informants noted that there are several gaps in service as a result of eligibility rules. For example, children graduating from high school suddenly face a cessation of services. There is also a growing population of mentally retarded children who receive primary care through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program and are nearing adulthood. When they become 21 they will no longer be qualified for primary care through EPSDT, but they still need regular check-ups and screenings. For adults, services are provided based on income and IQ, which leaves many without services. In regards to respite care (which is in strong demand by all age groups), at age 62 adults become

eligible for nursing home care. But there is a huge gap between the ages of 18 and 62 where services are not automatically provided.

In addition, key informants felt that some children may lack access to mental retardation services because the current public treatment system is organized by diagnosis, and many children have diagnoses, such as autism, which do not qualify them for services. For example, a young autistic adult with an IQ above 70 is not eligible for mental retardation services from the County because Pennsylvania is not mandated to serve individuals with I.Q.s that are higher than 70.

Lack of Activities for Children

Many focus group participants wanted their developmentally delayed children to be mainstreamed as much as possible, but activities designed for special needs children are limited.

> "I think all of us want our kids to be integrated into the mainstream to the extent that's possible. And I think to a large extent, whether it's physical or emotional, or physiological, I think we all have a large responsibility to incorporate kids into the mainstream. We just can't take this growing group of kids and isolate them."

Focus group participants wanted their children to be able to participate in the same types of activities as non-special needs children. Most playgrounds are not handicap accessible, forcing families with physically challenged and non-physically challenged children to forgo visiting a playground altogether.

> "For me and my girls, they're physically challenged, so the North Wales Park is wonderful, my older kids love it, but we can't go there because we can't get in, with the double stroller and I can't carry them both, and they don't walk yet, so I can't get in. My older kids are being held back from the few things we can do as a family because we can't access them."

In addition, there are few activities especially adapted to the growing number of children with autism or Pervasive Developmental Disorder. Participating in group activities is difficult for these children, so that activities have to be specially designed for them.

> "I just started with wrap around (services in the home) and one of my therapists told me there is soccer program in Hilltown for special needs kids. She's going to get me the information. It starts in the spring. Each child has a buddy, a volunteer, who stays with the child."

On the other hand, one key informant said that families of children with mental retardation and/or autism would like to have playgrounds and other gathering places where they can feel comfortable bringing their children. This key

informant felt that most families do not feel comfortable bringing their special needs child to a local playground because other parents stare or act uncomfortable with their child's behavior.

Summer activities, especially for younger school aged children with special needs, are particularly needed. Parents need to keep their children occupied when school is not in session and they also fear that their children will lose whatever gains they made during the school year. Many of the existing activities cannot accommodate the number of families who would like to participate.

> "I go out with some moms, all their kids are school age, and they all start stressing out with the summer. Apparently, in the summer it's a big issue…they just want to make sure that they're active…(they are afraid) that the child with special needs…is going to regress, that they're not going to get all this stimulation they need over the summer. But other programs are filled already…there's Variety Club and Easter Seals, but it's not enough."

> "I really wish they would have summer camp activities for the younger age group."

Most children who receive early intervention services for autism or Pervasive Developmental Disorder are placed in a special day care setting. However, according to key informants, obtaining mainstream day care for children with special needs is often very difficult. Day care staff may not be trained in how to handle the behavior of a child with mental retardation or autism and staff may have difficulty recognizing whether atypical behavior is due to a child's special needs or a behavioral problem resulting from the child's condition.

Lack of Respite Care

Short and long term respite care, both in the home and at off-site locations, is greatly needed for caregivers of mentally retarded and/or developmentally delayed children and adults. Affordable day programs for older adults with mental retardation are also needed. Several types of caregivers need respite care more than others: single parents, parents of mentally retarded adults, parents with other children, and parents of mentally retarded individuals with complex medical problems or severe behavioral problems. These subgroups, more than others, need respite care since they experience greater stress and carry more responsibility. Single parents have no one with whom they can share caregiving. Parents with several children must care for their child with special needs and, in addition, care for their other children. It is difficult to find caregivers who have all the skills and training needed to care for a child who has multiple medical and/or behavioral issues. The parents of these children are especially in need of respite care. One key informant said that there is a waiting list for residential respite services for those with mental retardation. According to this

key informant, many families prefer residential respite to respite provided in their own home. However, funding for residential respite is quite limited.

Focus group participants expressed their need for respite care, but were protective and often reluctant to leave their special needs child with a stranger. In addition, it is often very difficult to find someone who can provide respite care on a consistent basis and is qualified to address the child's special needs.

> "We have never ever taken advantage of it (respite care) for several reasons. One is your kids are your responsibility, you don't really have the opportunity to bail out when the going gets tough. But the bigger part of it is it's hard to find somebody, you know, you can't just get a 14 year old to watch the kids. There are too many issues. Ideally throughout the community we could watch each other's kids…that's the way foster care is supposed to be set up. We just don't go out much. Dealing with those special issues, even if the kids are asleep, if one wakes up, dealing with their issues it's not going to be a relaxing evening out for us."

> "It has to be somebody consistent that understands, who's almost part of your situation on a regular basis. It's not like we can just call."

> "I was blessed with somebody who had been through a similar situation and who now was older who gave me a check and said, "This is for respite." I mean, I had a stack of ten dollar bills and no one to give it to."

Lack of Transportation

Since many mentally retarded adults do not drive, the limited public transportation in the suburban and rural areas of both Bucks and Montgomery Counties is a barrier to accessing services. One key informant said that some adults with mental retardation could be placed in a day program, but that transportation is not available to take the clients to the program. Transportation is not a problem, however, for children receiving early intervention services, since they are either provided in the home or in the schools, and schools must provide transportation for these children.

Lack of Supportive Housing

Key informants from both counties said that there is a need for affordable housing and community living arrangements for mentally retarded adults. In Montgomery County, 700 mentally retarded adults are currently living in County-supported housing in the community, and there are 200 to 300 people on the waiting list for these group homes. One key informant explained that there are also not enough licensed personal care facilities to care for adults with mental retardation. Adults aged 65 and over are also in need of specialized housing. They have many of the same needs as other older adults but their needs are

often less likely to be met because few residential programs or nursing homes are equipped to care for older adults with mental retardation. Also, children with severe autism who cannot live with their families are particularly difficult to place since they often have multiple issues. Children and adults with autism need more structured residential placements than those with a diagnosis of mental illness or mental retardation alone.

PHYSICALLY DISABLED

Many different kinds of physical disabilities may limit mobility. Physical disabilities include sensory disabilities, such as blindness, deafness or severe vision or hearing impairment. Physical disabilities also include those which limit basic physical activities, like walking and climbing, and self-care disability which makes activities like dressing and bathing difficult. Key informants stressed the diversity among individuals with physical disabilities. They noted that the various kinds of disabilities and the time at which the individual developed the disability impact mobility in unique ways.

As shown in Table 6, a total of 32,480 adults and children aged five and over in the North Penn Area have some type of long-lasting physical, mental, or emotional condition; this represents 13.0% of the total population of 247,960 residents aged five and over. The percentage of individuals aged five and over with some type of disabling condition varies across the geographic sub-areas of the North Penn area from a low of 8.8% in Silverdale Borough to a high of 20.4% in Doylestown Borough. The largest number of disabled individuals, however, in the North Penn area (2,700) is found in Lansdale Borough. One explanation for these differences may be that there is a higher concentration of elderly individuals living in Doylestown and Lansdale due to the presence of retirement or continuing care communities.

Not surprisingly, because many physical disabilities are associated with advancing age, older adults aged 65+ are nearly three times as likely to be disabled as adults aged 21 to 64 years (32.1% versus 11.6%). Due to the age structure of the population, however, there are a greater number of disabled adults aged 21 to 64 years (18,300) than are aged 65 and over (11,000). An additional 3,200 North Penn area children and young adults aged 5 to 20 years are also disabled.

Information for the North Penn area from the 2000 U.S. Census shows that a smaller number of adults and children aged five and over have a specific physical, sensory or self care disability. A total of 7,436 out of 247,960 individuals aged five and over have a physical, sensory, or self care disability; this represents 3.5% of the population (Table 7). The most common type of disability is a physical disability, which occurs in almost 5,000 individuals, representing nearly 2% of the population. Not surprisingly, most adults with a

physical disability are elderly. About 2,870 out of 36,643 adults 65 years and older, 2,022 out of 171,528 adults ages 16-64, and 47 out of 43,595 children ages 5-15 have a physical disability (Figure 1). Although the number of younger and older adults with disabilities is relatively equal, consider that nine in 100 adults 65 years and older has a physical disability. In comparison, one in 100 adults, ages 16-64, has a physical disability (Figure 2). Sensory disabilities affect 2,440 people in the North Penn area, which is 0.9 % of the total population. According to age, 120 children ages 5-15, 1,161 individuals between the ages of 16 and 64, and 1,159 adults 65 years and older have a sensory disability. Self-care disabilities affect the least amount of people.[11]

Key informants reported that individuals with physical disabilities usually learn of services through word-of-mouth. Using one service also introduces individuals to various services. For example, individuals who have contact with the Office of Vocational Rehabilitation are likely to know about several services. Other well-connected and helpful formal and informal groups include the Kardon Institute of Performing Arts, the Supplemental Security Income (SSI) Network, and the paralympics. In addition, the internet is becoming a more popular source of information. Generally, key informants agree that the onus to find information is on the individual. If an individual is proactive, they can find services and agencies, but if a person is inactive or not involved in a network, it can be difficult to learn about available services.

Key informants identified the primary barriers that people with physical disabilities face:

- **Lack of access to public places**
- **Discrimination**
- **Poor quality health care**
- **Gaps in service**
- **Lack of access to transportation**
- **Lack of affordable housing**

Barriers

Lack of Access to Public Places

All key informants agreed that one of the most serious barriers for the physically disabled, if not the most serious, is the lack of access to public places. Mainstream society has not adapted to the needs of those with disabilities. Despite passage of the Americans with Disabilities Act, many buildings are not

[11] These numbers reflect the number of persons who have only one of these three disabilities: physical, self-care, or sensory. It is important to note that the number of persons in the North Penn area who are disabled is probably higher because many individuals have more than one disability or have disabilities other than the three specific disabilities discussed above.

wheelchair accessible, bathrooms do not always accommodate the needs of those with disabilities, and parking lots do not always have ample handicap parking spaces. This disregard for the needs of individuals with disabilities hampers every aspect of their lives, from leisure activities to professional employment and basic transportation.

Discrimination

Key informants cited discrimination as another major problem. They explained that society is generally ignorant about persons with disabilities. One key informant said that non-disabled individuals do not talk to disabled individuals and suggested that they may be afraid or may think that disabled individuals are unable to talk and think for themselves. Many assume that caregivers are in control and ignore the disabled individual. In addition, many persons with disabilities who want to work are unable to find employment. Consequently, the rate of unemployment among people with disabilities is higher than national figures. One key informant described a common situation: "Suppose there are two equally qualified applicants for a job. Par for par in every aspect. One has a disability and one doesn't. Who is the employer going to choose, the one who fits in easily or the one who needs major, expensive changes? The person with the disability will not get the job." Another key informant added that the fact that there has not been a stronger effort to make public places compliant with federal law also shows the powerful presence of discrimination.

Key informants explained that even when disabled individuals find employment, discrimination continues within the work place. For example, persons with disabilities are sometimes treated as children in the workplace. In other instances, supervisors are hypersensitive to their errors and blame the disability for mistakes. Sometimes, employers promise to make certain accommodations for disabled individuals and then do not follow through. One key informant told a story about a client who related that after this client was hired for a job, she began using a service dog. Her employer did not want this dog at the worksite, so the employer changed her location so she would not work directly with customers. Then the employer gave her tasks that she could not possibly complete due to her disability, such as climbing a ladder. The client did not quit, even though the job had become undesirable. Eventually the employer fired her.

Key informants say that one of the most helpful things the Foundation could do would be to assist in teaching disabled individuals to advocate for themselves. In the past, the disabled population has always been cared for. Now, it is important that disabled learn to take care of themselves. Key informants also believe that public education is desperately needed as a step in dissolving discrimination. "Education yields power," said one key informant. These key informants feel that funding for education projects would yield a huge benefit in improving quality of life for people with these disabilities.

Poor Quality Health Care

Individuals with disabilities who meet certain income requirements are eligible for health care coverage through Medical Assistance. Disabled adults can now choose between three different managed care organizations, Keystone Mercy, AmeriChoice, and Health Partners, which is an increase in selection from the previous single provider. However, many physicians do not accept the Medical Assistance managed care plans, and many disabled individuals with this type of coverage must use overcrowded clinics. Key informants report that individuals must wait six to eight weeks for medical appointments, which are often rushed. At each visit, a different physician treats the client, creating inconsistent medical care.

Key informants also felt that there is a great need to educate primary care physicians about physical disabilities. One key informant said that clients either have to find a physician who specializes in their condition or educate the primary care physician about their disability and medical condition. Another key informant explained that physicians often do not treat patients with respect and do not listen to the patients. This key informant said that individuals with disabilities often know their body better than anyone and that communication between physicians and patients needs to be more open.

Lack of Access to Transportation

Obviously, individuals with physical disabilities have special transportation needs. Adaptive services, such as "kneeling" buses, have been added to public transportation and paratransit is available to transport the disabled to medical appointments. However, transportation continues to be a major obstacle for persons with disabilities. Paratransit has several drawbacks. It operates within a defined route and is designed specifically to transport individuals to medical appointments. Someone who takes paratransit to a nonmedical appointment must pay $20. If the medical appointment is located outside of the route, there is also a $20 fee. In addition, reservations must be made in advance and must fit into the schedule, which is often infrequent. If one misses the scheduled paratransit ride because, for example, the physician is running late, he or she could wait up to four hours for another ride. It is clear that paratransit can not meet the needs of someone with a busy schedule. One key informant asked why disabled persons must be forced to simplify their lives because transportation is so limited. Some disabled individuals take taxi cabs or hire personal drivers. However, both of these alternatives are very expensive. Transportation is especially difficult for disabled older adults. Key informants agreed that improving accessibility must go hand in hand with growth in public education and empowerment. Accessible public transportation and public places are essential for the mainstreaming of people of with disabilities. Without this accessibility, people with disabilities will never be able to achieve the independence they seek.

Lack of Affordable Housing

Like many others living in the North Penn area, those with physical disabilities struggle to find affordable homes. Many people would like to live on their own, but can not afford it. In addition, it is often difficult to find a home that accommodates the needs of a person's physical disability; renovating a home is quite costly. Another issue which is linked to the availability of housing is that there is no service to help the disabled move from location to location.

SUBSTANCE ABUSERS

In the North Penn area about 11,700 out of 223,370 residents aged 12 and older abuse legal and illegal substances. This represents 4.3% of the population (Table 8). Alcohol is the most commonly abused substance. Younger adults ages 18-25 (20.0%) are the most likely age group to abuse substances. This represents 3,910 of 20,057 young adults in the North Penn area. Adolescents aged 12-17 years old abuse substances at one-half the rate of 18-25 year olds (10.1%), and adults 26 years and older are six times less likely to abuse substances than 18-25 year olds (3.0%) (Figure 3).

Substance abuse among high school students is of particular concern. An estimated one-third of high school students in the North Penn area (34.8%) currently[12] smokes cigarettes (Table 9). This represents 4,800 of 13,804 high school students. One-half of high school students currently uses alcohol, which represents about 6,900 students. An estimated one-third (31.5%) engage in binge drinking, which is defined as drinking more than 5 drinks on a single occasion (representing 4,350 students). Surprisingly, an estimated one-third (32.3%) drank alcohol and 11.0% tried marijuana before age 13. Currently, one-quarter of high school students use marijuana, which represents about 3,700 students.

In addition to marijuana, smaller percentages of high school students use other illicit drugs, such as cocaine, heroin, and steroids. An estimated 550 high school students in the North Penn area currently use cocaine (4.0%), and an estimated 330 students have tried heroin at some point in their lives (2.4%). Almost 4.0% have used steroids in their lifetime, representing about 500 high school students in the North Penn area.

Key informants believe that most individuals in need of drug and alcohol treatment know how to find information about services. While most are aware of available services, there are several populations that are largely unfamiliar with

[12] Current substance abuse is defined as using the substance one or more times in the past month.

drug and alcohol abuse treatment: the deaf and hard of hearing; racial and ethnic minorities, particularly Latinos and Asian-Americans; and those with a dual diagnosis of drug and alcohol addiction and mental illness.

Key informants note that most individuals have access to the services they need. However, many do not regularly take advantage of treatment opportunities because their addiction interferes with their ability to commit to treatment. People with physical disabilities have complete access to services, as all drug and alcohol facilities must be handicap accessible. There are also a few agencies that provide treatment in the home. Key informants also explained that there are no waiting lists for services at their sites and that assessments are completed within 72 hours of intake. However, one key informant explained that some agencies are not conveniently located. For example, there is only one site in Glenside that provides minimal drug and alcohol treatment for the deaf and hearing impaired. For more extensive drug and alcohol treatment services, deaf and hearing impaired substance abusers must go to New Jersey, or go as far as Massachusetts. In addition, as other key informants have noted, public transportation presents a barrier to accessing services. These key informants also explained that navigating through the process of obtaining services can be difficult at times and that many individuals with substance abuse problems need more assistance accessing benefits and services.

Key informants identified the top barriers for those with substance abuse:

- **Treatment for those with medical and substance abuse problems**
- **Treatment for those with dual diagnosis**
- **Lack of affordable housing and employment opportunities**

Barriers

Treatment for Those with Medical and Substance Abuse Problems

Individuals with both chemical addictions and serious medical conditions have difficulty finding a provider. Often, those who abuse alcohol have medical problems involving the central nervous system and the gastrointestinal system. Cocaine abusers may experience malnutrition, myocardial infarction, and stroke. Injection drug users are at higher risk for Human Immunodeficiency Virus, tuberculosis, sexually transmitted diseases, abscesses, and bacterial endocarditis. Elderly substance abusers are particularly at risk for poor health, since they are poorly served by the both the drug and alcohol and medical care systems. In addition, persons with brain damage due to many years of untreated alcoholism are often not appropriate for regular treatment. These individuals are better served in a nursing home environment, which is rarely available, except in an expensive private pay situation.

Treatment for Those with Dual Diagnosis

There are few services that cater to dually diagnosed individuals with substance abuse problems and mental health disorders. Approximately, 3.3% of adults 18 and older with mental illness also report substance abuse disorder. In North Penn, this represents about 1,326 adults. The number of services for dual diagnosis clients should increase in the near future, as both drug and alcohol facilities and mental health facilities are applying for licenses to provide both services. In the meantime, this group is largely underserved.

Lack of Affordable Housing and Employment Opportunities

Key informants felt that lack of housing and employment are the two issues that affect the largest number of substance abusers. Drug and alcohol treatment clients have extreme difficulty finding jobs, as employers rarely hire people with addictions. They also have trouble finding affordable housing that is in safe and relatively drug-free neighborhoods. Safety is of primary importance, as it is necessary for people with addictions to remove themselves from tempting environments. Both the lack of affordable housing and employment opportunities increase the likelihood of relapsing to addiction.

Key informants also suggested that the Foundation should support the following services:

- Parenting education;
- Support/Coping groups for parents;
- Aggressive, community outreach (as opposed to assistance in schools) by professional consultants who are trained in both adolescent mental health and drug and alcohol issues, who can also provide feedback on child and parental functioning and offer referrals where appropriate; and
- Intervention training to providers working with families.

CANCER SURVIVORS

A sizeable number of North Penn area residents, approximately 1,400 out of 270,104 adults and children, are diagnosed with cancer each year (Table 10).

Analyzing the incidence of different types of cancer in the Montgomery and Bucks Counties by age shows that among children 0-14 years old, the most common cancers are brain or other nervous system cancers, thyroid cancer, non-Hodgkin's lymphoma, Hodgkin's Disease, and leukemia. These cancers affect a total of 30 children annually in both Counties (Table 11). Brain and other nervous system cancers affect the most children: 6 children under 5 in Bucks and Montgomery Counties and 10 children in the 5 to 14 age group. Among adults,

the most common sites for cancer are the colon and rectum, lung, prostate, female breast, and urinary tract and bladder. Except for female breast cancer, the number of cancer cases dramatically increases with age. Although the total number of breast cancer cases is highest in the 65+ age group, the number of breast cancer cases among younger adults is only slightly lower. In the 25-54 age group, there are more women with breast cancer (371) than in the 55-64 group (241). Breast cancer is the most common cancer and prostate cancer is the second most common cancer in Bucks and Montgomery County (1,077).

Table 2 shows the number of new cancer cases in the year 2000 by municipality. In 2000 there were 1,437 new cases of cancer reported in the Foundation's service area; 1,017 in Montgomery County and 420 in Bucks County. As shown in Table 2, Whitpain Township had the largest number of new cancer cases reported in 2000 (136), although over 100 new cases were also reported in Lansdale (119) and Doylestown Boroughs (116) and in Horsham (110) and Lower Gwynedd Townships (110).

Cancer patients do not usually lack access to adequate health care, but focus group participants felt that the medical care system itself does not provide sufficient supportive services these patients and their families need at a critical time in their lives. Key informants and focus group participants felt that cancer patients have a great need for counseling due to the emotional trauma that accompanies a possibly life-threatening illness; religious counseling, as many who face death may have spiritual needs; family counseling to help strained relationships; and financial counseling, as cancer can be financially burdensome. Families of cancer survivors also need respite care to help them maintain their emotional strength in a time of great stress.

Key informants stated that those with cancer learn about these supportive services through health care professionals at hospitals, the Oncology Nursing Association, media reports about the services, websites, and word-of-mouth.

Key informants and focus group participants identified these <u>key barriers for cancer survivors and their families:</u>

- Lack of knowledge of supportive services
- Lack of sufficient nursing services for survivors recently discharged from hospital and those who live alone;
- Stigma against discussing cancer;
- Lack of information about diet and nutrition;
- Lack of respite care;
- Lack of supportive services, especially those designed for children and their families.

Barriers

There are many organizations that offer support services for cancer patients and their caregivers. For example, the Abington Memorial Hospital, the Wellness Place for the Cancer Community, North Penn Visiting Nurse Association (VNA), Doylestown Hospital, Gilda's Club, local YMCAs, Grandview Hospital, Warminster Hospital, and the Phoenixville Hospital all offer support programs and counseling in a variety of areas. In addition, a growing number of cancer patients and caregivers are joining online support groups.

Focus group participants felt that supportive services, generally, are not well advertised. In addition, the stigma associated with cancer prevents many people from participating in these groups. Many of those newly diagnosed with cancer, particularly men, are afraid to discuss their diagnosis with anyone, and are afraid that any support group would be depressing. These cancer patients and their families need to be educated about the need to discuss cancer in the open, and the benefits of unburdening themselves emotionally with other cancer survivors. Men are especially in need of outreach, since they are more likely to be unwilling to discuss their cancer.

Cancer survivors who participated in a focus group also stressed the need for emotional support during treatment and afterwards. Many told stories of situations in which mental attitude had helped cancer survivors endure treatment.

> "My radiation oncologist told me a story about two women who had radiation treatment. One woman was perfectly calm throughout the entire treatment and had no complaints. When the doctor asked her why she was so calm, she told him that she just stepped aside from her body and imagined the radiation killing the tumor inside of her. Another woman's skin was burned red, and she was so distressed that they had to drop the treatment. She said that the treatment reminded her of when she was in a concentration camp."

In addition to emotional support and counseling, other services for cancer survivors and their families which focus group participants felt were needed in the North Penn area are more respite care services for family members, more visiting nurses who can provide home care beyond that which is covered by insurance, volunteers to assist cancer patients who have just been released from the hospital and live alone, transportation to supportive programs for those who are undergoing treatment and are too sick to drive themselves, a dietician who can advise cancer patients, and a special facility for children with cancer.

Several cancer survivors who had surgery, particularly for breast cancer, spoke of being discharged from the hospital after only a short stay and having no one at home to help them with their wound care.

> "I was discharged from the hospital (after mastectomy) with a drain. I got home and the drain clogged, and it started hurting me, and my husband…is like, "I don't do this" and I had no one to tell me what to do. It was the middle of the night."

Children with cancer in the North Penn area are especially in need of services which meet their unique needs. Gilda's Club in Warminster is currently planning a special building for children, but this is at some distance from the North Penn area. The growing number of children in the North Penn area who are being diagnosed with cancer has prompted one local pediatrician to suggest that such a facility is an important need in the North Penn area also.

Key informants also discussed how additional funding would allow them to do things like increase outreach, pay counselors who volunteer their time, get help with grant-writing, and add more needed services.

RECOMMENDATIONS

The final section of this report, Recommendations, summarizes the needs identified during the assessment, and provides suggestions for future funding areas for the Foundation.

Most of the needs of the different special populations in the North Penn area which were identified by key informants and focus group participants were surprisingly similar: affordable housing, transportation, more information about available services, more available respite for caregivers, and more efforts to decrease the stigma associated with their special needs. These needs are listed below, in addition to specific needs which were identified for each population. Many of these issues which are identified below, such as poor public transportation, decreased public funding for services, and the lack of sufficient affordable supportive housing, are the result of national economic and social problems. Directly addressing these issues is not within the scope of the Foundation's mission. However, local efforts can still be made to improve the quality of life for residents with special needs by improving coordination and collaboration between government and providers, encouraging the recruitment and retention of volunteers to provide some services, and conducting more outreach and education locally.

The following table summarizes the issues which were identified for each population, the rationale for making these issues a priority, and suggested programmatic areas, followed issues which were common to all of the special needs populations.

SPECIAL POPULATION(S)	PRIORITY NEEDS	RATIONALE	POTENTIAL PROGRAM AREAS
Chronically Mentally Ill, Mentally Retarded, and Developmentally Delayed Children	Affordable supportive housing for adults More in-home and residential respite for caregivers More activities for children which are adapted to their needs and are handicapped accessible, especially in the summer and for autistic/PDD children	Adults need housing in the community to decrease institutionalization Caregivers will provide better care and use less public resources when they are less stressed Children will continue the gains made during the school year in programs offered in the summer	Encourage programs which decrease community opposition to supportive housing for the mentally ill and mentally retarded adults Encourage government and non-profits to attempt more supportive housing by providing information on the benefits of developing these ventures Encourage community volunteer efforts to provide consistent and quality in-home respite care, especially faith communities which are already providing care on a smaller scale. Assist non-profits and charitable organizations which already provide summer activities to expand their efforts to meet the demand.
Substance Abusers	More treatment programs for substance abusers with serious medical illnesses, older adult substance abusers, and chronically mentally ill substance abusers	These individuals are most in need of treatment but most likely to "fall through the cracks" since government agencies often only serve those in one diagnostic category	More facilities are treating chronically ill substance abusers, but government and providers need encouragement to serve these populations by forming collaborations to work together.
Cancer survivors	More outreach to cancer survivors to encourage participation in existing supportive programs Specialized supportive services for children with cancer and their caregivers	Decreasing stress may improve treatment outcomes	Assist collaborations between the medical community and supportive providers to increase outreach

ALL POPULATIONS WITH SPECIAL NEEDS	More funding for public services to decrease administrative delays, provide needed services, and improve the quality of treatment	Without access to quality, appropriate services which are provided in a timely manner, many adults and children with special needs become more ill.	Encourage providers and government to collaborate to identify areas where administration could be more efficient and funding allocated to higher priority areas
ALL POPULATIONS WITH SPECIAL NEEDS	More affordable, accessible transportation to non-medical appointments	Many do not drive; public transportation is poor and not always accessible	Encourage the expansion of volunteer transportation programs, especially in faith-based communities that have existing programs Encourage potential grantees to address the issue of transportation and fund van services where needed
ALL POPULATIONS WITH SPECIAL NEEDS	Decrease the stigma associated with the special needs populations	Stigma prevents people with special needs from living fully in the community	Assist government and non-profits to educate the general public, medical community, and potential consumers of services and their caregivers
ALL POPULATIONS WITH SPECIAL NEEDS	More information on available services for the general public, medical and treatment communities, and those with special needs and their caregivers	Increased access to needed services prevents more serious illness and conditions	Assist government and non-profit providers to publicize services, including a “cook book” approach for obtaining services for each special population

APPENDIX A: LIST OF KEY INFORMANTS

List of Key Informants
North Penn Community Special Needs Assessment

Marguerite Peashock
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Norristown, PA 19404

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Ken-Krest Services
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Phil Fenster
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APPENDIX B: KEY INFORMANT GUIDE

NORTH PENN COMMUNITY HEALTH FOUNDATION
SPECIAL NEEDS ASSESSMENT
KEY INFORMANT INTERVIEW GUIDE
FOR SERVICE PROVIDERS

INTERVIEWER:_____ **DATE:**___/___/____

KEY INFORMANT:_____ **TITLE:**_____

ORGANIZATION:_____

Introduction: The North Penn Community Health Foundation is conducting a study of the special needs of residents of the North Penn area who are mentally ill, and/or physically challenged or who have special needs. As part of the study, we are interviewing leaders in the community who are knowledgeable about area residents' special needs. We would like to know your opinions, based on your experience serving the community.

First, I would like to ask you some questions about your experiences working in the North Penn area.

1) What is your agency/organization's mission? Could you describe the people you serve?

(Probe for type of services provided, geographic area served, and characteristics of target population –

- Mentally ill, especially elderly 65+
- Mentally retarded
- Physically disabled, including blind, deaf, wheelchair bound
- Substance abusers, especially kids and elderly
- Dually diagnosed substance abuse/ mental illness
- Kids with terminal illnesses/cancer
- Issues of caregivers of all these special populations - respite and other supports
- Domestic violence victims

2) Approximately how many people do you serve in a year?
   - Are there any eligibility requirements?
     - If so, what are they?

   - Is there a waiting list for your services?

- How many people are on the waiting list?

- Are there any barriers to accessing your services?
  - If so, what are the barriers?
  - How do these barriers impact the people you serve?

3) What data sources do you rely upon to help you determine community need?

School district census
Federal census
MH/MR census
County / State data files: (specify which one(s) you use)

4) Does your agency use data to build your annual budget and/or marketing plan? If so how?

Now I would like to ask you some questions about the needs of clients with special needs and their caregivers.

5) Do special population clients and their caregivers have access to the services they need? Please indicate what sources of information (experience, roundtables or inter-agency meetings, county-based information, etc.) you are using to form your opinions.

- Do all, most, or only some of the populations have access to services to meet their needs?

- Do the special population clients and caregivers know where to go to obtain information about services? If not, what groups are experiencing difficulties?

- Do all, most, or only some of the clients and caregivers know where to go to obtain information about services?

6) How well are the health and social services and programs meeting the needs of clients with special needs?

- Which are some exemplary services/programs? Why are they exemplary?
- Are there services/programs that need improvement? Why?
- Are there any gaps in services? What are they?

7) What are the top five health and social service needs of the people you serve?

- Are these needs being met? If not, why not?
- Which of the needs not being met should have the highest priority for being met?
- What impact, if any, will likely occur if these needs continue to be unmet?

8) What in your opinion could the North Penn Community Health Foundation do to help meet these needs? *(Refer to North Penn Community Health Foundation guidelines so that comments have a context that is consistent with the foundation's mission, priorities and grantmaking guidelines.)*

Now I would l like to ask you some questions about those people caring for people with special needs.

9) Are respite care services needed for caregivers of persons with special needs?

- If so, what type of respite care is needed: short term respite, or longer term services? What specific respite care needs are available but not in sufficient quantity and what needs are totally unmet?

- Are there any population subgroups which particularly need respite care for caregivers? Which ones?
  - What is the specific need for respite care for caregivers of adults?
  - For parents of one child?
  - For parents of more than one child?
  - Are there any other special population subgroups?

10) What could the North Penn Community Health Foundation do to help meet the needs of these caregivers? Please ask this in the context of our grantmaking guidelines.

The North Penn Community Health Foundation guidelines state "an interest in promoting innovative and sustainable initiatives that will improve the overall quality and availability of health and human services in our community."

11) What organizations do you recommend be involved in planning services to improve the overall quality and availability of health and human services for people with special needs?

- Why do you recommend these agencies?
- What makes them an important contributor?
- What organizations do you recommend be involved in planning services for caregivers of people with special needs?
    - Why do you recommend these agencies?
    - What makes them a key contributor?

12) Do you have any further comments?

Thank you for your assistance with this important study. Please see North Penn Community Health Foundation website for additional information including the availability of application forms to apply for grants. The website is www.npchf.org. I will send you a copy of the North Penn Community Health Foundation brochure.

APPENDIX C: FOCUS GROUP GUIDE

North Penn Community Health Foundation

Special Needs Assessment

Focus Group Questions

Introduction

You have been asked to participate in this discussion group because you are residents of the North Penn area. The North Penn Community Health Foundation has asked the Philadelphia Health Management Corporation to collect information on the health and social service needs of residents of the North Penn area who are physically challenged, developmentally delayed, or seriously mentally ill and their caregivers. The PHMC is a private, non-profit public health organization.

There are 2 other discussion groups being conducted for this project. The information from these discussion groups will be combined with other information we are collecting into a report which will be sent to the Foundation. Our conversation tonight will be recorded by a tape recorder because we do not want to miss anything you say. I want to assure you that every thing you say here is confidential and your name will never be use din connection with anything you say in any written report that comes out of this group. My job is to act as moderator of the discussion and ask the questions. Since we have a lot of questions to get through today/tonight, I may have to cut short discussion of some questions to make sure we finish on time. Also, in order to make sure that everyone gets a chance to be heard, I ask that only one person talk at a time. Please feel free to leave and use rest rooms at any time during the discussion or to get up and help yourself to the refreshments.

In order to introduce everyone, let's go around the table. Please tell everyone your first name and where you live in the area.

Questions

As I mentioned earlier, we are very interested in learning what types of health and social service issues face people with special needs who live in the North Penn area.

1. How many people here have a doctor they can go to if they have a question about their health or are sick? What type of provider do you use: private practice doctor, clinic, emergency room, etc.?

2. Thinking back to the last visit to the place you USUALLY go for health care, how satisfied were you with the visit? Why? What is the most important quality to look for in choosing a health care provider? Other important qualities?

    - Quality of care

- Location
- Office hours
- Respectful treatment by staff
- Sensitivity to special needs
- Language spoken by staff
- Waiting time in office
- Waiting time to get appointment

3. Have you had a problem getting any health care and related services that you needed or thought you needed in the past two years? This includes primary care, emergency services, mental health, specialty care, dental care, prescriptions, eyeglasses, diagnostic tests, such as mammograms and prostate cancer screening.

4. If so, what were they and what was the problem?
   - Insurance
   - Care after hours and on weekends
   - Cost of prescriptions
   - Preventive and diagnostic tests
   - Eyeglasses
   - Dental care
   - Availability of specialists with experience in/willing to treat special needs patients
   - Transportation barriers

5. If there are problems getting health services, how should these problems be addressed?

6. Based on your own experience, what are the top health care needs of adults with special needs like yours in the North Penn area? What are the top health care needs of children with special needs in the area?

7. What are the top social service needs of persons with special needs like yours in the North Penn area?
   - Housing
   - Jobs/employment
   - Transportation

8. Have you had a problem getting any social services that you needed or thought you needed in the past two years? If so, what were they and what was the problem?

9. If there are any problems getting services, how should these problems be addressed?

10. Is there a need for services for caregivers of persons with special needs? What are these needs? Is there a need for respite care services? What type of respite care is needed? For whom?

11. How would you recommend the foundation spend their money? What kind of programs should they support?

12. Is there anything else you would like to add that we have not asked about?

APPENDIX D: TABLES

Table 1. Estimated Number and Percentage of Children Aged 9-17 with Mental Disorders Per Year in the North Penn Area

	#	%
Actual Number of Children	35,048	13.0
Any Anxiety Disorder	4,556	13.0
Any Mood Disorder	2,173	6.2
Depression	1,752	5.0
Disruptive Disorder	3,610	10.3
Attention Deficit and Hyperactivity Disorder	1,402	4.0
Substance Abuse Disorder	701	2.0
Any Disorder	**7,325**	**20.9**

Note: Numbers and Percentages are estimates for the North Penn area based on the U.S. Department of Health and Human Services: Mental Health: A Report of the Surgeon General (1999) and the U.S. Census, 2000

Source: U.S. Department of Health and Human Services: Mental Health: A Report of the Surgeon General, 1999

Table 2. Estimated Number and Percentage of Adults with One-month Prevalence Rates[1] of Mental Illness by Age in the North Penn Area

	Age									
	18-24		25-44		45-64		65+		Totals	
	#	%	#	%	#	%	#	%	#	%
Actual Number of Adults	17,047	8.5	84,304	41.9	62,955	31.3	36,643	18.0	**200,949**	**74.0**
Substance Use Disorder	1,159	6.8	4,046	4.8	1,322	2.1	330	0.9	**7,636**	**3.8**
Schizophrenic or schizophreniform disorders	136	0.8	927	1.1	315	0.5	37	0.1	**1,406**	**0.7**
Affective Disorder	750	4.4	5,395	6.4	3,273	5.2	916	2.5	**10,248**	**5.1**
Manic Disorder	102	0.6	506	0.6	126	0.2	0	0.0	**803**	**0.4**
Major Depressive Episode	375	2.2	2,529	3.0	1,259	2.0	256	0.7	**4,421**	**2.2**
Dysthymia	375	2.2	3,372	4.0	2,392	3.8	659	1.8	**6,631**	**3.3**
Anxiety Disorders	1,313	7.7	6,997	8.3	4,155	6.6	2,015	5.5	**14,669**	**7.3**
Phobia	1,091	6.4	5,817	6.9	3,777	6.0	1,759	4.8	**12,459**	**6.2**
Panic	68	0.4	590	0.7	378	0.6	37	0.1	**1,004**	**0.5**
Obsessive-Compulsive	307	1.8	1,349	1.6	566	0.9	293	0.8	**2,612**	**1.3**
Somatization	17	0.1	84	0.1	63	0.1	37	0.1	**201**	**0.1**
Antisocial Personality	153	0.9	674	0.8	63	0.1	0	0.0	**1,004**	**0.5**
Severe Cognitive Impairment	102	0.6	337	0.4	755	1.2	1,796	4.9	**2,612**	**1.3**
Any Disorder	**2,880**	**16.9**	**14,584**	**17.3**	**8,373**	**13.3**	**4,507**	**12.3**	**30,946**	**15.4**

[1]Refers to subjects who reported both symptoms of a mental illness in lifetime and presence of at least one of these mental illness symptoms in past month

Note: Survey of community households, excludes insititutionalized individuals

Note: Totals found in the "Any Disorder" and "Totals" categories do always equal totals for individual categories because percentages are age-adjusted.

Source: One-month prevalence of mental disorders in the United Staes and Sociodempgraphic chracteristics: The Epidemiological Catchment Area Study by Regier, D. A. et al. 1993a

Table 3. Estimated Number and Percentage of Suicide-Related Activity Among High School Students in the North Penn Area

	#	%
Actual Number of High School Students	13,804	5.1
Seriously considered attempting suicide in past year	2,664	19.3
Made a suicide plan in past year	2,001	14.5
Attempted suicide one or more times	1,146	8.3
Suicide attempt required medical attention	359	2.6

Note: Numbers and Percentages are estimates for the North Penn area based on the Center for Disease Control's Yourth Risk Behavior Surveillance, United States (1999) and the U.S. Census, 2000

Source: Center for Disease Control: Youth Risk Behavior Surveillance, United States, 1999

Table 4. Estimated Number and Percentage of Individuals with Mental Retardation in the North Penn Area by Age

	Age									
	0-15		15-24		25-64		65+		Total	
	%	#	%	#	%	#	%	#	%	#
Actual Number of Persons	21.6	58,278	10.3	27,924	54.5	147,259	13.6	36,643	100.0	270,104
	0.7	408	0.7	195	0.7	1,031	0.4	147	**0.7**	**1,781**

Note: Numbers and Percentages are estimates for the North Penn area based on the U.S. Census Bureau's 1996 Survey of Income and Program Participation (1997) and the U.S. Census, 2000

Source: U.S. Census Bureau, 1996 Survey of Income and Program Participation: August - November 1997

Table 5. Special Education Enrollments in North Penn Area School Districts by Diagnosis

	School District							
	Hatboro-Horsham SD	**Methacton SD**	**North Penn SD**	**Souderton Area SD**	**Wissahickon SD**	**Central Bucks SD**	**Pennridge SD**	**Totals**
Diagnosis								
Mental Retardation	29	10	159	30	0	36	35	**299**
Deafness/ Hearing Impairment	2	2	22	3	8	11	22	**70**
Speech/ Language Impairment	33	46	320	33	147	351	161	**1091**
Blind/Visual Impairment	2	2	7	3	1	5	2	**22**
Serious Emotional Disturbance	67	142	123	23	94	162	69	**680**
Physical Disability	0	1	0	0	0	0	5	**6**
Other Health Impairment	46	10	25	1	1	22	32	**137**
Specific Learning	366	301	1,062	584	398	1,376	499	**4586**
Deaf-Blind	0	0	0	0	1	0	0	**1**
Multiple Disabilities	8	6	10	14	12	15	10	**75**
Autism	21	12	34	13	15	44	18	**157**
Traumatic Brain Injury	9	2	1	0	0	6	6	**24**
Totals	**583**	**534**	**1,763**	**704**	**677**	**2,028**	**859**	**7148**

Note: Students are 6-21 years of age.

Source: Pennsylvania Department of Education, Bureau of Special Education: Special Education Statistical Summary 2001-2002

Table 6. Number and Percentage of Individuals with Any Disability[1] in North Penn Townships and Boroughs by Age											
	Age										
	5 to 20			21 to 64			65+			TOTAL	
Township/Borough	Pop	#	%	Pop	#	%	Pop	#	%	#	%
Franconia Township	2,335	134	5.7	6,128	384	6.3	2,148	685	31.9	**1,203**	**11.3**
Souderton Borough	1,357	97	7.1	3,950	559	14.2	863	227	26.3	**883**	**11.7**
Hatfield Township	3,610	269	7.5	10,056	1,356	13.5	1,745	577	33.1	**2,202**	**14.3**
Hatfield Borough	497	40	8.0	1,620	276	17.0	270	100	37.0	**416**	**17.4**
Lansdale Borough	3,077	260	8.4	9,418	1,677	17.8	2,192	759	34.6	**2,696**	**18.4**
Montgomery Township	4,634	181	3.9	12,865	1,161	9.0	2,212	693	31.3	**2,035**	**10.3**
Horsham Township	5,439	216	4.0	14,458	1,406	9.7	2,314	731	31.6	**2,353**	**11.8**
Lower Gwynedd Township	2,292	166	7.2	5,166	686	13.3	2,147	782	36.4	**1,634**	**17.0**
Whitpain Township	3,976	175	4.4	10,784	861	8.0	2,671	808	30.3	**1,844**	**10.6**
Worcester Township	1,738	17	1.0	4,302	320	7.4	1,190	336	28.2	**673**	**9.3**
Upper Gwynedd Township	3,038	164	5.4	8,609	1,067	12.4	1,676	408	24.3	**1,639**	**15.9**
Towamencin Township	3,699	171	4.6	10,331	1,320	12.8	2,264	727	32.1	**2,218**	**13.6**
Lower Salford Township	3,196	270	8.4	7,637	638	8.4	946	315	33.3	**1,223**	**10.4**
North Wales Borough	721	67	9.3	2,035	235	11.5	351	112	31.9	**414**	**13.3**
Ambler Borough	1,272	72	5.7	3,611	669	18.5	881	266	30.2	**1,007**	**17.5**
Telford Borough, Montgomery County	905	50	5.5	2,611	369	14.1	732	283	38.7	**702**	**16.5**
Silverdale Borough	293	9	3.1	575	63	11.0	61	10	16.4	**82**	**8.8**
Hilltown Township	2,751	152	5.5	7,060	976	13.8	1,381	432	31.3	**1,560**	**13.9**
New Britain Township	2,425	141	5.8	6,252	511	8.2	1,296	388	29.9	**1,040**	**10.4**
New Britain Borough	1,074	57	5.3	1,625	212	13.0	279	103	36.9	**372**	**12.5**
Chalfont Borough	883	35	4.0	2,355	242	10.3	345	67	19.4	**344**	**10.5**
Doylestown Township	3,513	129	3.7	9,414	966	10.3	2,146	572	26.7	**1,667**	**11.1**
Doylestown Borough	1,142	54	4.7	4,531	645	14.2	1,746	812	46.5	**1,511**	**20.4**
Warrington Township	4,037	250	6.2	10,441	1,366	13.1	1,476	444	30.1	**2,060**	**12.9**
Telford Borough, Bucks County	905	50	5.5	2,611	369	14.1	732	283	38.7	**702**	**16.5**
Total	**58,809**	**3,226**	**5.5**	**158,445**	**18,334**	**11.6**	**34,064**	**10,920**	**32.1**	**32,480**	**13.0**

[1]Disability is defined as a long-lasting physical, mental, or emotional condition. These conditions can make it difficult for a person to walk, climb stairs, dress, bathe, learn, or remember and can also impede a person from being able to go outside the home alone or to work at a job or business.
Source: American FactFinder, U.S. Census, 2000

Table 7. Number and Percentage of Individuals with Selected Disabilites by Age in the North Penn Area

	Age							
	5-15		16-64		65+		Total	
	#	%	#	%	#	%	#	%
Actual Number of Persons	43,595	16.1	171,528	63.5	36,643	13.6	247,960	91.8
Sensory Disability[1]	120	0.3	1,161	0.7	1,159	3.5	**2,440**	**0.9**
Physical Disability[2]	47	0.1	2,022	1.2	2,868	8.6	**4,937**	**1.8**
Mental Disability[3]	1,252	2.9	1,019	0.6	246	0.7	**2,517**	**0.9**
Self-Care Disability[4]	6	0.0	45	0.0	8	0.0	**59**	**0.0**
Total	**1,425**	**3.3**	**4,247**	**2.5**	**4,281**	**11.7**	**9,953**	**3.7**

[1]Blindness, deafness, or a severe vision or hearing impairment

[2]A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying

[3]A condition which makes learning, remembering, or concentrating difficult

[4]A condition which makes dressing, bathing, or getting around inside the home difficult

Note: These figures only include individuals with a single disability. Individuals with multiple disabilities were excluded from these figures.

Source: U.S. Census, 2000

Table 8. Estimated Number and Percentage of Individuals with Past Year Substance Abuse in the North Penn Area by Age

	Age							
	12-17		18-25		26+		Total	
	#	%	#	%	#	%	#	%
Actual Number of Persons	22,421	8.3	20,057	7.4	180,892	67.0	223,370	82.7
Any Illicit Drug	448	2.0	401	2.0	543	0.3	**1,392**	**0.5**
Alcohol	740	3.3	1,624	8.1	416	2.3	**2,780**	**1.0**
Alcohol or Any Illicit Drug	1,076	4.8	1,885	9.4	4,522	2.5	**7,483**	**2.8**
Total	**2,264**	**10.1**	**3,910**	**19.5**	**5,481**	**3.0**	**11,655**	**4.3**

Note: Numbers and percentages are estimates for the North Penn area based on the Substance Abuse Mental Health Services Administration, Office of Applied Studies' National Household Survey on Drug Abuse (1999) and the U.S. Census, 2000

Source: Substance Abuse and Mental Health Services Adminstration, Office of Applied Studies, National Household Survey on Drug Abuse, 2001

Table 9. Estimated Substance Abuse Among High School Students in the North Penn Area		
Substance Abuse	**#**	**%**
Actual Number of High School Students	13,804	5.1
Current cigarette use[1]	4,804	34.8
Current frequent cigarette use[2]	2,319	16.8
Smokes > 10 cigarettes/day[3]	718	5.2
Current alcohol use[4]	6,902	50.0
Episodic heavy drinking[5]	4,348	31.5
Drank alcohol before age 13 years	4,445	32.2
Current marijuana use[6]	3,686	26.7
Tried marijuana before age 13 years	1,560	11.3
Current cocaine use[7]	552	4.0
Current inhalant use[8]	580	4.2
Lifetime heroin use[9]	331	2.4
Lifetime methamphetamine use[10]	1,256	9.1
Lifetime illegal steroid use[11]	511	3.7
Lifetime illegal injecting drug use[12]	248	1.8

[1]Smoked cigarettes on more than 1 of the 30 days preceding the survey

[2]Smoked cigarettes on more than 20 of the 30 days preceding the survey

[3]Smoked more than 10 cigarettes/day on the days smoked during the 30 days preceding the survey

[4]Drank alcohol on more than 1 of the 30 days preceding the survey

[5]Drank 5 drinks of albohol on more than 1 occasions on more than 1 of the 30 days preceding the survey

[6]Used marijuana more than 1 times during the 30 days preceding the survey

[7]Used cocaine more than 1 times during the 30 days preceding the survey

[8]Sniffed glue or breathed the contents of aerosol spray cans or inhaled any paints or sprays to become intoxicated 1 times during the 30 days preceding the survey

[9]Ever used heroin

[10]Ever used methamphetamines

[12]Ever used illegal steroids

[11]Ever used illegal drugs

Note: Numbers and Percentages are estimates for the North Penn area based on the Center for Disease Control: Youth Risk Behavior Surveillance, United States (1999) and the U.S. Census, 2000

Source: Center for Disease Control's Yourth Risk Behavior Surveillance, United States, 1999

Table 10. Number of Residents Diagnosed with Cancer in North Penn Area by Municipality, 2000

Township/Borough	Number of Cases
Franconia Township	60
Souderton Borough	33
Hatfield Township	78
Hatfield Borough	8
Lansdale Borough	119
Montgomery Township	95
Horsham Township	110
Lower Gwynedd Township	110
Whitpain Township	136
Worcester Township	34
Upper Gwynedd Township	60
Towamencin Township	74
Lower Salford Township	52
North Wales Borough	13
Ambler Borough	28
Telford Borough, Montgomery County	7
Silverdale Borough	2
Hilltown Township	51
New Britain Township	47
New Britain Borough	18
Chalfont Borough	21
Doylestown Township	89
Doylestown Borough	116
Warrington Township	60
Telford Borough, Bucks County	16
Total	**1,437**

Source: PA Department of Health, 2000

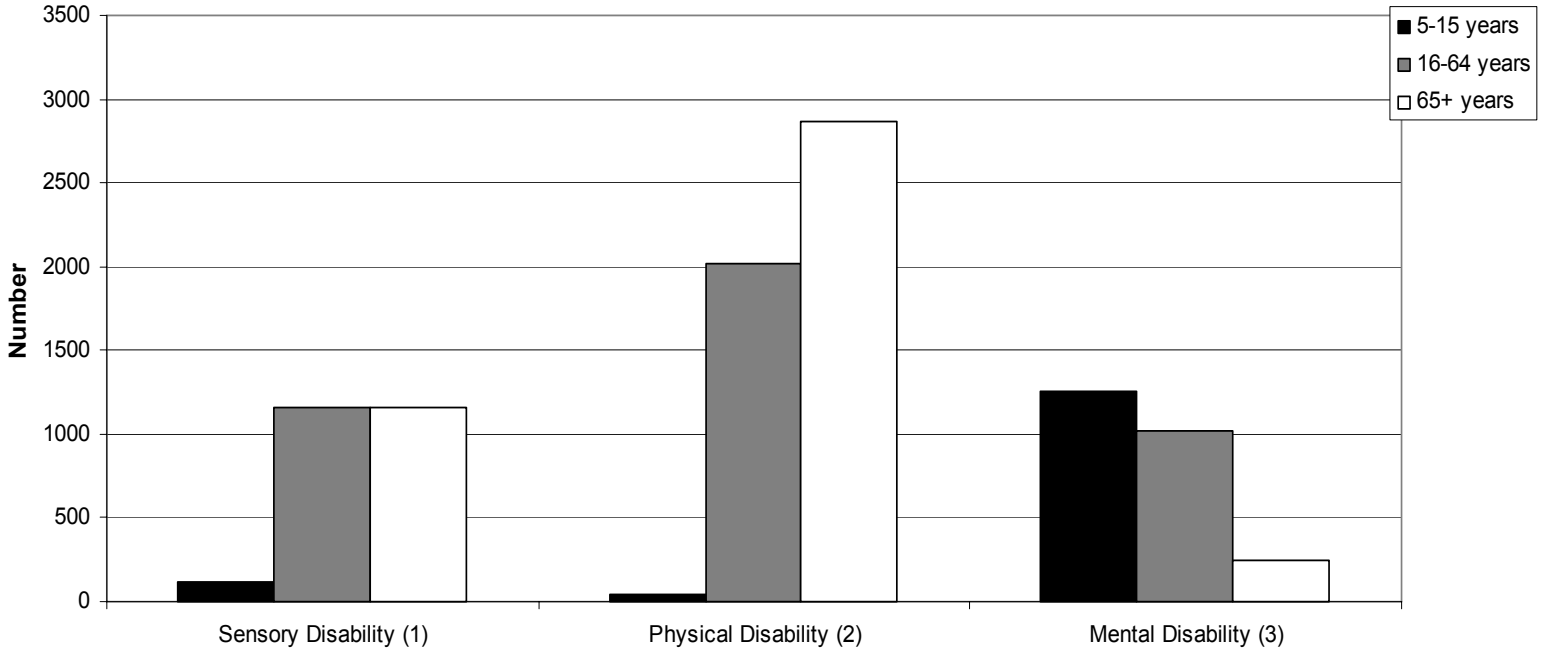
Table 11. Annual Incidence of Cancer in Montgomery and Bucks Counties by Site and Age

	Age													
	Under 5		5 to 14		15-24		25-54		55-64		65+		Total	
	Mont. Co.	Bucks Co.	Mont. Co.	Bucks Co.	Mont. Co.	Bucks Co.	Mont. Co.	Bucks Co.	Mont. Co.	Bucks Co.	Mont. Co.	Bucks Co.	Mont. Co.	Bucks Co.
All Cancers	11	7	11	12	19	17	778	690	781	651	2,557	1,703	**4,157**	**3,080**
Top 5 Cancers in Adults:														
Colon and Rectum	0	0	0	0	1	0	43	61	63	64	386	243	**493**	**368**
Bronchus and Lung	0	0	0	0	0	0	53	54	98	81	409	308	**560**	**443**
Breast	0	0	0	0	0	0	203	168	132	109	293	207	**628**	**484**
Prostate	0	0	0	0	0	0	47	48	173	126	421	262	**641**	**436**
Urinary/Bladder	0	0	0	0	1	0	23	25	27	34	169	102	**220**	**161**
Top 5 Cancers in Children:														
Brain/Other Nervous System	5	1	5	5	1	3	9	13	17	4	24	16	**61**	**42**
Thyroid	0	0	0	0	1	1	58	51	13	14	14	13	**89**	**79**
Lymphomas	0	0	1	1	1	2	50	30	33	24	112	67	**197**	**124**
Hodgkin- Lymphomas	0	0	0	2	1	4	13	10	2	3	6	3	**22**	**22**
Leukemias	2	3	3	2	3	2	14	11	7	9	55	48	**84**	**75**

Source: Commonwealth of Pennsylvania- Department of Health, Bureau of Health Statistics and Research, 2000

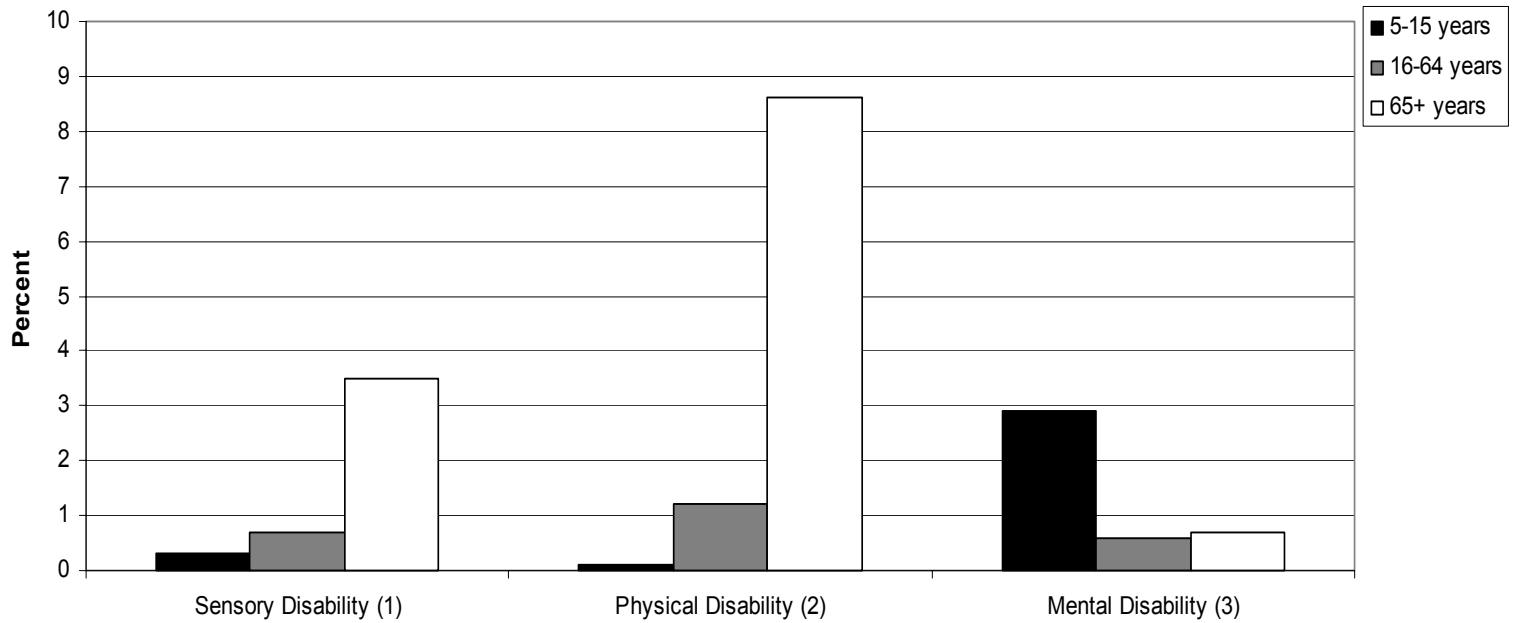
APPENDIX E: FIGURES

Figure 1: Number of North Penn Individuals with Selected Disabilities by Age



[1]Blindness, deafness, or a severe vision or hearing impairment
[2]A condition that substantially limits one or more basic phyisical activities such as walking, climbing stairs, reaching, lifting or carrying
[3]A condition which makes learning, remembering or concentrating dificult
Source: U.S. Census, 2000

Figure 2: Percentage of North Penn Individuals with Selected Disability by Age



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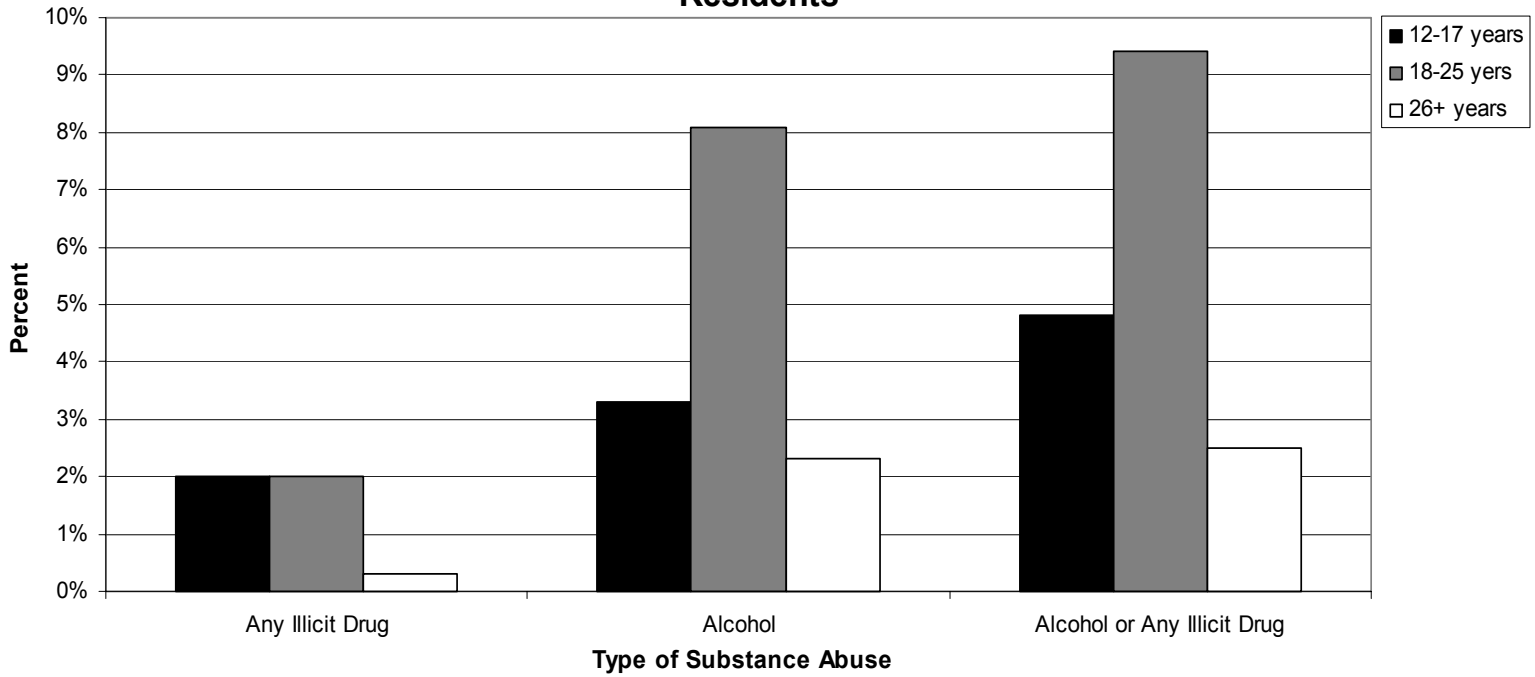
[2]A condition that substantially limits one or more basic phyisical activities such as walking, climbing stairs, reaching, lifting or carrying

[3]A condition which makes learning, remembering or concentrating dificult

Source: U.S. Census, 2000

Figure 3: Substance Abuse in Past Year by Age among North Penn Residents



Note: Percentages are estimates for the North Penn area based on the U.S. Department of Health and Human Services' National Household Survey on Drug Abuse (1999) and U.S. Census, 2000

Source: Substance Abuse and Mental Health Services Administration, Office of Applied Studies, National Household Survey on Drug Abuse, 2001